

**Broadening what counts as expertise in perinatal health of under-served populations in
Canada: participatory methods and Bayesian updating contextualize evidence synthesis in
stakeholder knowledge**

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List of acronyms

CI: confidence interval

CrI: credible interval

OR: odds ratio

RR: relative risk

TRC: Truth and Reconciliation Commission

Abstract

This doctoral research addresses the under-representation of under-served populations in published literature on perinatal health in Canada. This has consequences for policy, resource allocation and service delivery. My first thesis objective was to identify perinatal outcomes and experiences among under-served populations in Canada. My second objective was to develop a procedure, called Weight of Evidence, to contextualize published evidence in stakeholder experience, with a focus on engaging historically under-served populations. I applied Weight of Evidence to contextualize published evidence on perinatal health outcomes and experiences in the perspectives of pregnant and parenting adolescents and those delivering their care as my third objective. This thesis constitutes five scientific articles, two published and three either under review or being prepared for submission.

This thesis presents both methodological and substantive contributions. It introduces Weight of Evidence as an accessible, transparent, and reproducible procedure to contextualize evidence syntheses. Through the combined use of fuzzy cognitive mapping and Bayesian updating, Weight of Evidence transforms evidence-based and stakeholder-identified data into a weighted relational structure, led by participant expertise. As stakeholders interpret the evidence base, refine explanatory accounts and their implications, and prioritize intervention areas, Weight of Evidence broadens what counts as expertise, influencing both problem definition and relevant interventions.

This thesis identifies how social and economic exclusion may contribute to perinatal health outcomes. Pregnant and parenting adolescents reinforced findings from the literature review, prioritizing stigma and social and economic exclusion as important influences on perinatal health. I used Weight of Evidence to contextualize evidence on prenatal child protection risks among pregnant and parenting adolescents, prompting a re-examination of risks. Findings suggest that protection investigations are not without harm, as adolescents reported shouldering individual blame for risks often outside the sphere of parental influence, including poverty and lack of kin and community-based supports.

Future areas of research include streamlining Weight of Evidence with systematic review protocols to contribute to more responsive and relevant evidence synthesis and guidance. Advancing evidence-based and community-led approaches to perinatal risk reduction also requires further development to better align research and the provision of services with community needs.

Résumé

Cette recherche doctorale porte sur la sous-représentation des populations mal desservies dans la documentation publiée sur la santé périnatale au Canada. Cette situation a des conséquences sur les politiques, l'allocation des ressources et la prestation des services. Mon premier objectif de thèse était d'identifier les résultats et les expériences périnatales parmi les populations mal desservies au Canada. Le deuxième objectif était d'élaborer une procédure, appelée Weight of Evidence (Poids des Preuves), pour contextualiser les données probantes publiées dans l'expérience des intervenants, en mettant l'accent sur la participation des populations historiquement mal desservies. Le troisième objectif était d'appliquer la méthode Weight of Evidence pour contextualiser les données probantes publiées sur les résultats et les expériences en matière de santé périnatale du point de vue des adolescentes enceintes et en parentés et de ceux qui leur prodiguent des soins. Cette thèse comprend cinq articles scientifiques, dont deux ont été publiés et trois sont en cours d'examen ou en préparation pour être soumis.

Cette thèse présente des contributions tant méthodologiques que substantielles. Elle présente Weight of Evidence comme une procédure accessible, transparente et reproductible pour contextualiser les synthèses de preuves. Grâce à l'utilisation combinée de la cartographie cognitive et l'actualisation bayésienne, Weight of Evidence transforme les données probantes et les contributions de les parties prenantes en une structure relationnelle priorisée, dirigée par l'expertise des participants. Au fur et à mesure que les parties prenantes interprètent les données probantes, affinent les explications et leurs implications, et hiérarchisent les domaines d'intervention, Weight of Evidence élargit ce qui est considéré comme de l'expertise, influençant à la fois la définition du problème et les interventions pertinentes.

Cette thèse identifie comment l'exclusion sociale et économique peut contribuer aux résultats de la santé périnatale. Les adolescentes enceintes et en parentés ont renforcé les conclusions de l'analyse documentaire, en donnant la priorité à la stigmatisation et à l'exclusion sociale et économique comme influences importantes sur la santé périnatale. J'ai utilisé Weight of Evidence pour contextualiser les données sur les risques de protection prénatale de l'enfance chez les adolescentes enceintes et les parents, ce qui a provoqué un réexamen des risques. Les résultats suggèrent que les enquêtes sur la protection de l'enfance ne sont pas sans risque. Les adolescents ont déclaré porter la responsabilité

individuelle de risques souvent hors de leur sphère d'influence, notamment la pauvreté et le manque de soutien de la part de la famille et de la communauté.

Les futurs domaines de recherche comprennent la rationalisation de Weight of Evidence avec des protocoles de revue systématique pour contribuer à une synthèse des preuves et à des conseils plus adaptés et pertinents. La promotion d'approches de la réduction des risques périnataux fondées sur des preuves et dirigées par la communauté doit également être développée afin de mieux aligner la recherche et la fourniture de services sur les besoins de la communauté.

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Contribution to original knowledge

My doctoral research makes methodological and subject area contributions.

Methodological contributions

1. The thesis develops and demonstrates an accessible, transparent, and reproducible procedure to contextualize published evidence in stakeholder knowledge through the combined use of fuzzy cognitive mapping and Bayesian updating (described in Ch 3,4,6).
2. This thesis advances participatory research as stakeholders interpret the evidence base, refine explanatory accounts and their implications, and prioritize intervention areas, broadening what counts as expertise, influencing both problem definition and relevant interventions (described in Ch 3,4,5,6).

Subject area contributions

1. The thesis advances understanding of social and structural contributors to poor perinatal health outcomes and experiences among under-served populations in Canada by
 - a. examining social and economic exclusion as a common exposure across population groups (described in Ch 2)
 - b. demonstrating the value of participatory and strengths-based research that accounts for social and structural determinants of health (described in Ch6)
2. This thesis broadens the evidence base on how judgement influences perinatal outcomes and experiences of pregnant and parenting adolescents by
 - a. demonstrating how stigma is experienced by pregnant and parenting adolescents and how it influences access to health and social care throughout the perinatal period (described in Ch 5, 6)
 - b. demonstrating how pregnant and parenting adolescents conceptualize risk reduction in relation to child protection involvement throughout the perinatal period (described in Ch 5, 6)

Chapter 1: Introduction and contributions of authors

In Canada and around the world, stubborn inequities in health overlap with social fault lines: people living in worse socioeconomic conditions have poorer health than those with greater access to resources and educational opportunities. (Freedman & Kruk, 2014; D. Shaw et al., 2016) This pattern of inequities is also reflected in the perinatal outcomes of people who experience social and economic exclusion in Canada. (Baxter, 2007; Daoud et al., 2014; Gagnon et al., 2013; Luo et al., 2010; Shankardass et al., 2014) This doctoral research aims to contribute knowledge of what is needed to improve perinatal outcomes and experiences of under-served populations in Canada by broadening what counts as relevant expertise.

People expect to have a say in services and service providers and program and policy makers need ways to hear the voices of their patients and communities. Rigorous and transparent methods are needed to better understand evidence and its relevance at the local level. This thesis describes the development and application of a procedure to ground evidence in the knowledge and understanding of stakeholders, with a focus on engaging stakeholders who have not historically contributed to decision-making spaces in perinatal care in Canada. I demonstrate the value of this procedure through its application to address inequities in perinatal health among people living with social and economic exclusion, and more specifically, through its application with pregnant and parenting adolescents living with complex social needs in the Ottawa area.

Overarching topic and aim of thesis

Research plays a key role in improving and better understanding the experience of pregnancy and birth in Canada. Much of the scientific literature on pregnancy and birth draws on a biomedical lens to describe perinatal health of under-served populations in Canada focusing on improving care during pregnancy, delivery, and until 6-weeks postpartum. This lens focuses on curing and controlling disease and responding to physiological factors. While a biomedical approach has contributed to important reductions in maternal mortality and morbidity in Canada and internationally, it does have limitations in identifying broader contextual factors capable of bringing health improvements. (Napier et al., 2014; World Health Organization, 2009)

Communities themselves, or in collaboration with academic centres, have advocated for and contributed to the inclusion of contextual understanding to improve maternity, postpartum and newborn care. (Chalmers, 1991; Gill, Black, Dumont, & Fleming, 2016; Levy & Weber, 2011; Thorton, 2008; Vedam et al., 2017) Across Canada, evidence-based and community-informed approaches to perinatal care receive increasing attention, particularly for under-served population who may face barriers accessing more mainstream services. (Abrahams et al., 2007; Fleming, Tu, & Black, 2012; Nathoo et al., 2015; Ordean & Kahan, 2011; Smylie et al., 2016) Several initiatives demonstrate important improvements in perinatal outcomes, including preterm birth and low birth weight, and in adjacent outcomes, such as mental health. (Fleming et al., 2012; Nathoo et al., 2015; Ordean, Kahan, Graves, Abrahams, & Boyajian, 2013) Cultural continuity and community leadership are increasingly recognized in successfully re-framing, developing, implementing and evaluating prenatal, reproductive and child health services. (Blackstock, Cross, George, Brown, & Formsma, 2006; Clarke, Hasford, Gudge, & Mills-Minster, 2018; Smylie et al., 2016) This suggests that better bridging of biomedical literature with community-based understandings of perinatal care needs might contribute to improving outcomes, particularly for under-served populations.

This doctoral research builds on growing interest in including stakeholders, often meaning the public and particularly those most affected by the issues at hand, professionals and decision-makers, in health systems research and evidence syntheses. (A. George, Mehra, Scott, & Sriram, 2017; Pollock et al., 2018) The collaborative generation of knowledge by academics and stakeholders resonates with the science and practice of participatory research. (Greenhalgh, Jackson, Shaw, & Janamian, 2016; Wallerstein & Duran, 2006) Through a focus on collaborative learning and leadership with stakeholders, participatory research enacts the important principle that people have a right to be involved in decisions that shape their lives. Participation also makes research processes and interventions more relevant to local priorities, and therefore, more effective. (A. George et al., 2017) Philosophies of participation and community engagement can exist along a continuum of having a utilitarian focus, with participation resulting in more acceptable and appropriate interventions, and a social justice focus that promotes broader social and structural change by supporting people to participate in, negotiate with and hold accountable institutions that shape their lives. (Brunton et al., 2017)

Co-creation of knowledge through participatory research does not diminish the important contributions of biomedical and other forms of research nor does it suggest that one type of knowledge has a hierarchy over others. Commitment to participatory research stems from the belief that people make better decisions when they benefit from both scientific and more informal forms of knowledge. This includes contributions from evidence transferred through theoretical or statistical inferences, often developed through empirical studies or syntheses. It also includes context-specific understanding, meaning knowledge claims based on local settings, experience and tacit understanding of practice and organizational 'know how'. (Oliver et al., 2018) In the health sciences, systematic reviews and meta-analysis have long been considered the highest value synthesis of evidence, not least because finding the same or compatible results in different settings is convincing. (Shea et al., 2007) Systematic reviews benefit from strict demands on the quality and scope of included studies. This often leads to the exclusion of context-specific understanding. (Harris, Croot, Thompson, & Springett, 2016)

The combining of qualitative and quantitative findings, often derived from differing epistemologies, is an increasingly important approach to leveraging contextual understanding in systematic reviews. (Batalden & Davidoff, 2007; Greenhalgh et al., 2016; Harris et al., 2016; Pluye & Hong, 2014) Greater involvement of stakeholders in evidence syntheses can support greater inclusion of social and organizational factors that may influence interventions and review findings. (Harris et al., 2016) Several authors highlight the challenges of engaging stakeholders in reviews, including poor operationalization and description in evidence synthesis literature as well as a lack of understanding of how stakeholder input influences evidence interpretation and translation. (Haddaway et al., 2017; Harris et al., 2016; Pollock et al., 2018) Most stakeholder engagement in evidence syntheses to date focuses on stakeholders who have some understanding of research evidence and already have a seat at decision-making tables. Two recent systematic reviews of stakeholder and community engagement highlight that stakeholder involvement in evidence synthesis focuses primarily on the engagement of health professionals, academics and decision-makers with only 30% of studies including patients and communities as stakeholders. (A. George et al., 2017; Pollock et al., 2018) There is little guidance on ways to include the perspectives of underserved populations in evidence syntheses or the translation of findings to inform decision-making. This doctoral research aims to demonstrate the value of engaging under-served populations in the contextualization and interpretation of evidence on issues that affect their lives. My focus on perinatal health aims to contribute context-based understanding to

broaden our understanding of strategies to improve outcomes and experiences for under-served populations, specifically pregnant and parenting adolescents.

Research questions and objectives

This doctoral research sought to address the under-representation of under-served populations in available evidence in the context of perinatal health. I developed and applied a procedure to interpret, expand upon, and prioritize evidence from an existing synthesis, engaging populations historically left out of planning and decision-making, despite likely being among the most affected by those decisions.

My central hypothesis was that published literature on the perinatal care of under-served women in Canada does not adequately reflect the perspectives of under-served populations or the challenges their providers and policy and program advisors face in delivering care to this population. Broadening what counts as expertise in perinatal health of under-served populations may contribute both to shifting how we collectively understand the barriers to addressing perinatal inequities and potential solutions. This thesis sought to answer two research questions:

- 1) How do perspectives of the factors contributing to poor perinatal outcomes among under-served populations differ between different stakeholder groups and from published literature?
- 2) How do under-served populations prioritize evidence and interventions to improve perinatal care outcomes and experiences?

To answer these questions, my first thesis objective was to **identify patterns in perinatal outcomes and experiences among under-served populations in Canada**. A literature review confirmed that under-served populations consistently experience poorer maternal and newborn outcomes and experiences than comparator populations. It also pointed to the consistent role of social and organizational factors in influencing perinatal health across different populations.

A second thesis objective was **to develop a systematic approach to contextualize published evidence in stakeholder experience, with a focus on engaging historically under-served populations**. Stakeholder involvement can improve the relevance and translation of primary research and evidence syntheses, but stakeholder involvement in evidence synthesis remains poorly operationalized. (Carman et al., 2013; Chalmers, 1991; Harris et al., 2016; Pollock et al., 2018;

Thorton, 2008) Focused on engaging stakeholders historically excluded from formal planning and decision-making, this procedure, called Weight of Evidence, set out a transparent procedure for stakeholders to interpret, expand upon and prioritize an evidence base. Applying this procedure opened analysis and decision-making processes to greater scrutiny and facilitated a collaborative conceptualization of priority issues.

The scientific work of piloting this procedure, including validation within the broader scientific community, sensitivity analyses around variations in the method, and the development of implementation guidelines and training guides, is separate from my doctoral research. I developed this work in parallel to my doctoral research and is described in more detail in Appendix 5A and 5B.

A third thesis objective was to **apply Weight of Evidence to contextualize published evidence on perinatal health outcomes and experiences in the perspectives of under-served populations and those delivering their care.** Through a partnership with a community-based health and social service agency for pregnant and parenting adolescents in Ottawa, I led a participatory evidence-based priority setting process to identify the most important issues affecting adolescent experiences of pregnancy and parenting. Applying Weight of Evidence to better understand the prioritized concern of child protection involvement during pregnancy and early parenting demonstrated how the inclusion of relevant perspectives in problem definition broadened the menu of possible interventions to mitigate risk factors. Because I also engaged service providers in interpreting evidence and adolescents' contextualizing of that evidence, this approach also has implications for the larger systems of service delivery.

Defining terms and scope

This research seeks to broaden what counts as expertise in the context of perinatal health of under-served populations in Canada. Each of these terms are defined below.

Broaden: Examining multiple perspectives on a complex issue can generate new insights and understanding through the comparison and sometimes combining of different ways of knowing and experiencing the same phenomenon. (Greene & Hall, 2010) Engaging with research and understanding from more than one epistemological stance or way of knowing leads to a richer understanding of the issue at hand, both by identifying shared understanding and by engaging

respectfully with difference. (Greene & Hall, 2010) Broadening system boundaries can be helpful to understand underlying values, offer insights about how a particular system works and identify improvement strategies. (Foster-Fishman, Nowell, & Yang, 2007; Midgley, 2000) This is not to suggest that one type of knowledge has a hierarchy over others, but that holding space for multiple perspectives and interpreting them in context leads to better understanding and decision-making. (Oliver et al., 2018)

What counts as expertise: Wrestling with questions of what counts as valid knowledge requires that we examine evidence in context, engaging multiple perspectives on complex social problems. This raises issues of relative quality and trustworthiness. Several approaches guide researchers through detailed protocols to ensure that rigorous processes generate trustworthy evidence. Epistemological perspectives condition each approach, often with little questioning of who decides what is good evidence for a specific context and how best to take it into account alongside other knowledge sources. (Di Ruggiero, 2018; Mertens & Hesse-Biber, 2013) The argument for a pluralistic view of what counts as expertise, recognizing the knowledge held by different ways of knowing and through experience, is an argument long-made by leading feminist, Indigenous, disability-rights and working-class academics, activists and communities, as well as within mixed methods research. (Collins, 1986; Harding, 2003; Lavell-Harvard & Anderson, 2014; Maxwell & Mittapalli, 2010; Tuck, 2008) What comes to the fore and what remains as silence is shaped by social and scientific norms about what knowledge is important in a particular context and society. (Guidry-Grimes & Victor, 2012; Johnson et al., 2004; Serrant-Green, 2011) Although poor and socially marginalized groups are often very clear about how marginalization impacts their health, the issue is often poorly reflected in available evidence bases. (Serrant-Green, 2011) The absence of regularly collected data on both outcomes and experiences of under-served populations limits the relevance of available primary evidence, which is then carried through when evidence is synthesized and translated as evidence-based practice. Under-representation in the evidence base also acts to limit the visibility and voice of under-served populations in research about themselves. Populations carrying the greatest burden of health inequities need a stronger voice in the planning and implementation of their health care and the systems meant to support it, yet for the most part, remain excluded from decision-making processes. (Borda, 1996; Cho, Crenshaw, & McCall, 2013; Serrant-Green, 2011)

In the context of perinatal health: Perinatal health includes biomedical, psychosocial, and structural factors

that contribute to health and well-being during pregnancy and postpartum. For this doctoral research, the perinatal period refers to pregnancy, labour, delivery, and 12 months postpartum. While 6-weeks post-partum is the most common understanding of the postpartum period for clinical practice, given the focus of this research on the social and structural factors influencing perinatal outcomes, I consider perinatal outcomes up to 12-months post-partum. Perinatal health outcomes and experiences include biomedical and psychosocial considerations, as well as local and community determinants of what is needed to support family well-being throughout pregnancy and to the first year of life. (Katz, Hardy, Firestone, Lofters, & Morton-Ninomiya, 2020)

Under-served populations in Canada: Being “under-served” or “marginalized” are often used if vague terms in health science and public health literature. The lack of definition risks false or damaging narratives filling in the blanks left by vague or ambiguous terminology. (Katz et al., 2020) Despite these shortcomings, I use these terms to describe groups known to face barriers in accessing and fully benefiting from perinatal care services in Canada due primarily to the influence of social determinants of health. (Raphael, Bryant, & Curry-Stevens, 2004) My interest is in highlighting common experiences of how social, economic, historical and political structures contribute to inequities. (Cho et al., 2013; Crenshaw, 1991) This lens shifts from identifying and documenting poor conditions and outcomes for particular populations, to the systems, structures and decisions, historical and contemporary, that contribute to outcomes. (Katz et al., 2020) This perspective searches for the causes beyond the individual and more squarely with a system not equipped to meet the needs of the entire population. (Cho et al., 2013; Crenshaw, 1991)

To meet my thesis objectives, I used participatory methods and Bayesian updating to contextualize evidence in stakeholder knowledge. To present the methods applied in my doctoral research, each of these terms are described below.

Participatory methods: Participatory methods offer ways to engage with the insights and experiential knowledge of people and communities around issues that matter to them, while reflecting a diversity of perspectives with precision, rigour and trustworthiness. (Chevalier & Buckles, 2013; Guishard, 2009; Mertens, 2013; Tuck, 2008) The use of participatory methods alone does not make research participatory. Applying participatory methods with a transformative objective requires being attentive to what is considered credible knowledge. Beyond utilitarian intentions, it considers how practices,

beliefs and norms, both in the research process and in relation to the substantive area of research, may contribute to maintaining an unjust status quo while also building a vision more aligned with participants self-defined objectives. (Katz et al., 2020; Mertens, 2013; Tuck, 2009) My doctoral research explores the implications of recognizing stakeholder knowledge on equal footing with other forms of evidence to improve perinatal health of under-served populations.

Bayesian updating: Bayesian methods provide a statistical procedure to learn from data (or knowledge that has been quantified) and incorporate this data together with established models. (Gelman et al., 2013; Joseph, 2000) A frequentist approach to empirical studies considers each study independently, generating a unique estimate of effect and confidence in that effect. A Bayesian approach recognizes that knowledge, including relative confidence about that knowledge, exist beyond any individual empirical study. Bayesian statistics offers a formal procedure to combine knowledge (for example from stakeholders or qualitative studies) with an estimate and confidence from empirical studies. In this thesis we describe learning by incorporating knowledge external to an empirical study as Bayesian updating. (Marcot, Steventon, Sutherland, & McCann, 2006) Bayesian updating can be used to combine qualitative and quantitative findings from studies, either by quantifying qualitative data, coding the presence and absence of themes in both the qualitative and quantitative literature, or by drawing on qualitative data to create prior distributions. (Crandell, Voils, & Sandelowski, 2012; Roberts, Dixon-Woods, Fitzpatrick, Abrams, & Jones, 2002; Voils et al., 2009) Disciplines outside of health science have also drawn on Bayesian statistics to contextualize published literature in end-user perspectives. (Badampudi & Wohlin, 2016; Badampudi, Wohlin, & Gorschek, 2019) I leverage this method to juxtapose and to combine stakeholder knowledge with empirical evidence reflected in a synthesis.

Contextualize evidence: Contextualizing evidence is often considered part of knowledge translation where once published evidence is synthesized, it is assessed and interpreted for local relevance. Effective translation requires evidence be understood and applied in relation to local context and practical wisdom, incorporating insights from clinical experience and patient experience to define meaningful interventions. (Booth et al., 2019; MacDermid & Graham, 2009) Sometimes referred to as ‘practice-based evidence’, this context-based understanding is necessary to translate evidence to effective and sustainable interventions. (Badampudi et al., 2019; Barkham & Mellor-Clark, 2003) Knowledge translation is more likely to contribute to evidence-based practice and decision-making if research

evidence is clear and of high quality, however not all evidence is equally relevant across different contexts or for different stakeholders. (MacDermid & Graham, 2009) My doctoral research contributes to contextualizing evidence with under-served populations to better understand and address their priority concerns.

Stakeholder knowledge: Stakeholder engagement in research and knowledge translation is an important field in medicine and health sciences. It draws on literature examining community-based participatory research, engagement in health systems research and primary health care, stakeholder involvement in evidence synthesis as well as patient engagement in quality improvement initiatives. (Carman et al., 2013; A. George et al., 2017; Pollock et al., 2018; Rifkin, 2009) While these perspectives operationalize involvement of end-users differently and for different purposes, they share some common features. They examine issues from a systems perspective, recognizing entities interact in adaptive and path-dependant ways, generating outcomes that cannot be fully predicted in advance. (Greenhalgh et al., 2016) These approaches also place experience (of individuals or communities) as a central focus for both inquiry and design of interventions. (Brunton et al., 2017) Increased recent interest across these fields has blurred definitions and distinctions between community, stakeholder, and patient engagement. In this doctoral research, I refer to stakeholder engagement to include populations or individuals that have a stake or interest in an issue. I have not referred to the group of pregnant and parenting adolescents who contributed to this work as ‘a community’ as it was not clear that they saw themselves that way. Instead, they shared an externally imposed identity by virtue of experiencing a major life event at similar life stages.

Ontology and epistemology

This research is informed by a critical realist perspective, which integrates a realist ontology, believing a real world exists independent of our perceptions, theories, and constructions, together with a constructivist epistemology, recognizing our understanding is grounded in our perspectives and experiences. (Maxwell, 2011) Therefore, while a real world does exist under critical realism, it can never be objectively known. This understanding has important implications in recognizing the value of engaging multiple perspectives to identify robust features of reality as distinguished from factors that are a function of a particular view, model, or perspective. (Greene & Hall, 2010) This invites a layered understanding of reality by recognizing the inherent value of differing perspectives to develop greater understanding. (Maxwell, 2004; Mingers, 2000)

Several defining features of critical realism influence my research. The first is the recognition of beliefs, values, and social practices as having causal power. As Sayer states, “what the practices, institutions, rules, roles or relationships are depends on what they mean to society and to its members.” (Sayer, 2000) Mental states, values, and beliefs are not always observable, but they can be inferred based on what we experience and observe. (Bhaskar, 2008) From a critical realist perspective, individual perspectives and social norms are real phenomena that can interact with one another, as well as with other influential factors. (Maxwell, 2011)

A second concept that critical realism brings to my work is a process-based approach to causality which seeks to develop an understanding of processes, inclusive of social and structural phenomena, that generate the events and discourses that shape one’s understanding of reality. (Mingers, 2000) This understanding of causality is not based on the regularity of observations (often derived through a positivist perspective), but instead is theory-informed and adapted throughout the research process. (Mingers, 2005) Despite different understandings of causality, the results of positivist (and often quantitative) research can be helpful in developing a realist understanding of causation in identifying patterns, major relationships and constraints that may suggest underlying structures or mechanisms. (Maxwell, 2011; Mingers, 2005)

A third helpful concept offered by critical realism is the understanding of difference as a generative phenomenon. (Greene & Hall, 2010; Maxwell, 2004) Realism recognizes perspectives of reality are constructed from individual experiences, allowing that individuals may have different responses to similar situations, depending on specific personal or social characteristics relevant to an outcome. (Lipscomb, 2008; Putnam, 1990) Building on Greene’s dialectic stance in mixed methods research, meaningfully engaging with difference provides fundamentally generative insights and understanding useful at both conceptual and methodological levels. (Greene & Hall, 2010) By inviting multiple ways of knowing, this research seeks to recognize and unpack differences in meaningful and respectful ways to identify how and when these differences arise and with what consequences. (Greene & Hall, 2010)

My research grapples with questions of who can contribute to and who decides what counts as valid knowledge. Navigation of these issues is guided by the explicit recognition of people’s expertise over their own experiences, rooted in participatory research approaches and guided by both standpoint and

inter-sectionality theories. (Wallerstein, 1992; Collins, 1986; Harding, 2003; Crenshaw, 1991) Standpoint theory recognizes that knowledge is socially situated and that one's social position and context affect how they understand and navigate the world. Standpoint theory also suggests disadvantaged groups have critical perspectives to offer in understanding the status quo as they navigate more mainstream systems from a position of marginalization. (Collins, 1986; Harding, 2003) Inter-sectionality theory provides a helpful complement by asking us to examine how services and institutions that do not explicitly consider the contexts and needs of marginalized populations are likely to leave already marginalized groups further underserved. (Crenshaw, 1991) While my doctoral research seeks to engage a broad range of stakeholders, both standpoint and inter-sectionality theories inform the prioritizing of perspectives of under-served groups in examining how research can contribute to more responsive perinatal support services and systems.

Overview of thesis

To orient the reader, I have outlined each of the objectives and methods used to address them below,

Objective 1: identify patterns in perinatal outcomes and experiences among under-served populations in Canada (addressed in Chapter 2)

Methods: An integrative review collated qualitative and quantitative studies describing perinatal health outcomes and experiences of under-served groups in Canada. I used inductive thematic analysis to categorize qualitative data and descriptive statistics to juxtapose quantitative data. I applied Price's framework for the social analysis of reproductive health to interpret the common experiences and outcomes across the different population groups. (Price & Hawkins, 2007)

Objective 2: develop a systematic approach to contextualize published evidence in stakeholder experience, with a particular focus on engaging historically under-served populations (addressed in Chapters 3 and 4)

Methods: I developed a transparent and systematic procedure for stakeholders to interpret, expand upon and prioritize evidence from a synthesis, with a particular focus on engaging populations historically left out of decision-making. Called Weight of Evidence, a theoretical perspective

introduced in chapter 3 sets up a pilot study examining unmet postpartum care needs among immigrant women from the perspectives of family physicians and community doulas in chapter 4. This procedure represents different knowledge sources as fuzzy cognitive maps, offering an accessible and systematic way to represent published literature and stakeholder priorities. Association weighting assigned by stakeholders through the mapping process function as priors to formally contextualize published literature in stakeholder perspectives through Bayesian updating. Explanatory accounts accumulate from the original evidence base, analysis of the similarities and differences between the literature and stakeholder perspectives as well additional evidence identified from stakeholder priorities. Consistent with realist methods, I consolidated and grouped explanatory accounts according to main themes. The completed procedure shares these themes with stakeholder groups to identify short and long-term evidence-based and stakeholder-led interventions.

Objective 3: apply Weight of Evidence to contextualize published evidence on perinatal health outcomes and experiences in the perspectives of under-served populations and those delivering their care (addressed in Chapters 5 and 6)

Methods: This objective was addressed through a partnership with a community-based health and social service organization for pregnant and parenting adolescents, which includes a maternity shelter for precariously housed adolescents in Ottawa. For the demonstration case developed as part of objective two, I selected the focus topic for Weight of Evidence, however, for this objective, I conducted a participatory evidence-based priority setting process to identify the focus area. Described in chapter 5, I drew on outcomes and experiences of adolescent pregnancies summarized as part of Objective 1, and together with trained peer researchers, engaged clients and service providers in identifying priority areas that influence the well-being of being of pregnant and parenting adolescents. I focused the application of the Weight of Evidence around the adolescents' prioritized concern of being identified for child protection investigations, as described in chapter 6. This began with a mixed methods review on factors that contribute to child protection investigations among adolescent parents in Canada, followed by the representation of qualitative and quantitative findings as a fuzzy cognitive map. I contextualised published evidence in the experience of young mothers exposed to child protection investigations using fuzzy cognitive maps and shared the contextualized perspectives with child protection workers specialized in pre- and post- natal risk assessment at the local Children's Aid Society. I updated the published literature with the perspectives of young mothers and generated

explanatory accounts to describe how specific factors and relationships between them may contribute to having perinatal child protection involvement. Together with pregnant and parenting adolescents, I co-created a framework to identify intervention areas to improve their perinatal and early parenting experience.

Contribution to each chapter

I am the primary author of all chapters in this thesis, and accordingly, each of the manuscripts that make up chapters 2-6. I am grateful for the oversight and helpful comments provided by my supervisor Dr. Neil Andersson, as well as members of my thesis advisory committee. I describe author contributions for each of the manuscript-based chapters and appendices below.

Chapter 2: The influence of social and economic exclusion on perinatal health outcomes and care experiences in Canada: An integrative review (Manuscript #1)

Dion A, Macaulay A, Nakajima A, Zarowsky C, Andersson N. The influence of social and economic exclusion on perinatal health outcomes and care experiences in Canada: An integrative review (for submission to BMC Reproductive Health)

I am the first author of this chapter. Dr. Macaulay, Dr. Nakajima, Dr. Zarowsky and Dr. Andersson reviewed the data and contributed to the interpretation and implications of findings.

Chapter 3: Grounding evidence in experience to support people-centered health services (Manuscript #2)

Dion A, Joseph L, Jimenez V, Gutierrez AC, Ameer AB, Robert E, Andersson N. Grounding evidence in experience to support people-centered health services. *International journal of public health* 2019 Jun 1;64(5):797-802.

I am the first author of this chapter. Under the guidance of Dr. Neil Andersson, I worked with Dr. Lawrence Joseph to develop the methodology around the use of stakeholder weights from fuzzy cognitive maps as Bayesian priors for updating of the literature, and with Dr. Émilie Robert to ground the *Weight of Evidence* in a realist philosophy. Together with Dr. Joseph and Dr. Robert, Dr. Andersson

and I developed the overall method and conceived of the pilot study. I led the pilot study and Dr. Vania Jimenez, Dr. Alessandro Gutierrez and Amal Ben Ameer all contributed to the pilot study.

Chapter 4: *Weight of Evidence*: using participatory methods and Bayesian updating to contextualize evidence synthesis in stakeholders' knowledge (Manuscript #3)

Dion A, Carini-Gutierrez A, Jimenez V, Ameer AB, Robert E, Joseph L, Andersson N. Weight of Evidence: participatory methods and Bayesian updating to contextualize evidence synthesis in stakeholder knowledge. *Journal of Mixed Methods Research* (accepted for publication)

I am the first author of this chapter. Under the guidance of Dr. Neil Andersson, I worked with Dr. Lawrence Joseph to develop the methodology around the use of stakeholder weights from fuzzy cognitive maps as Bayesian priors for updating of the literature, and with Dr. Émilie Robert to ground the *Weight of Evidence* in a realist philosophy. Together with Dr. Joseph and Dr. Robert, Dr. Andersson and I developed the overall procedure and conceived of the pilot study. I led the pilot study and Dr. Vania Jimenez, Dr. Alessandro Gutierrez and Amal Ben Ameer all contributed to the pilot study.

Chapter 5: Evidence-based priorities of under-served pregnant and parenting adolescents: Addressing inequities through a participatory approach to contextualizing evidence syntheses (Manuscript #5)

Dion A, Klevor A, Nakajima A, Andersson N. Evidence-based priorities of under-served pregnant and parenting adolescents: addressing inequities through a participatory approach to contextualizing evidence syntheses. *International Journal for Equity in Health* May 2021, 20:118

I am the first author of this chapter. Dr. Neil Andersson, Dr. Amy Nakajima and I conceived of the study and contributed to its design. I worked with Aime Klevor to conduct the research and the analysis together with Dr. Andersson. I drafted this chapter and Aime Klevor, Dr. Andersson and Dr. Nakajima all contributed to its development.

Chapter 6: How adolescent mothers interpret and prioritize evidence about perinatal child protection involvement: participatory contextualization of published evidence (Manuscript #6)

Dion A, Andersson N. How adolescent mothers interpret and prioritize evidence about perinatal child protection involvement: participatory contextualization of published evidence. *Child and Youth Services Review* CYSR-D-21-00230

I am the first author of this chapter. Dr. Andersson and I conceived of the study, I conducted out the research and completed the analysis together with Neil Andersson. I drafted this chapter and Dr. Andersson made substantive contributions.

Chapter 7: Discussion of all the findings

This chapter describes how each of the chapters contributes to answering the research questions and summarizes my contributions. I am the author of this chapter. Dr. Neil Andersson provided conceptual oversight and provided helpful suggestions to the text.

Chapter 8: Conclusion

This chapter describes the contributions of this thesis. I am the author of this chapter. Dr. Neil Andersson provided oversight and provided helpful suggestions to the text.

Thesis Appendices:

Appendices 1-11 are the appendix file at the end of this thesis. Additional files associated with chapter 2-6 are included in Appendices 1-4 are described in each of the respective chapters.

Appendix 1: Includes additional files for Chapter 2

Appendix 2: Includes additional files for Chapter 4

Appendix 3: Includes additional files for Chapter 5

Appendix 4: Includes additional files for Chapter 6

Appendix 5a: Guideline for the Weight of Evidence procedure

This is an implementation guide for mid-level researchers and health policy analysts to understand how and why to adopt the Weight of Evidence procedure. I am the primary author of this guide, building on the intellectual contributions of Dr. Emilie Robert, Iván Sarmiento, Dr. Lawrence Joseph, and Dr. Neil Andersson.

Appendix 5b: Evaluation of resources to support Weight of Evidence

This is a protocol developed to evaluate the presentation and resources to support the use of the Weight of Evidence procedure. I am the second author of this protocol and worked with Dr. Émilie Robert under the guidance of an Advisory Committee made of Dr. Serge Djossa Adoun, Dr. Zack Marshall, Dr. Valéry Ridde and Dr. Kate Zinszer to develop this protocol.

Appendix 6: Fuzzy cognitive mapping and soft models of indigenous knowledge on maternal health in Guerrero, Mexico

As co-author on this publication as I contributed to both the methods and analysis of the findings. This manuscript is published in BMC Medical Research Methods and is included in the appendix.

Appendix 7: Combining conceptual frameworks on maternal health in indigenous communities -- Fuzzy cognitive mapping using participant- and operator-independent weighting

I am a co-author on this publication as I contributed to both the methodology applied in this study and to the analysis of the findings. This manuscript has been accepted for publication with Field Methods.

Appendix 8: Making sense of fuzzy cognitive mapping: four analytical approaches

I am a co-author of these teaching notes developed for a doctoral-level 3-credit class on Advanced Participatory Methods (FMED 702).

Appendix 9: Fuzzy Cognitive Mapping As Tool to Advance Evidence Synthesis

I am the primary author of these teaching notes developed for a doctoral-level 3-credit class on Advanced Participatory Methods (FMED 702).

Appendix 10: PhotoVoice exhibit as knowledge translation strategy to support findings from application of *Weight of Evidence* with pregnant and parenting adolescents

This appendix presents the final products of the PhotoVoice project conducted as a knowledge translation strategy following the application of the Weight of Evidence. The focus was on defining supportive relationships with pregnant and parenting adolescents. Materials distributed at the event are included in this appendix.

Appendix 11: Ethics approval certificate for doctoral research

Chapter 2: The influence of social and economic exclusion on perinatal health outcomes and care experiences in Canada: An integrative review (Manuscript #1)

This chapter presents the findings of an integrative review to synthesize qualitative and quantitative studies describing perinatal health outcomes and experiences of under-served groups in Canada, using inductive thematic analysis to synthesize qualitative data and descriptive statistics to synthesize quantitative data. I conducted this literature review to understand the current state of the literature describing perinatal outcomes and experiences among under-served populations in Canada. Findings from this review, and specifically those relating to recent immigrant women and pregnant and parenting adolescents, contribute to subsequent chapters focused on the contextualization of available evidence by relevant stakeholders.

I am the first author of this chapter. Dr. Macaulay, Dr. Nakajima, Dr. Zarowsky and Dr Andersson provided conceptual and methodological oversight and contributed to interpreting the findings. This manuscript is in preparation for submission to BMC Reproductive Health.

Background: In Canada, people living with economic and social exclusion experience worse maternal and newborn outcomes. Much of the available research examines individual populations or a specific aspect of the broader context affecting perinatal health outcomes. The objectives of this review are to characterize the perinatal outcomes and experiences of under-served groups in Canada and examine social and structural determinants influencing perinatal health.

Methods: We conducted an integrative review and followed a systematic approach to synthesize qualitative and quantitative studies describing perinatal (during pregnancy to 12 months post-partum) health outcomes and experiences of under-served groups in Canada, from articles published in French or English after the year 2000. We searched Medline, CINAHL and Web of Science. We used inductive thematic analysis for qualitative data and descriptive statistics for quantitative data from primary studies and used a framework for the

social analysis of reproductive health to help interpret the common experiences and outcomes across the different population groups.

Results: Quantitative findings suggest that each of the populations described in our review are at greater risk of poor maternal and newborn outcomes than comparator populations. While not all populations experience the same processes that contribute to poor outcomes, we identified poverty and social exclusion, living outside acceptable norms of pregnancy and parenting, and individualization of perinatal care as key factors shaping perinatal care.

Conclusion: Centering research and health service design around the needs of those they are intended to serve will contribute both to shifting how we collectively understand the barriers to addressing perinatal inequities and potential solutions. Several care delivery models have shown that it is possible to address perinatal inequities in Canada by broadening interventions to also address social and structural determinants of perinatal health.

Background:

Canada has a strong maternal care system with a low maternal mortality rate of 6.1/100 000 births and most women report positive birth experiences. (1) The 2006 Maternity Experiences Survey asked over 6400 women across Canada about their maternity experiences. The majority received care from an obstetrician or family physician (84%), and over 85% reported being happy with the support and care they received. The women included in the survey were overwhelmingly Canadian born (81.1%), married or common-law (91.9%), between 20-39 years of age (67%) and had university or some other post-secondary education (75%). (2,3)

However, in Canada and around the world, stubborn inequities in health overlap with social and economic fault lines: people living with economic and social exclusion experience worse maternal and newborn outcomes. (4-10) Examining maternal and newborn health outcomes and experiences of under-served or marginalized populations are important to identify specific gaps in care. Quality improvement literature around health inequities tends to centre the locus of change at the individual level, either with under-served populations themselves or by providers, suggesting strategies to change behaviours and increase compliance with existing services (e.g. increase prenatal attendance, decrease smoking, address personal biases, increase

awareness of additional services). (11,12) These are all important actions by individuals to promote health during pregnancy and in the post-partum period.

Researchers, clinicians, advocates and policymakers have called for the examination of social, economic, historical and political factors that also contribute to poor perinatal health. (5,13-16) Much of the available research examines individual populations or a specific aspect of the broader context affecting maternal and newborn health outcomes. This review examines maternal and newborn outcomes across populations that do not share biomedical characteristics (other than pregnancy), but all face a common experience of navigating Canada's perinatal health and social services living with multiple forms of social and structural exclusion. Our interest in undertaking this broad analysis across populations was to identify patterns in outcomes and experiences that may point to how social and economic contexts and the structure of maternity care may itself contribute to the stubbornly consistent inequities in maternal and newborn outcomes in Canada.

We are attentive to the words we use to describe populations excluded from or under-served by current care services. Being “*under-served*” or “*marginalized*” does not define those who experience it, nor does it suggest the burden of improvement lies with them. (4,17,18) It identifies the ‘problem’ outside of the individual and more squarely across multiple systems, including health and social services and education, among others, that are not equipped to meet the needs of the entire population. Our review was guided by the question: *what are the perinatal and postpartum health outcomes and experiences of people living with social and economic exclusion in Canada?* The specific objectives were to 1) characterize the perinatal outcomes and experiences of under-served groups in Canada; 2) synthesize findings across diverse groups to identify patterns in outcomes and experiences; and 3) examine organizational issues, policies and broader contextual factors influencing perinatal health.

Methods:

We included qualitative and quantitative studies describing outcomes and experiences among this population. We followed a systematic approach to searching, following the process set out by Arksey. (19,20) With the help of a health sciences librarian, we searched databases relevant to biomedical and clinical maternity care, as well as the social sciences and humanities to

include reports of clinical outcomes and experiences throughout their maternity care. Where available, we also included studies describing the experience of healthcare providers caring for under-served populations. We searched Medline, CINAHL and Web of Science for primary research describing perinatal (during pregnancy to 12 months post-partum) health outcomes and experiences of under-served groups in Canada, including all articles published in French or English after the year 2000. We focused on identifying studies in more general databases rather than specialized databases or journals focused on marginalized populations as our aim was to understand how these experiences are described in the more accessed literature and more likely to find their way to influence policy or management decisions.

While increasing numbers of women are seeking out the care of midwives to support them through pregnancy and childbirth, the majority of Canadian women receive antenatal care from an obstetrician or a family physician with additional obstetric training. (1) Accordingly, this paper focuses on antenatal care experiences relative to care provided by physicians.

While we use the terms *under-served* or *marginalized* as an umbrella-term to describe excluded populations as a whole, we used specific search strategies to identify populations known to be under-served and/or experience high-levels of discrimination both in healthcare settings and Canadian society in general. (17,21) We followed a systematic approach to identifying studies, using MESH keywords and further refining search terms based on keywords used in included studies. A draft MEDLINE search can be found in the appendices (Appendix 1- Additional File 2.1). This search strategy was modified as necessary for other databases. We supplemented our search by backward and forward citation tracking to be as comprehensive as possible.

Study Selection: Consistent with approaches to integrative reviews, we prioritized studies for relevance, rather than a particular study design. (22,23) We excluded clinical guidelines and articles that described outcomes and experiences following interventions aimed to address social and economic exclusion experienced by specific population groups. Where we identified a systematic or other form of review, we reviewed references for studies that met our inclusion criteria to ensure we included all eligible research papers.

Data analysis

We used inductive thematic analysis to extract qualitative data and descriptive statistics to extract quantitative data from primary studies. (24-26) We analyzed data in a two-stage process aimed at addressing the three research objectives: 1) to characterize the perinatal outcomes and experiences of under-served groups in Canada; 2) synthesize findings across different groups to identify patterns in outcomes and experiences; and 3) examine organizational and broader contextual factors influencing perinatal health. We used Price and Hawkins' framework for the social analysis of reproductive health to help interpret the common experiences and outcomes across the different population groups. This framework emphasizes an examination of how context influences how reproductive health needs are identified and addressed. As suggested by the authors, the aim of our analysis was not to address every concept described in the framework but to use it deductively to identify the key issues and concepts described across each of population groups we included in our review. (27) Article screening, data extraction and analysis was completed by the lead author as part of a doctoral thesis.

Results

Our initial search returned 4391 results. The lead author screened all reviews by title, abstract and full text. We grouped articles according to the population they most directly addressed, though some articles contributed to multiple population groups (e.g., articles describing the experience of young Indigenous mothers contributed to the analysis of both adolescents and of Indigenous populations). The number of articles for each population, grouped by whether articles were qualitative or quantitative, is shown in Table 2.1. We did not identify any mixed methods studies.

To address our first objective, we present results of both quantitative and qualitative studies to characterize the perinatal outcomes and experiences of under-served groups in Canada. Data extraction tables by population group are shown in the appendices (Appendix 1-Additional File 2.2).

Table 2.1: Number of identified and eligible articles identified for each population

Population group	Total number identified	Eligible articles		Total eligible articles
		Qualitative	Quantitative	
Poverty	48	2	4	6
Vulnerable	36	1		1
Marginalized	326	All assigned to other categories		
Adolescent	771	11	24	35
Indigenous, First Nations, Inuit and Métis	315	17	17	34
Immigrant and Refugee	93	14	27	41
Lesbian, gay, bisexual, trans, queer, two-spirit	8	1	3	4
People who use substances	116	9	7	16
People with disabilities	22	3	4	7
Total eligible articles	1733	58	86	144

POVERTY

Quantitative findings: Women living in lower socio-economic conditions often faced greater chronic stressors, including poverty, lack of social support, and intimate partner violence. (10,28) Women living in low socio-economic conditions had worse pregnancy and birth outcomes, lower use of prenatal and postpartum care, and were at greater risk for poor perinatal outcomes. (3,10,29-32) Roughly 8% of Canadian women exhibited depressive symptoms in the first 12 weeks postpartum; however, this risk was higher for women with low household income (odds ratio (OR) 1.64; 95% confidence interval (CI) 1.27-2.11), for those with low postpartum social support (OR 3.95; 95% CI 2.77-5.62), who experienced stressful life events (OR 2.43; 95% CI 1.88-3.15) and who experienced interpersonal violence (OR 1.40; 95% CI 1.04-1.87). (30) Low-income women were also more likely to receive obstetric interventions with no clinical indication and have unaddressed post-partum concerns, particularly around depression. (3,10,32) These factors can have important implications for women's post-partum health as well as infant development. (6,33,34)

Qualitative findings: In a study of the experiences of healthcare providers providing care to inner-city women in a large Canadian city, providers recognized the challenge many families face in accessing regular prenatal care and education. Providers highlighted personal challenges facing clients in accessing prenatal care, including economic and time costs related to transportation, childcare, and precarious employment. Providers empathized with the challenge of prioritizing prenatal care among multiple and sustained competing demands, such as caring for other children and/or family members, managing debt, food insecurity and housing challenges. Other barriers identified included patients' distrust of the health system based on previous negative experiences, system pressures to maintain a high-volume practice contributing to short visits with little time to address barriers or establish trusting relationships, and patient experiences of social isolation from partners and extended family members, particularly for First Nations women who may have re-located to the city from more rural areas. (35)

ADOLESCENTS

Quantitative findings: Adolescent mothers were more likely than adult mothers to have a mental health diagnosis of anxiety and/or depression as well as other mental health disorders. (36) This is consistent with other studies reporting higher age-specific fertility rates among adolescents with major mental illness. (37) Pregnant and/or parenting adolescents were 2-4 times more likely ever to have experienced physical abuse, (38) more likely to be single and have a low income (less than \$40,000 a year). (39) Roughly 60% of young mothers accessing care at a youth pregnancy outreach clinic either completed or were in the process of completing high school. (40) Adolescents were more likely to have low birth weight infant, twice as likely to have preterm (<37 weeks gestation) and 4 times as likely to have extremely preterm (<34 weeks gestation) babies. (38,41) Pregnant adolescents were 10-47% less likely to attend prenatal care in the first trimester, often citing financial barriers, long waiting times, lack of privacy, fear of judgment and not wanting to miss school. (41) A summary of quantitative findings is shown in Table 2.2.

Table 2.2: Risk factors for poor perinatal outcomes among pregnant adolescents in Canada

Risk factor	Odds ratio (OR) with 95% CI
Experienced physical abuse in past year	OR= 4.87 (3.44-6.90) (38)
	OR=2.24 (1.53-3.29) (39)
History of substance abuse	OR=3.7 (2.47-5.56) (38)
Wanted to be pregnant later	OR= 6.16 (4.41-8.61) (38)
	OR= 4.49 (2.93-6.87) (39)
No prenatal care in first trimester	OR=2.54 (1.74-3.71) (38)

Qualitative findings: Themes identified in qualitative studies reflect the complexity of emotions surrounding pregnancy and motherhood. Themes include gratitude for their children, while also experiencing pervasive social stigma navigating education, employment and social services for themselves and their children. (42,43) Identified themes and illustrative quotes are shown in Table 2.3.

Table 2.3: Themes identified in qualitative literature describing perinatal experiences of adolescent women in Canada

Theme	Illustrative Quote
Motherhood as Transformative	“I was pregnant and realized the path that I was going to bring another human being into the world. This was my choice – so there were two paths for me to go on. To continue going on this one and bring a child in that, not being in control of my life. And I knew that I couldn’t do that to a child. So, making the choice to go the straight path and know what is coming.” (44)
Support not judgment	“When nurses were perceived as judgmental, adolescent mothers were inhibited from asking them for assistance. Several of the mothers described how they would rather have no nursing care than the judgmental care that they received.” (45) “While they were grateful for the non-judgmental support and guidance, they explained that this support was not very common in their lives. They expressed frustration that they are not treated like other mothers, and frequently experienced judgmental stares and comments”. (46) “I am not ashamed of being a teen mother. However I do feel that if someone had guided me when I was going through my eating disorder, addictions, and insecurities that my life could have been different.” (42)
Being seen as a risk	“She chose not to take any painkillers during her labour, in part, because she was afraid that it might demonstrate to child protection workers that she was not a suitable mother.” (11)
Challenging norms	Society sees young parents as irresponsible kids that have kids. I am a single mother raising my son alone, I go to school, I live on my own, I pay my rent, I do the groceries, buy clothes, do dishes every night, clean every night—those are all things that you need to be strong for, and I don’t think people should put you down for doing those things.... People should show us more respect. (47)

	“Participants interpreted their experiences of being judged as societal stigma rooted in the common belief that young women should not be pregnant or parenting and that they are incapable of being good mothers.” (48) ‘We have middle class values that we’re trying to impose on clients who may or may not have middle class values.’ (43)
Social determinants of health	“Umm, just healthy foods. I find that they're really hard to access. That ties in really huge with women's health right?” (42)
	“if you don't have a safe place to call home, then you're not going to be able to get any other supports for yourself in place including anything for your sexual health.” (42)

INDIGENOUS PEOPLE

Quantitative findings: Pregnant First Nations women in Quebec and British Colombia were more likely to live in small communities (< 10 000), be single, under the age of 20 and primiparous. (49,50) Several studies highlighted the lack of access to procedures considered the standard of care both prenatally and postpartum. First Nations women with Type 2 pre-pregnancy diabetes in Ontario were more likely to have no or inadequate prenatal care and no postpartum maternal or infant follow-up visits compared to non-First Nations women with diabetes. (51) Similarly, First Nations primiparous women in British Colombia were less likely to have an ultrasound at 20-weeks gestation, to have at least 4 antenatal care visits or to receive an induction after prolonged (<24 hours) labour, prelabour rupture of membranes or at post-dates gestation. (50) Selected measures are shown in Table 2.4.

People living in Inuit-inhabited areas in Quebec and Canada experienced higher rates of adverse birth outcomes, such as pre-term birth (<37 weeks gestation). (8,49,52-54) Both First Nations and Inuit women had significantly higher rates of high birth weight babies (>4500g) than non-Indigenous women. (49,54,55) Several authors point to the high prevalence of Type 2 diabetes combined with a lack of access to perinatal care as contributing to disproportionately high rates of high birth weight deliveries among First Nations communities. (56) First Nations and Inuit infant mortality rates were two to six times the rate of non-Indigenous populations respectively. (49,54,55,57) Authors emphasized that the high infant mortality (>28 days post-partum and under 1 year of age) rates reflect inadequate broader determinants of health, particularly around housing and the newborn's immediate environment, which in themselves are symptoms of on-going under-funding and neglect experienced by First Nations and Inuit populations. (57,58) Selected measures are shown in Table 2.5.

Table 2.4: Measures of access to quality care measures among Indigenous population in Canada

Quality of care measure	First Nations Living on Reserve in Ontario (51)	Non-First Nations in Ontario (51)
Received antenatal obstetric care	64.4%	94.9%
No postpartum maternal primary care follow-up visits	29.6%	7.9%
No postpartum infant primary care follow-up visits	33.2%	16.5%
Received post-partum glucose tolerance test	<4%	18.8%
	First Nations compared to non-First Nations in British Colombia (50)	
Less than 4 prenatal visits	Adjusted risk difference= -3.6 (-4.6- -2.6)	
U/S before 20 weeks	Adjusted risk difference = -10.2 (-11.3- -9.3)	

Table 2.5: Measures of perinatal outcomes among Indigenous population in Canada compared to non-First Nations and non-Inuit populations (geographic area specified in brackets; Qc= Quebec)

Outcome	First Nations	Inuit
Pre-term birth (<37 weeks)	OR=1.42 (0.61-3.30) (Canada) (55) adjusted OR=0.69 (0.59-0.82) (Qc) (8) adjusted OR= 0.99 (0.93-1.05) (Qc) (49)	adjusted OR= 1.44 (1.36-1.52) (Qc) (8) adjusted OR=1.33 (1.19-1.5) (Qc) (49)
High Birth Weight (>4500g)	OR=2.45 (0.52-11.47) (Canada) (55) OR=4.76 (4.36-5.19) (Qc) (8) OR=3.02 (2.9-3.15) (Qc) (49)	OR=1.07 (0.99-1.14) (Qc) (8) OR=1.38 (1.25-1.53) (Qc) (49)
Post-neonatal death	OR=1.51 (1.14-1.99) (Canada) (55) OR=2.62 (1.59-4.33) (Qc) (8) OR=2.28 (1.63-3.2) (Qc) (49)	OR=6.01 (4.05-8.9) (Nunavut) (59) OR=2.66 (2.31-3.05) (Qc) (8) OR=6.01 (4.05-8.9) (Qc) (49)

Qualitative findings: Experiences of racism and discrimination were recurring themes through qualitative studies describing the perinatal experiences of Indigenous women in Canada, as highlighted in Table 2.6. The dismantling of traditional systems of maternity care, parenting and family structure in Indigenous communities across Canada was tied to both the poorer outcomes and pervasive experiences of exclusion and disadvantage experienced by Indigenous women and families. (60-62) This includes a history of forced sterilizations, the undermining of traditional midwifery, the mandatory medical evacuation of pregnant women living in remote areas and the disproportionate rate of child welfare interventions experienced by Indigenous women and their families. (15) Intersecting provincial and federal jurisdictional responsibilities for health and social care in Indigenous communities was highlighted as an important contributor to the fragmentation of care, unique to the colonial organization of healthcare experienced by Indigenous people. (63)

Indigenous women sought out care where their identity and knowledge as mothers were respected and where Indigenous approaches to pregnancy, childbirth and motherhood were valued. (64) When Indigenous-centered care was not available, women were often faced with assumptions of incompetence as mothers and reported that the fear of apprehension and of experiencing racism and discrimination prevented them from accessing health services. (65) Studies described how implicit and overt biases can be perpetuated within health services and create barriers to access or limit the effectiveness of available services. (64,66) Women reported that experiences of discrimination and the fear of apprehension often deterred care-seeking for their own health concerns, however, did not impact women's decision to access healthcare services for their children. (65)

Table 2.6: Themes identified in qualitative literature describing perinatal experiences of Indigenous people in Canada

Theme	Illustrative Quote
Colonialism and traumatic pasts	“[Women] most often expressed a sense of surprise at seeing the multiple types of trauma they had experienced, survived and, in some cases, healed from.” (62) “Many of the women linked the absence of early cultural connections with substance use.....women expressed regret that traditional teachings and cultural activities had not been a bigger part of their lives when growing up and associated this with a lack of belonging and their search for approval and acceptance.” (62)
On-going discrimination	“[I] have not drank for many years . . . [even if you tell them] “Oh, I’ve been sober for 10, 12, 15 years”, [they will ask] “Are you sure? Are you sure you put your own pants on this morning?” That’s what he said to me.” (67) “Sometimes I feel like I’m being belittled or being talked down to, and I’ve been fighting that all my life. For a very long time. So when I’m belittled I’d rather just cut it off and say “You know what? Thank you for your time, but I think I’ll just move on.” (67)
Poverty and other social determinants of health	“They’re going to [providers] who don’t have a concept about the culture, no concept of where they are coming from and no idea where that person is going to. Are they going back to a shelter tonight? There is such a disparity in the determinants of health between Aboriginal and non-Aboriginal”. (64) “I don’t have the resources to, but I really want to know and shape how my child is going to succeed in the next ten years’. Every mom wants that. But when she’s busy surviving she can’t even think about that. She can only love and protect what she has at that moment” (64) “I was always trying to get money, always. If not for me and my sisters and my mom, then when I had my kids and was sobered up, I was still

	trying to get money and feed my kids and clothe their backs. Ya [it goes] everywhere. It is a big thing. We struggled all our lives.” (62)
Fragmented care	“I think at the end of the day Aboriginal women, women at the very sort of deep basis level of family, are the victims of this incredible power play and this jurisdictional abyss.” (68)
Connection and relationships	“Regardless of their childhood experiences, forgiveness, reconnection and bonding with family members were identified as supporting their wellness, healing and recovery” (62) “... even just being around my daughter, just like makes all the yucky feeling go away, you know ... cause like we are doing a good job. Cause I am there with her.” (62)

PEOPLE WITH DISABILITIES

Quantitative findings: Mothers with intellectual and developmental disabilities in Ontario were more likely to be younger than 35, be primiparous at delivery, to live in low-income neighbourhoods, have other chronic health and mental health concerns and to have a low continuity of primary care. (69) Women with intellectual and developmental disabilities in Ontario were more likely to have labour induction and caesarean sections (adjusted risk ratio (adjusted relative risk (RR) =1.13, 95%CI 1.06-1.20 and adjusted RR =1.09, 95%CI 1.03-1.16 respectively). (70) Pre-existing conditions, such as psychiatric disorders, and complications, such as pre-eclampsia/eclampsia, did not fully explain these increased risks, suggesting that non-medical factors may also influence care decisions. (70) Women with intellectual disabilities in Ontario were more likely to have hospital readmissions within 12 weeks postpartum (adjusted RR=3.41, 95% CI 3.13-3.94), with higher rates for psychiatric admissions, compared to women without intellectual disabilities. (71) Postpartum, women with intellectual disabilities in Ontario were more likely to be offered both non-surgical (oral contraceptives, injectables or intra-uterine devices) (adjusted OR=1.22 95% CI 1.13-1.33) and surgical contraceptive methods (tubal ligation, tubal implants or hysterectomy) (adjusted OR=1.73 95% CI 1.43-2.08) than women without intellectual disabilities. (69) Selected measures are shown in Table 2.7.

Table 2.7: Selected outcomes identified in quantitative literature describing perinatal experiences of women with intellectual disabilities (RR=relative risk)

Perinatal outcome	Relative risk (RR) (95% CI)
Caesarean Section (70)	RR=1.09 (1.03-1.16)
Induction (70)	RR=1.13 (1.06-1.2)
Maternal postpartum hospital re-admission within 7 days (71)	RR=4.24 (3.74-4.8)
Maternal postpartum hospital re-admission within 12 weeks (71)	RR=3.41 (3.13-3.94)

Qualitative findings: Women with disabilities reported experiencing subtle and explicit judgement about their ability to navigate pregnancy, labour, delivery, and parenting. (72) Women shared they often had to weave together recommendations from different medical professionals to address their needs. This included educating perinatal healthcare providers about their disability related needs, and addressing concerns about interactions between pregnancy-related and disability-specific drugs. (73) Select themes and demonstrative quotes are shown in Table 2.8.

Table 2.8: Themes identified in qualitative literature describing perinatal experiences of people with disabilities in Canada

Theme	Illustrative Quote
Misunderstanding of disability-related needs	“We don't know. We've never had anybody like you before” ... I find it extremely hard to believe I'm the first person, the first mom with a disability, that you've ever come across But this is what they told me” (72)
Seen as incapable	“I went in for my appointment [to my OB and after] I went up to the secretary to book the next appointment. She actually whispered to the doctor, “She's not pregnant, is she?” (73) “Je veux dire, ça fait quoi 7 mois que tu me suis là, je suis capable de le faire toute seule! Elle était, comment on dit, fâchée contre moi. Elle me dit ‘Non tu devrais m’attendre, on avait une entente’. ‘Come on, je suis capable!’» (“<i>I mean, you've been following me around for seven months, I can do it on my own! She was, how do you say, angry with me. She said, 'No you should wait for me, we had an agreement'. Come on, I can do it</i>”; translation provided by review authors)(74)
Disability as separate	“There's a lot of siloing that goes on in the medical community, especially if you have a complex disability like mine when you have issues dealing with chronic pain and a physical disability that the two don't communicate. You get excellent care in those two separate areas but they don't communicate with each other.” (72) “I felt like disability wasn't an expected part of this high-risk clinic, even though high risk was usually associated with medical conditions” (72)

IMMIGRANTS: RECENT IMMIGRANT POPULATIONS

Quantitative findings: Pregnant immigrants and refugees often faced barriers to fully benefiting from Canadian health and social systems due to chronic stressors including poverty (OR=4.14 95% CI 3.89-4.40), lack of social support (adjusted OR=2.31 95% CI 1.73-2.24), discrimination, migration history, communication barriers, and lack of information. (75-79) This often translated to greater challenges in meeting their health needs, lower use of preventive services, social services, and medical care, and consequently, increasing the risk for negative health outcomes. (33,77,78,80-83) A study of recent immigrant women (within 5 years of their arrival to Canada) found that they are not only at a greater risk for post-partum health problems than Canadian-born women (OR=1.69 95% CI 1.46-1.96), but they are more likely to have concerns about post-partum depression, pain, abnormal blood pressure and lack access to contraception unaddressed at 1 week (adjusted OR=2.24 95% CI 1.73-2.9) and 4 weeks postpartum (adjusted OR=2.36 95% CI 1.75-3.19). (9,84) Recent immigrant women were also more than twice as likely to report not having enough information about infant care and sudden infant death syndrome, community supports and emotional changes related to pregnancy compared to Canadian-born women (79,85) Selected outcomes are shown in Table 2.9 and 2.10.

There is conflicting data on Caesarean section rates among immigrant women in Canada. Some studies report that immigrant women were at a significantly higher risk of caesarean section (82,83,86-88), while others have reported no difference in rates between immigrants and Canadian-born women. (79,89,90) One study reported low-risk pregnant women from South and Central Asia are more than twice as likely to have a Caesarean section compared with Canadian-born women of the same low-risk profile; another reported increased risk of unplanned Caesarean section among migrants of sub-Saharan Africa/Caribbean origin. (80,91) Immigrant women with unplanned Caesarean sections were more likely to report feeling uninformed, not respected or encouraged during labour than Canadian-born counterparts. (91) A study in the prairies reported that recently arrived immigrants were more likely than Canadian-born women to receive a Caesarean section, more likely to report giving birth in the lithotomy position, and more likely to have an instrumental delivery. (86) However, not all studies show excessive instrumental deliveries or Caesarean sections among recent

immigrants, suggesting that some immigrant women have similar or lower rates of instrumental delivery than Canadian women with similar risk profiles. (80,87,92)

Table 2.9: Selected outcomes describing perinatal experiences of recent immigrant and refugee women in Canada compared to Canadian-born women

Outcome	Presence of postpartum health concerns @ 4 weeks; OR (95%CI)	Concerns unaddressed @ 4 weeks; OR (95%CI)
Post-partum depression, abnormal blood pressure, pain, and/or lack of access to contraception among refugee women (9,84)	OR=1.91 (1.61-2.27)	OR=2.17 (1.57-3.02)
PPD, Abnormal BP, Pain, Contraception a Post-partum depression, abnormal blood pressure, pain, and/or lack of access to contraception among immigrant women (<5 years) (9,84)	OR=1.69 (1.46-1.96)	OR=2.36 (1.75-3.19)
Unable to see healthcare provider for physical need (85)		OR= 1.02 (0.3-3.48)
Unable to see healthcare provider for physical need emotional need (85)		OR=4.00 (0.97-6.55)

Table 2.10: Selected outcomes describing perinatal experiences of recent immigrant women in Canada compared to Canadian-born women

Outcome	OR (95% CI)
Low social support during pregnancy (81) postpartum (79)	OR=2.54 (1.96-3.3) OR=2.31 (1.73-3.08)
Unable to get enough support for household tasks (85) reassurance (85) financial security (85)	OR=3.04 (1.39-6.67) OR=3.33 (1.28-8.33) OR=3.09 (1.00-9.51)
Did Not Have Enough Information postpartum about infant care (85) community supports (85) emotional changes (83) physical changes (85) sudden infant death syndrome (79) postpartum depression (79)	OR=2.85 (2.12-3.83) OR=2.93 (2.16-3.98) OR=2.21 (1.65-2.98) OR= 2.24 (1.67-3.00) OR=2.53 (1.89-3.38) OR=1.61 (1.16-2.25)

Qualitative findings: Poverty and a lack of strong social ties limited women's overall stability. Lack of access to secure housing and increased vulnerability and directly influenced women's access to postpartum care, limiting access to transportation or critical postpartum services not covered by public insurance, such as contraceptive devices or mental health counselling. (32,80,89,90)

Articulating health needs across language barriers, cultural differences and past experiences of poor treatment were highlighted as important challenges to access care. (22,78,93,94) Several authors also highlight that when policies and resource allocations did not match community needs, providers lacked the support of strong inter-professional collaborations, pushing them to 'work outside their license', with patient follow-up falling through cracks between different organizations or care teams. (4,5,95,96)

IMMIGRANTS: REFUGEES AND ASYLUM-SEEKING POPULATIONS

Quantitative findings: Similar to recent immigrant women, refugee and asylum-seeking women were also more likely to have concerns about post-partum depression, pain, abnormal blood pressure and lack access to contraception at 1 week (refugee: adjusted OR=1.91 95% CI 1.61-2.27; asylum-seeking, adjusted OR=1.33 95% CI 1.14-1.55) and have these concerns unaddressed at 4 weeks postpartum (refugee: adjusted OR=2.17 95% CI 1.57-3.02; asylum-seeking: adjusted OR=1.68 95% CI 1.28-2.20) than Canadian-born women. (9,84) Undocumented women were 62% less likely to receive an ultrasound during pregnancy and 82% less likely to receive any blood tests during pregnancy compared to refugee women. (97) Another study reported that women without insurance were more likely to receive inadequate prenatal care (uninsured 54% vs insured 20%). (83)

Qualitative findings: Refugees highlighted barriers to accessing perinatal health and social services such as a lack of transportation, information, and financial resources as well as communication barriers. (78,81) Women also reported hesitancy accessing services when unsure of their rights out of fear that it might jeopardize their migration status. (77,78) Despite refugee and asylum-seeking women consistently reporting a lack social support, few women reported being supported by programs and centers with mandates to serve this population. (77)

Several studies highlighted provider challenges in providing care to undocumented or asylum-seeking families, who often do not qualify for provincial or federal health insurance. (9) While some physicians reported reluctance in providing care to this population, others reported being motivated by a sense of shared humanity and the economics of prevention. Physicians reported often shifting their role from a provider of direct care to one of advocating for patients and supporting system navigation through the health system. (98-100) This included paying for costs out of their own pocket when coverage was not available, donating their own and their staffs' time and negotiating with other providers to provide services for little or no compensation in high pressure and time sensitive contexts. (98,100)

Providers emphasized the importance of clear communication, understanding people's migration journey and how this might affect both needs and health behaviours. They also described investing time in navigational and logistical support to ensure that referrals and tests were completed appropriately. (100) Providers highlighted the amount of time invested to navigate complicated and changing health insurance coverage for refugees to ensure their patients received the maximum coverage for which they were eligible. This was particularly challenging for providers outside of centres specializing in care for refugee and asylum-seeking populations. (100) Themes and illustrative quotes are included in Table 2.11.

IDENTIFYING SHARED THEMES ACROSS POPULATIONS

Quantitative findings suggest that each of the populations described in our review are at greater risk of poor maternal and newborn outcomes than comparator populations (e.g., immigrant vs. Canadian-born; Indigenous vs. non-Indigenous, living with a disability vs. not living with a disability). While not all populations experience the same processes that contribute to consistently poorer outcomes, we elaborate on three shared themes identified across the studies included in our review: how poverty and social exclusion shape perinatal care, the experience of living outside of social norms of pregnancy and parenting, and the individualization of perinatal care. Each theme is explored in turn, recognizing that they interact with one another to influence outcomes and experiences.

Table 2.11: Themes identified in qualitative literature describing perinatal experiences of recent immigrant and refugee women in Canada

Theme	Illustrative Quote
Social and economic isolation	“One of the nurses came and she said you know, if you spend the night here you have to pay \$1,500. [...]. I cannot forget that night, there was a big snowstorm....and I went with the baby. Because I could not stay another day at the hospital to pay another \$1,500”. (97) “Some women don’t ask for help, mostly because they don’t know there is help. Others are ashamed or not used to asking for help. I knew a person who was inside her home all day. She didn’t know the language and she didn’t go out at all until somebody told her, you cannot survive without getting help.” (94)
Communication barriers	“I felt that it wasn’t my place to talk about my feelings. It was not welcome there and not enough time so I just preferred not to say anything.” (94)
Discrimination	“It was difficult, mainly because for the fact of being immigrant and to find a doctor for the baby. When I tried to find a doctor, they asked me where I was from and when I told them, I notice a change from them.... there might be some racism. I don’t know. I wanted to run. I felt helpless.” (33)
Understanding of health	“I would seek attention if sick, but not if I am upset” (33) “It’s my tradition. I believe in it, you know. I have to do what I believe.” (93)

Social and economic exclusion

Population groups experienced multiple forms of exclusion, with many studies describing how different forms of exclusion both overlap and reinforce one another. Findings can be organized according to four aspects of exclusion, where each contribute to perinatal outcomes by shaping membership in society and produce (and reproduce) unequal opportunities to sustain health and well-being. (101,102) Material or social isolation contributes to peoples' exclusion from civil society and public participation, leading to a lack of representation. The absence of data and inclusion of certain populations within the body of perinatal research, as well as in research, programmatic and policy decision-making spaces contributes to the lack of representation and identification of, and subsequent action to address, disparities in outcomes, in perinatal research, programme and policy decision-making spaces. By not being counted, or by being mis-counted, population needs are left unidentified and may contribute to maintaining perinatal inequities. (103) The lack of data on maternal health outcomes and experiences among Métis and non-status First Nations is an example of remaining data gaps, along with gaps relating to perinatal outcomes among people with physical disabilities and trans communities, among others. (15,57,104) The denial of, or failure to provide for, the needs of particular populations, such as accommodations for people with disabilities, translation services for people who do not speak English or French, ensuring people's basic needs are met (such as housing or nutrition) as well as neglecting to enforce sanctions to deter discrimination and abuse also contribute to exclusion. All populations included in this review reported either a disconnect between services offered and their needs, including around cultural considerations in pregnancy, birth and infant care, or a lack of protection or action against discriminatory comments and actions. (33,61,64,66,67,93,105) Neglecting culturally rooted practice, whether intentionally or not, particularly in the context of pregnancy, birth and parenting can also contribute to exclusion. Studies reported the lack of recognition or active discouragement of culturally-rooted approaches to pregnancy, labour, birth and child-rearing particularly among Indigenous and recent immigrant populations. (9,61,93,105) Finally, exclusion from socially acceptable forms of livelihood and participation in the labour market contributes to economic exclusion. Studies across all population groups highlighted the role that poverty played in shaping perinatal outcomes and peoples' ability to meet and sustain basic needs. (13,35,106-108) Several studies reported that people's access to perinatal care was undermined by structural determinants that limited available time and opportunities to

respond to both curative and preventive health needs. (102) These include lack of secure housing, food insecurity, lack of funds for needs not covered by public insurance (such as prenatal vitamins, contraceptive devices or mental health services), precarious or inflexible employment and a lack of accessible and affordable transportation and childcare. (33,42,58,78) While people may be offered multiple referrals for care, people experiencing economic and social exclusion often face many additional challenges in complying with expectations and best practices. (33,64,100)

Living beyond social norms

Social norms around pregnancy, parenting and motherhood play a large role in the experiences of all populations explored in our study. (109-111) Women who do not follow dominant norms around pregnancy and motherhood may be seen as unfit, as a source of risk, irresponsibility or as unable to adequately care for their children. (13,16,60,112,113) This is, in part, the result of deeply engrained norms around who is deserving of health and social care and how people should be supported through their transition to motherhood. Whether social, economic or physical, studies described barriers built into the structure and organization of institutions affecting women's access to health, opportunities for education, financial support, housing, often exacerbating existing vulnerabilities, even in the absence of individual prejudice or discrimination on the part of care providers. (114)

Access and acceptability of care are shaped by perceived risk, comfort with providers, together with past experiences with the health system, social norms around care and health as well as by broader experiences of marginalization or discrimination throughout people's lives. (14,22,110,115,116) How one conforms to social norms affects how people access and engage with services, as well as how providers offer care, including communication effectiveness, nonverbal attention, empathy, courtesy and the provision of information. (18,117) Patient characteristics, including socioeconomic status and race, also influence patient candidacy, service navigation and accessibility, the assignment of diagnostic categories and the adjudications on eligibility of certain treatments. (18,22,118) This can be particularly important in maternity care if 'high-risk' categorisation of women from marginalized groups is primarily rooted in historical, economic or social exclusion. (119,120)

When an already marginalized person interacts with a public institution that reinforces prevailing social norms, these institutions can compound and reinforce marginalization by creating additional barriers to securing their well-being and care. (121) Whatever the good intentions of caring clinicians and staff involved, diagnostic labels can add the burden of stigma. (13) Repeated labelling often leads to internalizing of negative stereotypes, and can influence people's perceived control over their own circumstances, willingness to seek care, as well as how care is acted upon and what is refused. (116,122) Fearing rejection, women reported guarding themselves against or avoided potentially threatening interactions with health and social care systems. Women also found themselves labeled as 'non-compliant' when they did not access care that did not take into account the structural dimensions of their needs. (13,66,115) Despite personal intentions to provide the best care possible, services and institutions that do not explicitly consider the contexts and needs of oppressed or excluded populations are likely to leave already marginalized groups further underserved. (115) The influence of social norms around motherhood and parenting is perhaps seen most dramatically in the dismantling of traditional systems of maternity care, parenting and family structure as part of historical and ongoing intergenerational trauma experienced by Indigenous people enacted by Canadian institutions. (60,61,63,108,123,124)

Individualization of perinatal care

Organizational characteristics of health systems also influence the delivery of perinatal care. (121) There has been a 50-fold reduction in the number of days people spend in the hospital following childbirth from 5-7 days in the 1960s to between 3-48 hours after a normal vaginal delivery in 2012. (95) Many care responsibilities have shifted from institutional settings to community and home care settings. (96) Reduced length of stay and higher workloads have contributed to less time for emotional care (for example, breastfeeding advice and infant care), and reduced care for 'time-intensive' patients who do not speak English or French, or who may have complex care needs. In this context, visible minority women report a lack of response to requests for analgesics and feeling overlooked for their 'white, easier neighbours'. (96)

Shifting care to communities without proportionate increases in services to meet community-specific needs risks further excluding under-served populations. Accessing care through

publicly or privately-funded community-based services requires families have adequate levels of health literacy, economic security, self-efficacy, and that the local financial, community and social resources both exist and meet their health needs. (78) Where publicly-funded post-birth services exist, they are often a single visit from a public health nurse, with the possibility of referral, and in some places in Canada, this has been reduced to a phone call. (95) Publicly funded services are also unevenly distributed, often to the disadvantage of already underserved communities. Most notably is the longstanding inequitable funding gap for health and social services for First Nations children on reserve, where First Nations families are deprived of the same access to services as other Canadians, particularly around funding to support family maintenance and mitigate child protection risks. (63) Gaps in community-specific perinatal and early childhood support services are also needed to better serve African Canadian families. (125) This is combined with a chronic and widespread lack of accessible community supports often leaving families feeling alienated from an unsupportive system rather than integrated into a responsive community. (126) When policies and resource allocation do not align with community needs, providers may also lack the support of strong inter-professional collaborations to provide integrated and community-based perinatal care. (95,96,115)

Discussion

This integrative review describes the perinatal outcomes and experiences of people living with social and economic exclusion in Canada. Shifting the focus from individual population groups, this review aims to identify social and structural factors that may contribute to perinatal inequities.

Families experiencing social and economic exclusion in Canada are both more likely to experience poorer perinatal outcomes and be left with greater unmet health and social needs postpartum. Importantly, the experience of being ‘othered’ while navigating perinatal health and social services was a recurring theme across all populations. Our findings have implications for both research and practice. This integrative review identified several areas where data was not available for populations known to experience poorer health outcomes in general in Canada. This is in part due to an underfunded and disjointed maternal health surveillance system unable to capture maternal health indicators among populations living along Canada’s social fault lines, including the continuing lack of race-based data on perinatal

health outcomes. (103) These findings echo the calls to action of Canada's Truth and Reconciliation Commission (TRC), which calls on the federal government to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities. The TRC highlights several areas critical to reducing reproductive health inequities in Canada, including discrepancies in infant mortality, maternal health, suicide, mental health, addictions, infant and child health issues, chronic diseases, and the availability of appropriate health services. (127) That Canada does not routinely collect race and ethnicity data linked to perinatal outcomes reflects the types of outcomes that have been valued. What data is prioritized and routinely captured and what remains as silence is shaped by social and scientific norms about what knowledge is important in a particular context and society. (104,121,128) Those at the margins are rarely heard within institutional decision-making structures and therefore have little influence over academic research and clinical practice. (104) Those carrying the greatest burden of health inequities need a stronger voice in the planning and implementation of their health care and the systems meant to support it, yet for the most part, remain excluded from decision-making processes. (104,129,130)

This work also has significant implications for the training of healthcare providers. The majority of health professionals have been trained under a biomedical model that focuses on curing and controlling disease and managing physiological processes. (131) Several approaches aim to equip healthcare providers with the skills and cognitive frameworks to deliver appropriate and comprehensive care to all patients. A common approach focuses on cultural competence and trauma-informed care, which draw attention to cultural and social factors influencing health, well-being and health behaviours, encouraging more personalized and comprehensive care based on individual patients' needs. (132) Less common, but more transformative approaches include cultural safety training, where specific attention is given to power differentials between service users and providers. This approach places the burden on the providers to examine the institutional discrimination and relational power imbalances that shape vulnerabilities and the patient-provider relationships. (15,133) While cultural safety training offers great promise for improved care of marginalized groups, consideration of institutional and organizational barriers is also necessary to address the needs of marginalized women and those providing perinatal care. (15,121) Researchers, healthcare providers and administrators also have an opportunity to influence the systems they work in by pushing for

curriculum change, equitable admissions processes, and supporting the work of under-served communities who may not hold the same levels of financial and social capital. These findings are echoed by calls to recognize the contributions of Indigenous health and healing practices to the care and well-being of Indigenous populations, which includes training on cultural safety and the social responsibility of health and social professions, with some suggesting this also requires shifting the culture of medical practice itself. (127,134)

Findings from this review reinforce the increasing attention across Canada in family-centered, trauma-informed approaches to perinatal care. While currently limited in reach and capacity, several care delivery models have shown that with a more responsive and comprehensive approach to care, they have been able to address many of the inequities described in this review. (66,135-138) Many of these programs shift away from deeply held attitudes and beliefs that lead to labelling, devaluing and discriminating and while also re-designing care to pushback against the processes that maintain these perceptions as dominant ones. (116,139) Evidence demonstrates that harm reduction approaches offered during pregnancy are effective in improving health outcomes and decreasing costs for people with complex care needs due to substance use, mental health concerns, experiencing violence and living with low socio-economic support. (137,138) In a matched cohort study, Fleming et al. found adolescents receiving specialized multidisciplinary community-based perinatal care had significantly lower risks of low birth weight and preterm delivery, and higher rates of prenatal visits, prenatal class attendance and group B streptococcus screening compared with adolescents across Ontario, despite higher levels of tobacco, alcohol and other substance use than the control group. (138) Increasing evidence also suggests the importance of cultural continuity and community leadership in shaping perinatal care, particularly for communities most likely to experience racism and discrimination in the health system. These initiatives help to re-frame, develop, implement and evaluate prenatal, reproductive and child health services grounded in culturally-meaningful understanding. (105,124,125) These promising results suggest the organization and delivery of health-systems have an important influence on perinatal outcomes for families experiencing economic and social exclusion. They point to successful strategies such as broad inter-professional collaboration, comprehensive care including both health and social care and non-judgmental and supportive approaches to understanding families' needs. Other initiatives aim to influence perinatal health by addressing

more upstream determinants. A study by Brownell et al. showed higher birth weights and less preterm births in a cohort of low-income women who received a small monthly income supplement in the prenatal period. (140) These results underscore the important role that poverty plays in shaping reproductive health and the potential for intersectoral public policy to improve perinatal outcomes.

This review has recognizable limitations. Our reporting does not include all findings from all extracted studies, which biases interpretations towards the stated interest of the review. We are working to also include studies reporting on outcomes and experiences from pregnant people who use substances, who identify as lesbian, gay, bisexual, transgender, queer and/or two-spirit, people who are incarcerated, or identified as obese. To fit with the concern of the larger project with who is left out of the scientific literature, we only searched major databases to identify how perinatal outcomes are described to a broad audience. More contextualized evidence may be available by searching in more specialized databases and grey literature. The screening, data extraction and interpretation were done by the lead author in consultation with senior authors (NA, AN).

We recognize that our organization of population categories is not comprehensive. Some categories overlap and can change over time. Our interest was not to examine under-served populations as categories or identities. Instead, we wanted to highlight common experiences of how social, economic, historical and political structures contribute to inequities, guided by intersectionality theory. (115,130) We did not try to identify, for example, how being Indigenous affects perinatal outcomes, but rather how existing political, structural and organizational contexts selectively impose vulnerability upon Indigenous families. (130) In our analysis of shared themes, we highlighted how social and structural inequalities contribute to a shared experience of navigating perinatal care.

Conclusions

This review presents a broad analysis of perinatal health among populations that face a common experience in navigating Canada's perinatal health and social services while living with multiple forms of structural and social exclusion. Much of perinatal health literature focuses on the downstream effects of a longer process of social exclusion. (141) This review

focuses on identifying patterns in outcomes and experiences among under-served populations to identify how more upstream social and structural determinants may shape perinatal health.

The review underscores the role of social and scientific norms around what knowledge is important in a particular context and society. We highlight the need for research to be informed by the lived experience of communities carrying the greatest burden of perinatal inequities in Canada. Centering research and health service design around the needs of those they are intended to serve, as well as providers working within a system that doesn't always provide the space or incentive to enable them to offer the level care they would like, will contribute both to shifting how we collectively understand the barriers to addressing perinatal inequities and potential solutions. This also requires updating data and surveillance systems to better capture the risks and outcomes prioritized by under-served groups to understand system improvements and remaining gaps. This review also importantly demonstrates how the organization of health systems can be re-oriented to foster responsive, comprehensive, and non-judgmental care addressing both health and social care needs of under-served populations. These changes require knowledgeable and caring administration together with adequate funding and culturally safe professional services for all those living with social and economic exclusion.

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Chapter 3: Grounding evidence in experience to support people-centered health services (Manuscript #2)

The previous chapter's literature review highlighted the importance of examining how social and organizational factors influence perinatal health, as well as how epistemological assumptions shape what is considered relevant knowledge and which questions receive sustained research attention. These findings further focused my doctoral research around the challenge of integrating perspectives of socially excluded populations with the best available evidence, motivated by the desire to contribute to more respectful and useful services for under-served populations. Several authors have highlighted the challenges of stakeholder involvement in evidence synthesis more broadly, including poor operationalization and a lack of understanding of how stakeholder input influences evidence interpretation and translation. (A. George et al., 2017; Pollock et al., 2018)

This chapter introduces Weight of Evidence as a systematic approach to contextualize published evidence in stakeholder experience. I draw on findings from the literature review presented in the previous chapter on unmet postpartum needs among recent immigrant women to demonstrate each step in Weight of Evidence. The method introduced in this chapter, and described in more detail in the next chapter, offers a formal procedure to contextualize evidence in stakeholder knowledge to support more responsive service design and quality improvement.

I am the first author of this chapter. Under the guidance of Dr. Neil Andersson, I worked with Dr. Lawrence Joseph to develop the methodology around the use of stakeholder weights from fuzzy cognitive maps as Bayesian priors for updating of the literature, and with Dr. Émilie Robert to ground the Weight of Evidence in a realist philosophy. Together with Dr. Joseph and Dr. Robert, Dr. Andersson and I developed the overall method and conceived of the pilot study. I led the pilot study and Dr. Vania Jimenez, Dr. Alessandro Gutierrez and Amal Ben Ameur all contributed to the pilot study. This chapter is published in the International Journal of Public Health.

“Making health care truly universal requires a shift from health systems designed around diseases and health institutions towards health systems designed around and for people.”
(Zsuzsanna Jakab, WHO Regional Director for Europe) (James et al. 2018)

Introduction

Evidence-informed and equity-oriented public health policy and practice require that people’s voices, especially those less heard, be central to decision-making in public health (Serrant-Green 2011). Stakeholder engagement is particularly urgent in the context of health inequities, where perspectives of those who carry the greatest burden of inequities are often poorly reflected in published literature (Serrant-Green 2011). Decision-makers in public health need robust and locally relevant tools that take account of both biomedical and cultural understandings of health and that support people’s participation in planning, implementation and evaluation (Napier et al. 2014). Leveraging several well-established tools from participatory research, systems science and Bayesian analysis, under a critical realist philosophy, we present a novel approach to knowledge synthesis, called the Weight of Evidence. This approach pushes conventional boundaries of who (or what) constitutes health service expertise through the formal inclusion of experiential knowledge from patients and/or communities, care providers and resource decision-makers, together on even footing with epidemiological studies (Borda 1996; Midgley 2000). This method unfolds in five steps:

1. A conventional mixed methods synthesis of the research literature summarizes what is known about an outcome of interest, representing this knowledge as a map;
2. Independently, stakeholders generate cognitive maps that identify and weight factors they believe influence the outcome;
3. Update the literature-based map with stakeholder knowledge using Bayesian analysis;
4. Suggest explanations of how social, economic and organizational contexts contribute to outcomes prioritized in cognitive maps; stakeholders adjust these explanations according to their experience; and
5. Stakeholders develop recommendations accordingly.

In this publication, we outline the Weight of Evidence process, highlighting some of the key insights from our pilot work addressing inequities in perinatal health in Canada, while a full description of our methodological development results is forthcoming. Weight of Evidence

proved an excellent way to engage meaningfully with divergent perspectives, creating space for multiple and complex ways of understanding health and health services.

Mapping evidence

Step 1 follows existing guidelines to support comprehensive mixed methods evidence syntheses, pooling effect estimates when appropriate using standard meta-analyses techniques (Pluye and Hong 2014). We converted all effect estimates to odds ratios and transformed them into a common scale (- 1 to +1) (Andersson et al. 2017). We then summarized findings in a concept map where nodes in the map represent themes from qualitative studies or independent variables from quantitative studies, and the strength of the arcs connecting nodes describe the effect estimates (Ozesmi and Ozesmi 2004; Giles et al. 2008). In our demonstration case, we focused on unmet postpartum care needs among recent immigrant women as an important health inequity in Canada (Gagnon et al. 2013). Our concept map also included evidence from the broader literature on perinatal health outcomes and experiences of recent immigrant women in Canada, as shown in Figure 3.1.

Co-producing evidence

For Step 2, determining who needs to be at the table is often driven by what expertise is considered relevant (Midgley 2000). This is of particular importance in matters of health inequities, as those who live with the everyday effects of vulnerability bring relevant expertise on their access to care and their ability to maintain their health and well-being yet are often excluded from decision-making processes (Borda 1996). Thoughtful and extensive consideration of who to engage, and how, has important implications for how the process unfolds. In our demonstration case, we recruited stakeholders for accessibility and their ability to contribute to the understanding of the issue as either a healthcare provider or social support to recent immigrant women in a large Canadian city.

Informed by published evidence, stakeholders are guided through the development of their own cognitive maps, describing factors they believe influence the outcome (Ozesmi and Ozesmi 2004; Giles et al. 2008). Stakeholders then assign a weight or perceived importance, on a scale of 1 through 5 and direction of effect (+ ve or - ve), to each relationship in their updated map. In our demonstration case, stakeholder-identified factors were notably more

actionable than those identified in the literature. Service providers and patient representatives focused less on conventional individual “risk factors” (e.g., education or specific health behaviors) and more on the support systems around women throughout the perinatal period. This illustrated how including stakeholder knowledge as a complement to published literature can broaden both the problem definition and the menu of interventions.

Cognitive maps that account for interdependence between factors can act as a decision aid for complex processes like clinical care, where artificially isolating associations within a de facto network or results chain can diminish the contextual understanding and relevance of decisions (Napier et al. 2014). Step 3 accounts for this interdependence first by normalizing stakeholder-assigned weights to the same - 1 to + 1 scale used for the literature-based maps, creating a comparable relative measure of the importance of each factor to our outcome of interest: 0 indicating no importance and +1 (or - 1) indicating great importance in determining the outcome. A transitive closure algorithm (ProbTC) allows weights between factors (scale of 0–1) to be analyzed using probability theory, (Niesink et al. 2013) as has been done in other areas of medicine and public health (Giles et al. 2008; Andersson et al. 2017). This algorithm adjusts each weight to account for all other factors in the map, and highlights walks, or underlying relationships between factors, identifying possible priorities in addressing the outcome (Niesink et al. 2013).

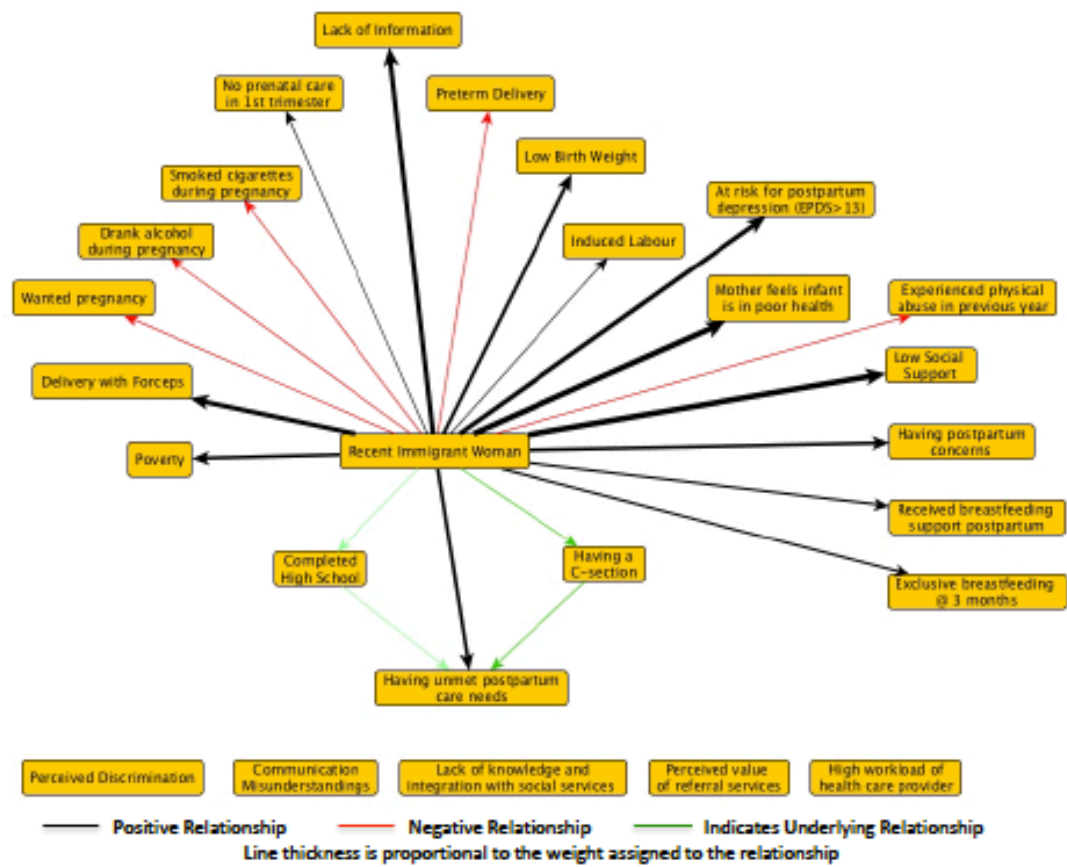


Figure 3.1: Fuzzy cognitive map of available literature on unmet postpartum care needs among recent immigrant women in Canada. EPDS is the Edinburgh Postnatal Depression Scale. A score greater than 13 on the EPDS is interpreted as probable depression (Cox et al. 1987) (Canada, 2016)

To bring these different perspectives in conversation with one another, we drew on Bayesian analysis as a formal method to integrate stakeholder perspectives with published literature. Conventional Bayesian analysis elicits prior weights from experts by asking how likely they consider the occurrence of an event to be (Gelman et al. 2013). Our approach instead asks patients and other stakeholders how important they consider each factor to be to the outcome, what (relative) weight would they place on this factor. Describing both stakeholder views and published evidence using weights normalized to the same (- 1, + 1) scale, Bayesian analysis combines what is known about a relationship with observed data about that same relationship, by calculating a posterior distribution using Bayes' theorem (Goldstein 2006; Gelman et al. 2013). This also allows for a formal accounting of the uncertainty around both epidemiological data and stakeholder perspectives, highlighting differences in perspectives both within and between knowledge sources. Each updating of published evidence with stakeholder knowledge produces a new architecture, as weights are reinforced where there are areas of agreement between stakeholders and published literature and diminished where there are areas of disagreement (Goldstein 2006; Kruschke 2015). Figures 3.2 and 3.3 show the published evidence on unmet postpartum care needs updated by family physician perspectives and patient representatives, respectively.

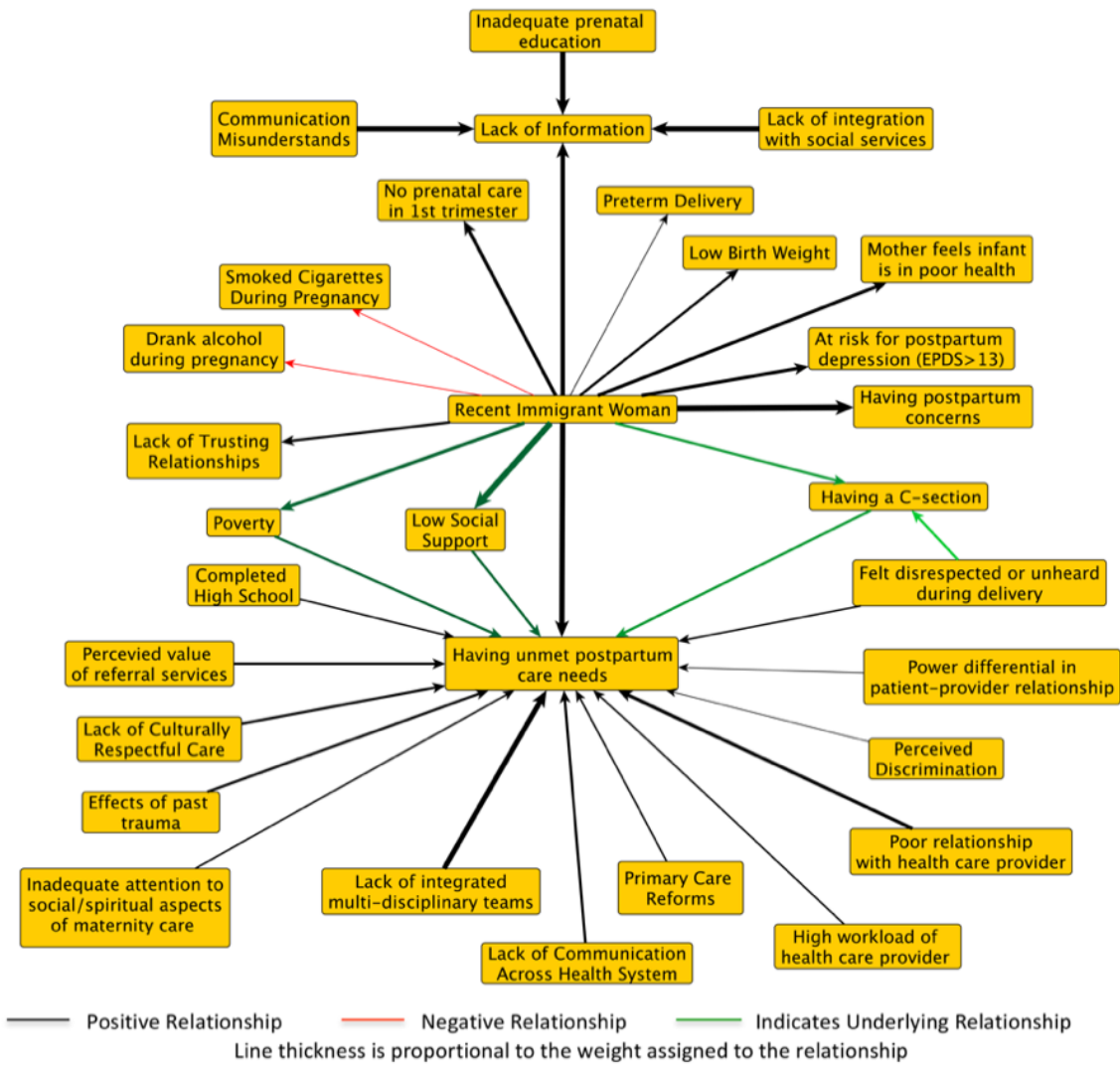


Figure 3.2: Fuzzy cognitive maps of the literature updated by family physicians. EPDS is the Edinburgh Postnatal Depression Scale. A score greater than 13 on the EPDS is interpreted as probable depression (Cox et al. 1987) (Canada, 2016)

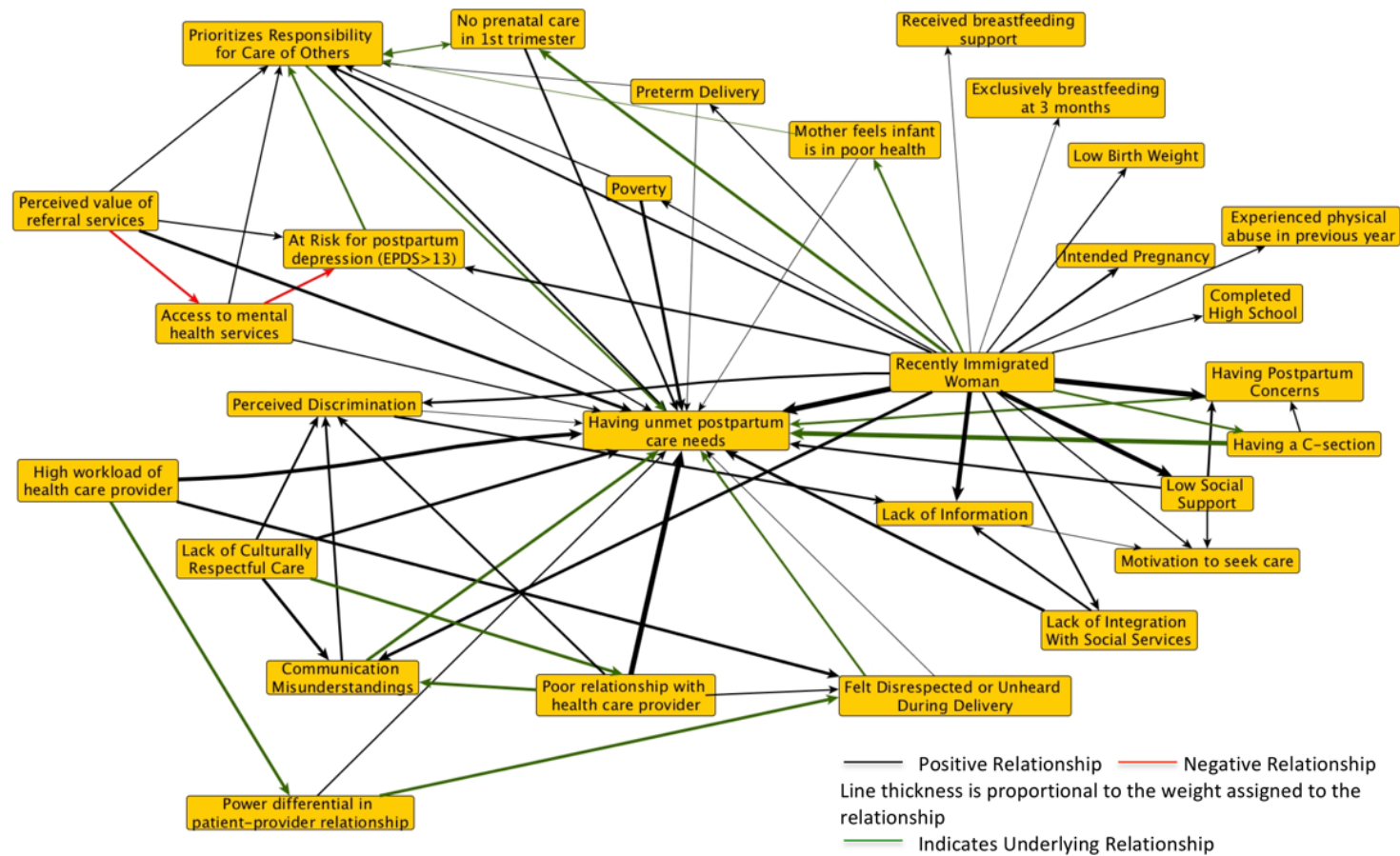


Figure 3.3: Fuzzy cognitive maps of the literature updated by patient representatives. EPDS is the Edinburgh Postnatal Depression Scale. A score greater than 13 on the EPDS is interpreted as probable depression (Cox et al. 1987) (Canada, 2016)

Patient-centered improvement strategies

Step 4 requires that we understand cognitive maps as conceptual, not probabilistic models (Mingers 2005). Along with the narratives that accompany their construction, they show how stakeholders make sense of their experience in the context of evidence from the literature. Here, explanatory power draws on critical realist philosophy, where explanatory accounts point to how social, economic and organizational contexts contribute to outcomes prioritized in the literature or in stakeholder maps (Pawson 2000; Bhaskar 2008).

Stakeholders are then asked to adjust these possible explanations to coincide with their experience. This is especially important when working with marginalized communities, a setting where theories and explanations generated outside the community may reinforce erroneous stereotypes (Tuck 2008). Bringing diverse perspectives together can balance often implicit assumptions within clinical practice, health services and policies with patient experience and understanding (Harris et al. 2016). Our demonstration case showed how the lack of supportive relationships for marginalized women influenced perinatal health and highlighted how specific policy or organizational structures can contribute to unresponsive care.

Step 5 focuses on the identification of care recommendations. Engaging stakeholders in the explanatory analysis in the previous steps creates space not only for different forms of knowledge about how a particular system works but also shifts the realm of possible improvement strategies (Midgley 2000).

Methods to support more responsive health services

Moving toward more people-centered health services requires that we take better account of how people's understandings of determinants of poor health intersect with conventional biomedical evidence (Napier et al. 2014). Yet few methods within primary healthcare research preserve divergent perspectives, ending up instead homogenizing and losing the richness within difference (Keller 1992). Weight of Evidence presents a rigorous and transparent approach to unpack differences, to identify how and when these differences arise and with what consequences.

We share this work as an invitation to include methodological innovations as part of our collective response to calls for more people-centered health systems (James et al. 2018). Citizens, particularly those carrying the greatest burden of health inequities, need to have a stronger voice in the planning and implementation of their health care and the systems meant to support it. Participatory methods that are both robust and transparent are key to getting us there.

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Compliance with ethical standards

Conflict of interest: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/doi_disclosure.pdf and declare: no support from any organization for the submitted work.

Ethical approval: The pilot work described in this study was carried out as a quality improvement initiative with contributing family physicians (VJ, ACG) and patient representatives (ABA, AD) included as authors. The full implementation of this method has been approved by the McGill Faculty of Medicine Institutional Review Board (A09-B51-17A).

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Chapter 4: *Weight of Evidence*: using participatory methods and Bayesian updating to contextualize evidence synthesis in stakeholders' knowledge (Manuscript #3)

Building on the introduction to Weight of Evidence in the previous chapter, this chapter offers a comprehensive description of the procedure, including its philosophical and methodological orientations. Each step is presented in detail, drawing on the pilot study examining unmet postpartum care needs among immigrant women introduced in the previous chapter. This chapter establishes and explains each operation through a worked example, envisioned as a resource for researchers who may wish to apply Weight of Evidence in their own work.

I am the first author of this chapter. Under the guidance of Dr. Neil Andersson, I worked with Dr. Lawrence Joseph to develop the methodology around the use of stakeholder weights from fuzzy cognitive maps as Bayesian priors for updating of the literature, and with Dr. Émilie Robert to ground the *Weight of Evidence* in a realist philosophy. Together with Dr. Joseph and Dr. Robert, Dr. Andersson and I developed the overall method and conceived of the pilot study. Iván Sarmiento contributed to our approach to analysis fuzzy cognitive maps as part of our methods. I led the pilot study and Dr. Vania Jimenez, Dr. Alessandro Gutierrez and Amal Ben Ameer all contributed to the pilot study. This manuscript is accepted for publication in the Journal of Mixed Methods Research.

Abstract

Wrestling with questions of what counts as valid knowledge requires examining evidence in context across multiple perspectives, to which mixed methods research is uniquely suited. This article introduces Weight of Evidence as a transformative procedure for stakeholders to interpret, expand upon and prioritize evidence from evidence syntheses, with a particular focus on engaging those who have been historically left out of planning and decision-making. We present the procedure's five steps using pilot data on perinatal care of immigrant women in Canada, engaging family physicians and birth companions. Combining cognitive maps across different stakeholder perspectives operationalizes a mixed methods dialectic stance, while our use of fuzzy cognitive mapping offers an accessible and systematic way to update published

literature with stakeholder priorities. This article presents a concrete example of how advanced statistical tools applied within a transformative perspective offers a transparent procedure to unpack differences, to identify how and when these differences arise and with what consequences, for a more comprehensive, context-specific, and actionable understanding.

Background

Systematic reviews and meta-analysis have long been considered the highest value synthesis of evidence in health sciences. (Shea et al., 2007) Systematic reviews have strict demands around quality and comparability, however this often leads to the exclusion of contextual information important to understanding the issues at hand. (Harris, Croot, Thompson, & Springett, 2016) Recent advances in mixed methods reviews demonstrate the value of combining qualitative and quantitative findings, often derived from differing perspectives and epistemologies, in evidence syntheses. (Batalden & Davidoff, 2007; Greenhalgh, Jackson, Shaw, & Janamian, 2016; Harris et al., 2016; Pluye & Hong, 2014) Knowledge synthesis approaches such as critical interpretive synthesis, realist reviews and narrative reviews, offer rich interpretations sometimes across different paradigms. (Dixon-Woods et al., 2006; Pawson, Greenhalgh, Harvey, & Walshe, 2006; Popay et al., 2001; Sandelowski, 1991) This can be complex when translating and synthesizing evidence from differing perspectives, requiring a diversity of concepts, theories and methods that may be at odds with one another. (Di Ruggiero, 2018; Mertens & Hesse-Biber, 2013)

Wrestling with questions of what counts as valid knowledge requires that we examine evidence in context and that we engage multiple perspectives on complex social problems, to which mixed methods research is uniquely suited. (Di Ruggiero, 2018; Mertens & Hesse-Biber, 2013) There are several tools and approaches to assess quality and trustworthiness of evidence during evidence synthesis. These approaches are often driven by adherence to methodological steps to assure the quality and rigour of evidence with little questioning of who decides what is good evidence for a specific context and how.

This article introduces Weight of Evidence as a transformative procedure to contextualize evidence in the understanding of relevant stakeholders. Weight of Evidence does not propose

a new way to conduct evidence syntheses but presents a transparent and systematic procedure for stakeholders to interpret, expand upon and prioritize evidence from synthesis, with a particular focus on engaging those historically excluded from planning and decision-making. Weight of Evidence can be used to inform local service improvements, program design or evaluation as well as to refine syntheses efforts. We expect this procedure to be of interest to mixed methods researchers as it draws on and operationalizes Greene and Hall's dialectic stance, where differences in understanding are generative and able to contribute to causal understanding and ultimately lead to more informed and consultative decision-making. (Befani & Stedman-Bryce, 2017; Greene & Hall, 2010)

This article begins with a description of Weight of Evidence's philosophical orientations and methodological approaches. Each step is then described together with a brief description of how the procedure was applied through a pilot study with family physicians and birth companions around unmet perinatal care needs of recent immigrant women in Canada. Finally, the contributions to mixed methods research accompany considerations for researchers interested in applying this procedure in their own work.

Method:

Philosophical pillars of Weight of Evidence

Three complementary philosophical approaches orient Weight of Evidence. The first is rooted in transformative participatory research that enacts the important principle that people have a right to be involved in decisions that shape their lives. (Borda, 1996; Mertens & Hesse-Biber, 2013; L. T. Smith, 2012; Wallerstein, 1992) Participation makes research processes and interventions more relevant to local needs and priorities, and therefore more effective. (George, Mehra, Scott, & Sriram, 2017) Commitment to participatory research stems from the belief that people make better decisions when they benefit from both scientific and more informal forms of knowledge. This includes contributions from evidence transferred through theoretical or statistical inferences, often developed through empirical studies or syntheses. It also includes context-specific understanding, meaning knowledge claims based on local settings, experience and tacit understanding of practice and organizational 'know how'. (Oliver et al., 2018) Weight of Evidence incorporates stakeholder perspectives on even footing with evidence synthesized from the literature.

A second orientation of the Weight of Evidence is a critical realist philosophy, which recognizes there is a real world with which we interact, though may never truly know, and that one's social position and context affect how they understand and navigate through the world. (Bhaskar, 2008; Maxwell & Mittapalli, 2010) Weight of Evidence is guided by critical realist reasoning in leveraging qualitative, quantitative and stakeholder-derived understanding to develop causal explanations. (Maxwell & Mittapalli, 2010)

A third orientation is standpoint theory, recognizing that all knowledge is socially situated and that one's social position and context affect how they understand and navigate through the world. Standpoint theory suggests that disadvantaged groups have critical perspectives to offer in understanding the status quo as they navigate more mainstream systems from a position of marginalization. (Collins, 1986; Harding, 2003) This is consistent with arguments long-made by leading feminist, Indigenous, disability-rights and working-class academics, activists and communities, as well as within mixed methods research. (Collins, 1986; Harding, 2003; Lavell-Harvard & Anderson, 2014; Maxwell & Mittapalli, 2010; Tuck, 2008) While Weight of Evidence seeks to engage all relevant stakeholders around a particular issue, it emphasizes meaningful engagement of groups historically excluded from contextualization and decision-making opportunities.

Methodological pillars of Weight of Evidence

Weight of Evidence is also informed by three complementary methodologies. Bayesian statistics provide a formal statistical procedure to learn from data (or knowledge) outside of conventional epidemiological models and incorporate this data together with established models. (Gelman et al., 2013; Joseph, 2000a; Sprenger & Hartman, 2019) This form of learning by incorporating knowledge external to an empirical study is called Bayesian updating. (Goldstein, 2006) Several studies have used Bayesian updating to combine qualitative and quantitative findings from studies, either by quantifying qualitative data, coding the presence and absence of themes in both the qualitative and quantitative literature, or by drawing on qualitative data to create prior distributions. (Crandell, Voils, & Sandelowski, 2012; Roberts, Dixon-Woods, Fitzpatrick, Abrams, & Jones, 2002; Voils et al., 2009) Disciplines outside of health science have also drawn on Bayesian statistics to contextualize published literature in

end-user perspectives. (Badampudi & Wohlin, 2016; Badampudi, Wohlin, & Gorschek, 2019) Weight of Evidence applies Bayesian statistics to juxtapose and to combine stakeholder knowledge with empirical evidence reflected in a synthesis.

A second methodological pillar is boundary critique, a systems thinking concept that argues that broadening system boundaries can be helpful to understanding underlying values and offer insights about how a particular system works. (Churchman, 1970; Flaspohler et al., 2003; Foster-Fishman, Nowell, & Yang, 2007; Midgley, 2000) Examining multiple perspectives on complex issues can generate understanding through the comparison and sometimes combining of different ways of knowing and experiencing the same phenomenon. (Greene & Hall, 2010; Ulrich, 1998) Weight of Evidence operationalizes boundary critique to broaden what counts as relevant expertise.

A third methodological pillar of Weight of Evidence is graph theory, building on a long history of using diagrams to represent how things relate to one another, spatially or conceptually. (Andersson & Silver, 2019; Biggs, Lloyd, & Wilson, 1998) In Weight of Evidence, fuzzy cognitive maps serve as a critical translation tool to make both epidemiological data and knowledge from stakeholders available to decision-makers. (Kosko 1988) Through data transformation, combining fuzzy cognitive maps brings different knowledge types in conversation with one another. (Fetters, Curry, & Creswell, 2013; Kosko, 1988; U. Özesmi & Özesmi, 2004)

Preparatory step: Identify focus and synthesize published literature

General description: Weight of Evidence begins once a systematic synthesis of published evidence is complete. The synthesis can be quantitative, qualitative, or mixed and of any design. While Weight of Evidence can be used with any type of question, it may be most useful for questions where considerable contextual understanding might influence intervention success and decision-making, such as complex interventions. (Booth et al., 2019)

In practice: We searched for primary studies describing perinatal (during pregnancy to 12 months post-partum) health outcomes and experiences of immigrant women within 5 years

of their arrival to Canada published in French or English after the year 2000 in Medline, CINAHL and Web of Science. Our search identified 91 publications. The lead author (AD) assessed all abstracts to determine eligibility and appraised eligible articles using the Joanna Briggs Institute (JBI) checklists for case control or cohort for quantitative studies and Interpretative & Critical Research (JBI QARI) for qualitative studies. Our protocol specified that studies would be excluded only if they had fatal flaws and scored below 60% on any scale, however no studies met this criteria. (Higginbottom, Hadziabdic, Yohani, & Paton, 2014; Joanna Briggs Institute, 2017b; 2017a; 2017c; 2017d) We extracted data from 39 relevant articles (24 quantitative, 15 qualitative) using inductive thematic synthesis for qualitative findings and descriptive statistics for quantitative findings. (Braun & Clarke, 2006; Pluye & Hong, 2014; Popay et al., 2001)

Among eligible articles, 8 publications (5 quantitative, 3 qualitative) focused on unmet postpartum care needs among recent immigrant women. This was selected as the outcome of interest for this pilot study because it is a clinically relevant outcome, addresses a core interest of our research group (the intersection of marginalization and perinatal health) and is well-described in the literature. (Auger, Giraud, & Daniel, 2009; Bouris, Merry, Kebe, & Gagnon, 2012; Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; Gagnon et al., 2010; 2007; Gagnon, Dougherty, Wahoush, Saucier, Dennis, Stanger, et al., 2013b; Gagnon, Merry, & Haase, 2013c; Gagnon et al., 2012; Higginbottom, 2013; Higginbottom et al., 2014; Merry, Gagnon, Kalim, & Bouris, 2011; Merry, Small, Blondel, & Gagnon, 2013; Mumtaz, O'Brien, & Higginbottom, 2014; Munro, Jarvis, Kong, DSouza, & Graves, 2014). Recent immigrant women to Canada are at increased risk of postpartum health concerns, including postpartum depression, abnormal blood pressure, maternal pain and lack of access to contraception compared with their Canadian-born counterparts (OR=1.69, 95%CI 1.46-1.96). (Gagnon, Dougherty, Wahoush, Saucier, Dennis, Stanger, et al., 2013b) They are more than twice as likely to have these concerns unaddressed at one week (OR=2.24 95%CI 1.73-2.9) and four months postpartum (OR=2.36 95%CI 1.75-3.17) compared with Canadian-born women. (Gagnon, Dougherty, Wahoush, Saucier, Dennis, Stanger, et al., 2013b)

Step 1: Represent evidence as fuzzy cognitive map

General description: Findings from the evidence synthesis are translated into a fuzzy cognitive

map. (Giles, Haas, Sajna, & Findlay, 2008) Cognitive maps are made up of concepts or nodes (factors impacting the issue) and links that describe the relationships between factors that can be weighted by relative importance. (Giles et al., 2007; U. Özesmi & Özesmi, 2004) To facilitate comparison, all effect estimates are converted to a shared format (e.g. odds ratio, relative risk). (Bornstein & Hedges, 2019; Giles et al., 2008; U. Özesmi & Özesmi, 2004) Qualitative themes are included as ‘un-attached’ nodes when the included studies suggest a that a theme or concept contributes to the outcome of interest.

Step 1 in practice: Summarize evidence as fuzzy cognitive map

All effect estimates were converted to odds ratios (OR). When other statistics were presented, they were converted to the standardized mean difference (d), and then to an odds ratio. (Bornstein & Hedges, 2019) If multiple effect estimates described the same relationship, estimates were pooled using a Bayesian hierarchical random effects model with non-informative priors to account for within- and between-study sources of variation. (Joseph, 2000a) Figure 4.1 shows the fuzzy cognitive map from the evidence synthesis of factors contributing to unmet postpartum care needs among recent immigrant women in Canada.

Step 2: Stakeholders generate cognitive maps

General Description: This step begins by identifying stakeholders - people (or groups of people) that have an interest or stake in the selected outcome. Who to include as stakeholders is a question of relevance and expertise balanced with access, resource and equity considerations. (Midgley, 2000; Wallerstein & Duran, 2006) This step builds on existing protocols to generate fuzzy cognitive maps (described in more detail below) but advances them in several ways. (Andersson & Silver, 2019; Khan & Quaddus, 2004; U. Özesmi & Özesmi, 2004) Giles et al. had previously used fuzzy cognitive maps to represent published evidence. (Giles et al., 2008) This approach is adapted in Weight of Evidence to make both quantitative and qualitative evidence accessible to stakeholders while not requiring extensive training in evidence synthesis methods. Stakeholders are invited to represent their own knowledge and understanding on that same issue in a systematic way. (Giles et al., 2008) Data integration occurs as stakeholders adapt the map of published literature, adding or removing factors and/or the relationships between them.

Interviews start by asking participants to identify what they consider to be important factors contributing to the outcome of interest. They generate ideas independently and may be prompted to identify any relevant social and structural influences based on factors identified in the literature. Participants record each of their ideas on small, laminated magnets and are introduced to the literature-derived cognitive map (created in the previous step) on a magnetic white board.

They are invited to adapt it, incorporating their own ideas, remove factors they considered irrelevant and label more magnets if necessary. (Andersson & Silver, 2019; U. Özesmi & Özesmi, 2004) After grouping similar or synergistic factors, participants assign a weight and direction of effect (+ve or -ve, from 1 to 5) to each relationship in their map. Detailed notes or a recording capture the discussion during map construction and a photo is taken of each cognitive map to facilitate analysis.

Final stakeholder maps represent quantitative and qualitative data from the literature review, together with stakeholder-identified factors, with relationships between factors weighted for their importance in relation to the outcome. As maps are created by different stakeholders and stakeholder groups, they can be combined together and/or compared with one another as well as with the fuzzy cognitive map of evidence from the literature. (Kosko, 1986; 1988)

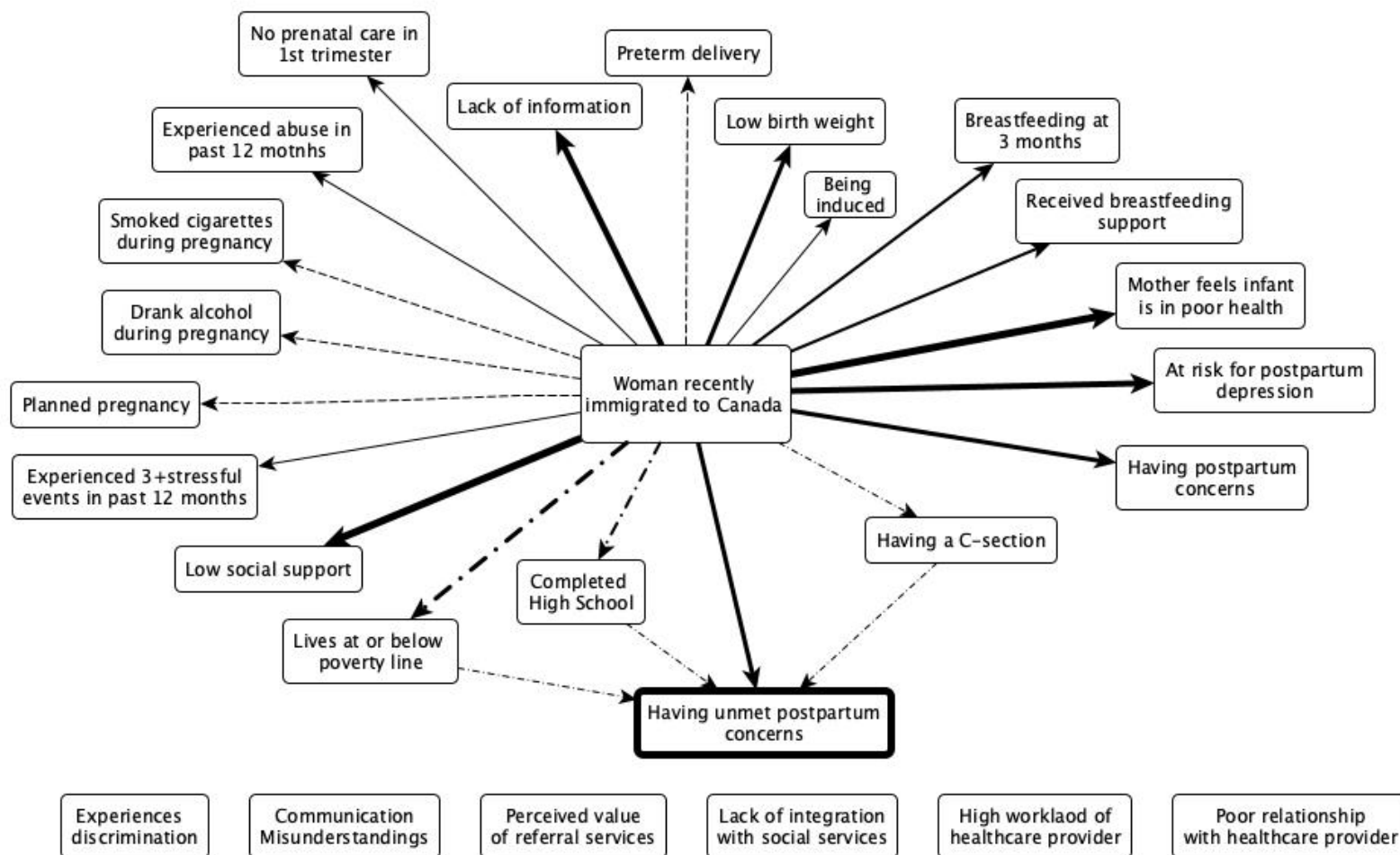


Figure 4.1: Fuzzy cognitive map of available literature on unmet postpartum care needs among recent immigrant women in Canada. Dashed lines indicate a negative relationship; dash-dot-dashed lines indicate an underlying relationship (described in Step 1)

Step 2 in practice: We purposively selected stakeholders for our pilot study based on expertise and interest in contributing to our pilot study. We interviewed three family physicians specialized in perinatal care of immigrant and refugee women for periods between 5 years to over 20 years in active practice, as well as two birth companions, with five- and eight-years experience in perinatal support to refugee and recent immigrant women. Birth companions provide physical, emotional and informational support, and help families navigate health and social services related to their pregnancy and early postpartum period. (Mahoney & Mitchell, 2016) The focus of this work was to demonstrate the Weight of Evidence procedure rather than to contribute directly to service improvements. Given there was no budget or organizational commitment to action the recommendations emerging from this study, our research group decided not to directly involve recent immigrant women. While not representing the perspectives of recent immigrant women, the inclusion of family physicians and birth companions provided a helpful example of how including different perspectives about a complex issue can provide valuable insight into understanding a problem and how these understandings together generate a more comprehensive understanding of the problem at hand.

The lead author conducted all semi-structured mapping interviews with birth companions and was joined by ACG (a family medicine resident) for the interviews with family physicians. Each mapping interview took approximately two hours. Fuzzy cognitive maps generated by family physicians and birth companions (Figure 4.2 and 4.3 respectively) identified many factors not in the literature. Both stakeholder groups described the experience of discrimination and a patient's feeling of not having a voice as important contributors to unmet postpartum care needs. Both groups also identified clinical factors, such as differences in the perceived value of referrals, socio-economic determinants, including poverty and social isolation, and structural or organizational factors, linking high provider workloads and fragmentation between health and social services.

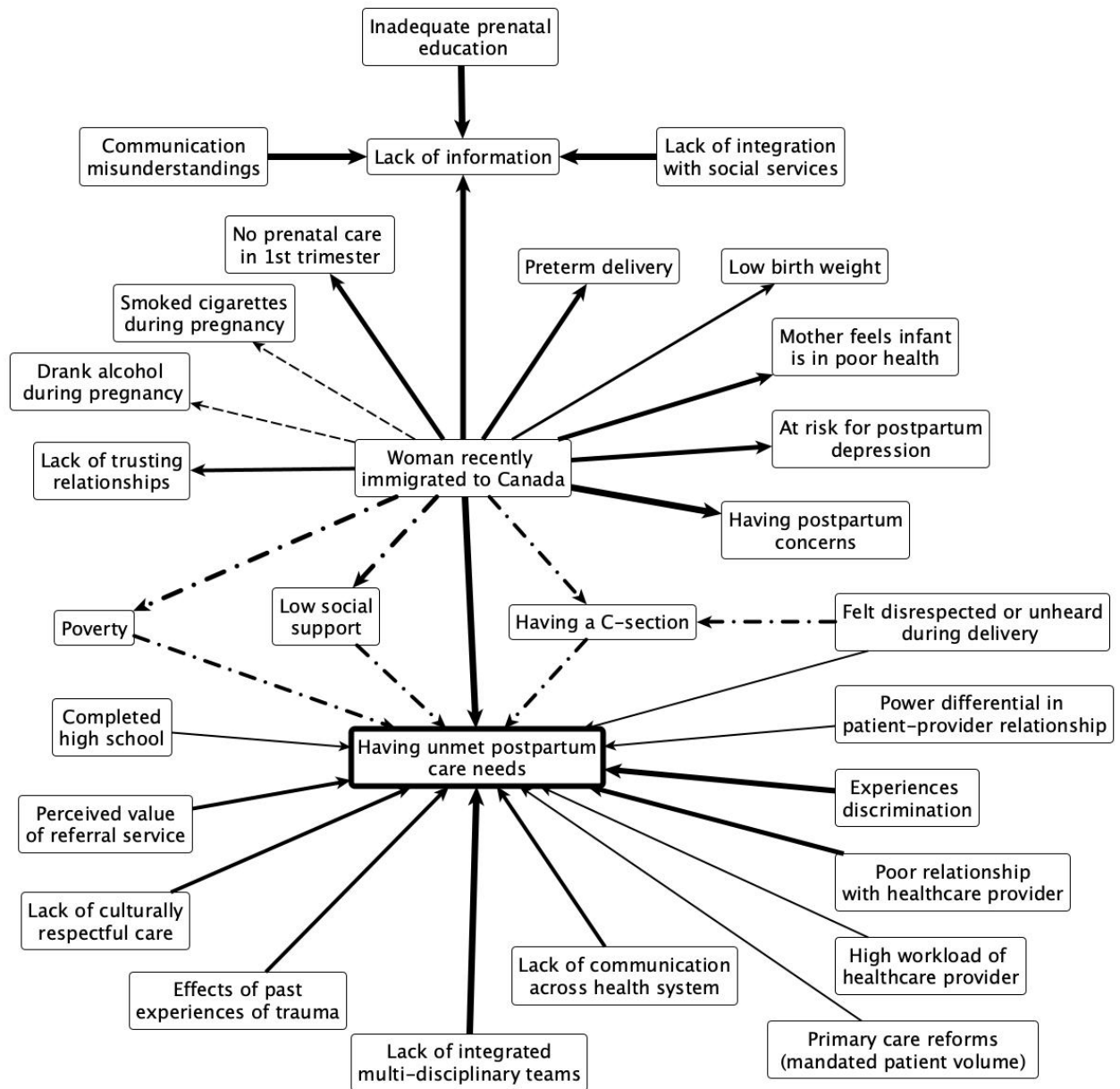


Figure 4.2: Fuzzy cognitive map of created by family physicians describing factors contributing to unmet postpartum care needs among recent immigrant women in Canada. Dashed lines indicate a negative relationship; dash-dot-dashed lines indicate an underlying relationship (described in Step 2)

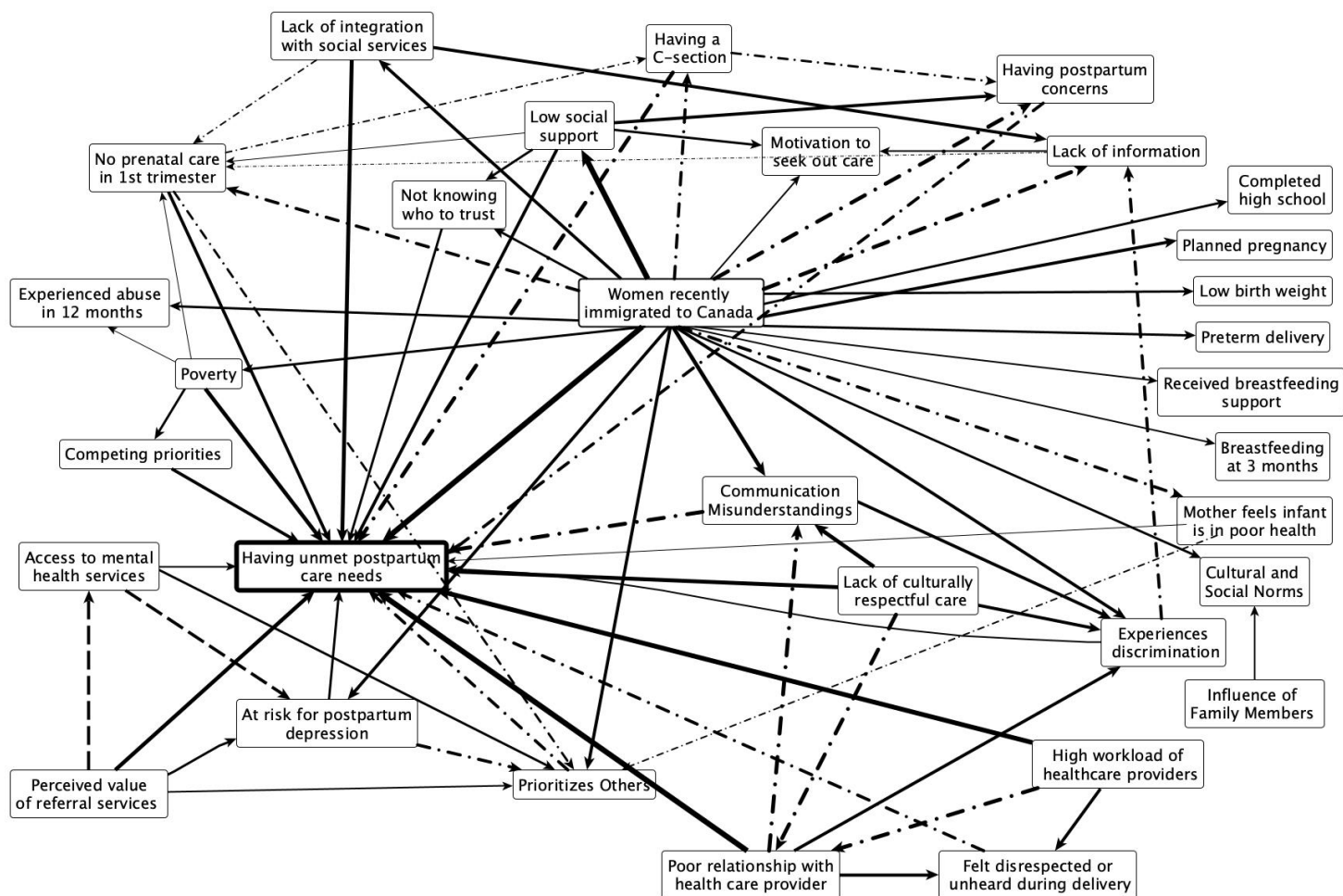


Figure 4.3: Fuzzy cognitive map of created by birth companions describing factors contributing to unmet postpartum care needs among recent immigrant women in Canada. Dashed lines indicate a negative relationship; dash-dot-dashed lines indicate an underlying relationship (described in Step 2)

Step 3: Compare and update literature-based evidence with stakeholder knowledge

General Description: This step operationalizes what Greene and Hall refer to as a ‘dialectic stance’ by engaging knowledge generated under different paradigms or mental models in respectful dialogue. In line with Greene and Hall, this step seeks to develop a more comprehensive understanding of a phenomena by comparing and combining knowledges, drawing on differences as generative, while documenting each perspective in a way that is transparent and ultimately traceable as to how each contributes to a more comprehensive understanding (Greene & Hall, 2010)

This dialectic stance is operationalized by first comparing and then combining different types of knowledge about a shared phenomenon. Fuzzy cognitive maps are converted to adjacency matrices to facilitate analysis, where factors are listed by row and column and the corresponding assigned weight at their intersection. To compare knowledge types, weights in both literature-based and stakeholder maps are normalized to the same scale of 0 (of having no influence) to 1 (of having the strongest possible influence). This creates a shared measure to represent the weight (or strength) of factors identified from the literature and stakeholder perspectives. While this puts weights on an equivalent relative scale, this does not change what those values represent, in that the effect estimates from quantitative literature remain measures of likelihood based on observed patterns of outcomes, and stakeholder weights represent a measure of perceived importance of what contributes to an outcome. Both represent measures of importance: one measured by patterns of observable outcomes, and the other through experiential knowledge by those with intimate understanding of the issue.

Normalizing maps to a probability-based scale (e.g., from 0 to 1) allows for the application of analytical tools that draw on probability science. In graph theory, reachability refers to the ability to get from one node to another within a graph. In directed graphs, this is calculated using transitive closure. (Niesink, Poulin, & Šajna, 2013) This algorithm accounts for all connections between pairs of concepts, as well as all implied connections between two concepts as a result of their being part of the same indirect pathway. (Giles et al., 2008; Morzaria & Šajna, 2016) Transitive closure accounts for how some factors might have small individual influence but all contribute as part of a sequence of events that have an important overall influence (Andersson, Beauchamp, Nava-Aguilera, Paredes-Solís, & Šajna, 2017; Giles

et al., 2008; Niesink et al., 2013) After applying a transitive closure algorithm to all maps, comparing factors, weights and walks between knowledge sets through a pattern matching table (Table 4.1) is a simple yet insightful way to identify areas of agreement and differences across knowledge sources.

Once on the same scale and relationships accounted for, maps can be put into conversation to formally update one knowledge source with another using Bayesian updating. (Goldstein, 2006) Bayesian statistics provide a formal statistical procedure to learn from data (or knowledge) outside of epidemiological models and incorporate this data together with established models. (Gelman et al., 2013; Joseph, 2000b) This use of weights from fuzzy cognitive maps as Bayesian priors to update published literature with stakeholder perspectives is an innovation unique to the Weight of Evidence.

A Bayesian model begins with a likelihood function over a set of parameters, a conventional measure of plausibility assigned to each parameter. In Weight of Evidence, these are the individual effect estimates and their measures of uncertainty (e.g., confidence interval) identified from the literature. In conventional Bayesian analysis, expert opinion, or other sources of data (e.g., observational studies) contribute to estimating a measure of certainty for each parameter. In Weight of Evidence, these are the stakeholder-assigned weights from the mapping process described in Step 2. Stakeholder-assigned weights for each factor combine to create a central measure and a distribution, representing the variability in stakeholder weights for that factor. These are represented as a normal distribution as it has an easily interpretable measure of central tendency and uncertainty (or variance). This forms the prior distribution, which when multiplied by the likelihood function, updates the parameters identified from the literature. (Gelman, 2013) The strength of Bayesian analysis lies in its ability to learn from the data in question by combining it with other forms of relevant knowledge, while explicitly accounting for the uncertainty in all types of knowledge. (Kruschke, 2015) The resulting posterior distribution represents updating on a conceptual, rather than probabilistic basis and contributes to generating explanatory accounts in the next step.

Step 3 in practice: Odds ratios from the literature-derived map (created in Step 1) were normalized using the formula $(1 - (2 / (OR + 1)))$. (Andersson et al., 2017) Stakeholder generated

maps (created in Step 2) were transformed by dividing the stakeholder assigned weights by the maximum weight possible (in our case 5). A transitive closure algorithm (ProbTC) was applied to each individual stakeholder map and the separate literature-based map. The resulting weight of any identified walk was calculated as the product of the weights of the component arcs or links. (Morzaria & Šajna, 2016; Niesink et al., 2013)

Figure 4.4 shows the walks identified through transitive closure across each of the three knowledge types. Figure 4.4 A shows the relationship between being an immigrant and low social support, living in poverty and having a Caesarean section identified by family physicians. Birth companions highlighted care responsibilities for other family and/or community members as a central element shaping unmet postpartum needs, particularly in the context of a high needs infant, having clinical signs of depression and not seeking out early prenatal care (Figure 4.4 Ci). Birth companions identified additional challenges around provider workloads, access to culturally safe and having access to accessible and appropriate information (Figure 4.4 Cii). While some of these factors were also mentioned in the qualitative literature, they were often done so without the explicit connection and weighting with respect to other factors influencing unmet care needs among recent immigrant women.

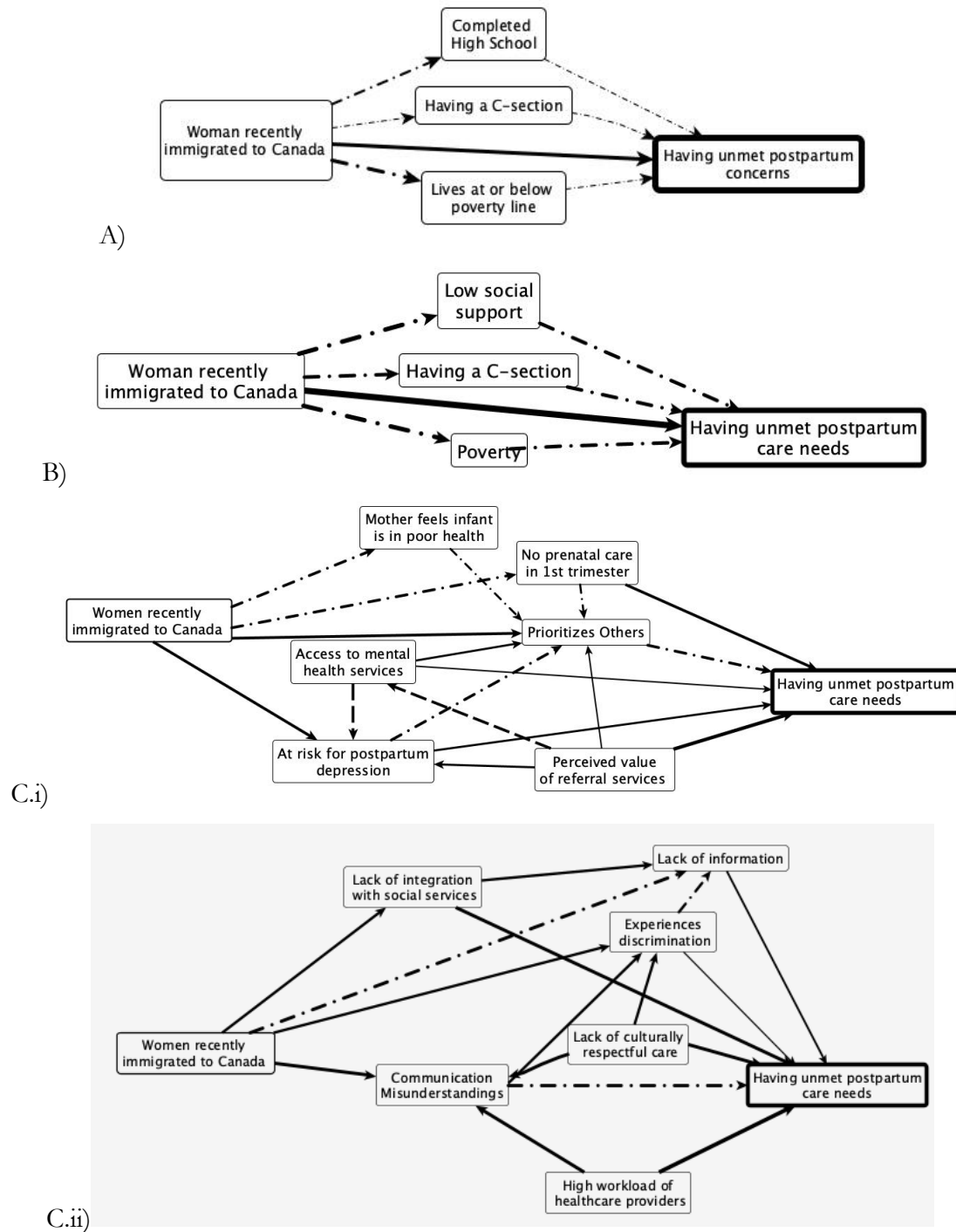


Figure 4.4: Underlying relationships in fuzzy cognitive maps by transitive closure in A) published literature B) maps created by family physicians and C) maps created by birth companions. Dash-dot-dashed lines indicate an indirect relationship identified by transitive closure

Weights averaged across each stakeholder group generate an average stakeholder-specific map, one representing clinicians and another representing perspectives of birth companions. Concepts and weights were compared across knowledge sources using a pattern-matching table (see Table 4.1). We calculated the average degree of disagreement between each of the different knowledge groups (literature, family physicians and birth companions) by calculating an average degree of disagreement between two knowledge sources, according to:

$$\bar{d} = \frac{\sum |d|}{N}, \quad (\text{Eq1})$$

where a higher value for $\bar{d}$ represents greater differences between knowledge groups. (Andersson & Silver, 2019) Consensus was greater between family physicians and birth companions ($\bar{d} = 0.31$) and lower between published literature and the birth companions ($\bar{d} = 0.45$).

Published literature was updated with prior weighting densities from the family physician perspectives, and separately from the birth companion perspectives for each non-zero cell in the adjacency matrices. (Bernardo & Smith, 2000; Joseph, 2000b) To simulate a full-scale implementation of this procedure, this analysis was also conducted with duplicated stakeholder maps to simulate a more appropriate sample size across each stakeholder group. A custom computer program using open access software was developed to implement three approaches to Bayesian updating (see Appendix 2- Additional File 4.2 for comparison of procedures). R statistical software was used to plot the weighting distributions for selected relationships identified in the data, stakeholder perspectives and from data updated by each stakeholder perspective. All maps were created using the open-access software *yEd*. (www.yworks.com/yed)

Table 4.1: Pattern matching table of factors and assigned weights relating to unmet postpartum care needs among recent immigrant women identified within the literature, and by stakeholder groups.

Concept	Literature	Family Physicians	Birth Companions
Similarities:			
Being an Immigrant	0.23	0.79	0.99
Poor relationship with provider		0.53	0.9
Having a Caesarean Section	0.17	0.46	0.8
Provider Workload		0.27	0.62
Lack of Respectful Care		0.33	0.5
Perceived value of care		0.4	0.5
Poverty	0.4	0.47	0.5
Low Social Support		0.47	0.48
Patient Has No Voice		0.27	0.32
Perceived Discrimination		0.6	0.22
Fragmentation between health and social services		0.47	0.5
Less Than High School	0.18	0.27	
Differences:			
Lack of multi-disciplinary teams		0.73	
Communication Misunderstandings			0.6
Family Responsibilities			0.4
History of Trauma		0.4	
Experience of Delivery			0.4
Risk for Depression			0.32
Not Knowing Who to Trust			0.32
Lack of Access to Mental Health Services			0.26
Degree of Consensus between Family Physicians and Birth Companions		0.31	
Degree of Consensus between Family Physicians and the Literature	0.37		
Degree of Consensus between Birth Companions and the Literature			0.45

Each combining procedure generated new weights and therefore a new map architecture. Each updated weight was represented by a central value (used to generate the updated maps in Figures 4.5 and 4.6) and a normal density around that central value (used to specify the density for each of the factors in Tables 4.2 and 4.3). The variance around the central weight decreased around factors where there was agreement between published literature and stakeholder perspectives and broadened (or increased) where there were areas of disagreement. In other words, agreement led to increased confidence and lower variability, and vice versa. Figures 4.5 and 4.6 respectively show the literature map updated (using duplicated data; Equation 4 in Appendix 2- Additional File 4.1) by family physicians and by birth companions.

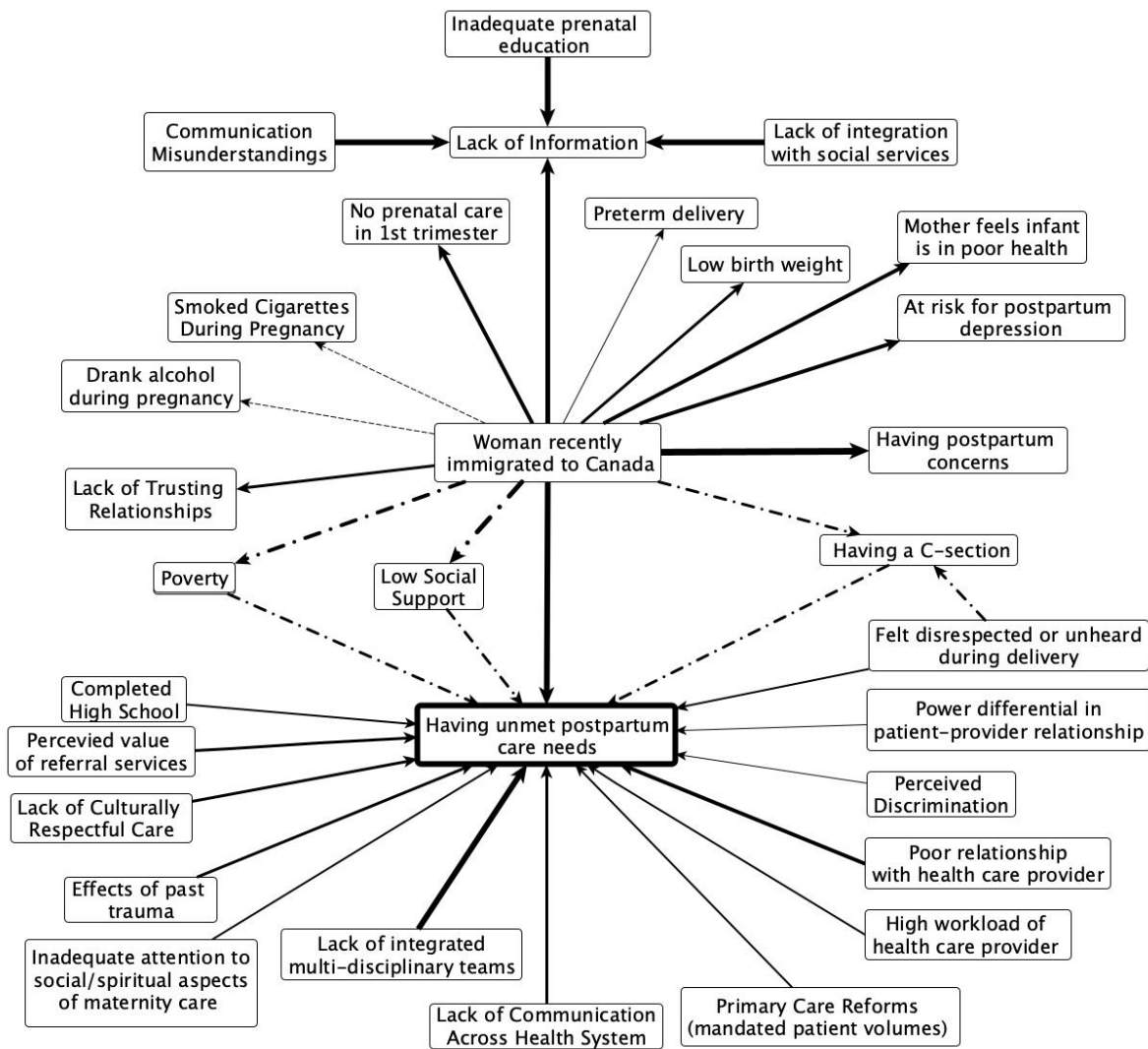


Figure 4.5: Fuzzy cognitive maps of the literature updated by the fuzzy cognitive maps created by family physicians. Dashed lines indicate a negative relationship; dash-dot-dashed lines indicate an indirect relationship identified by transitive closure

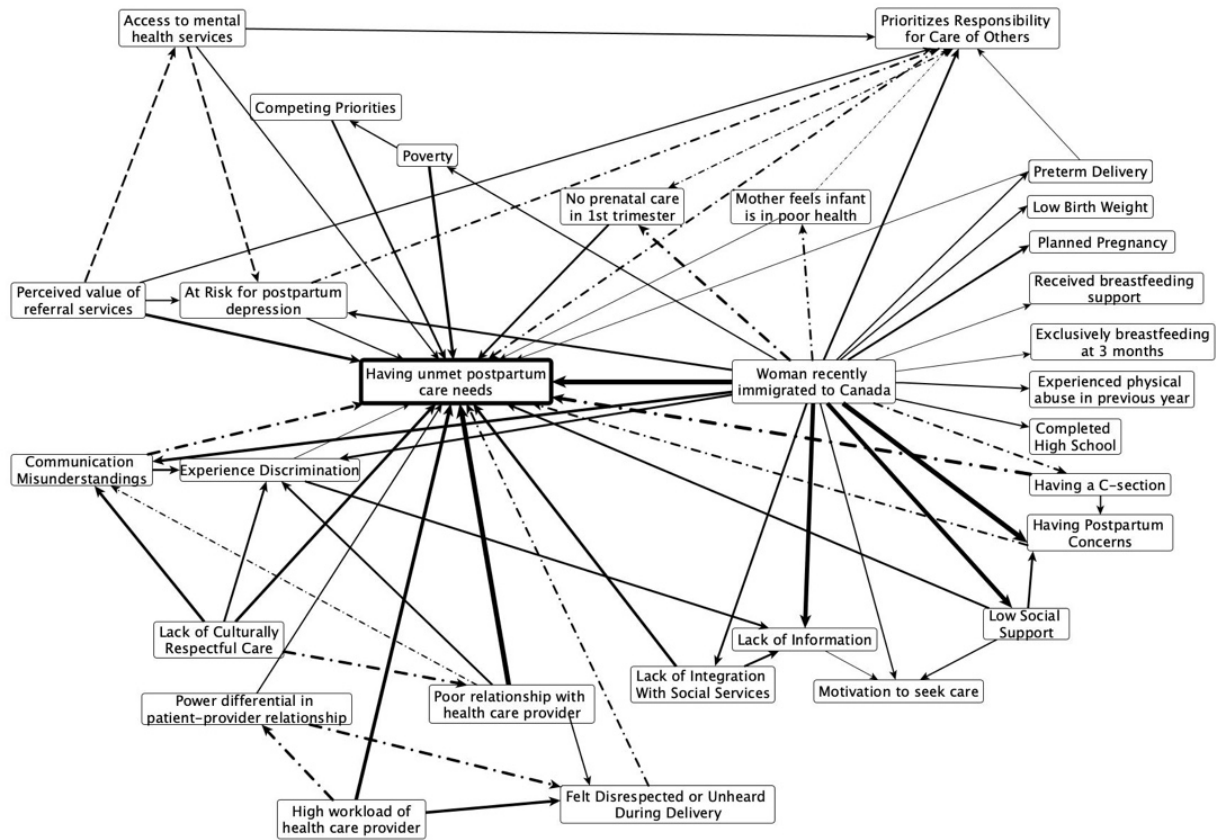
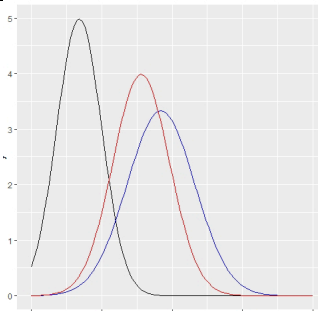
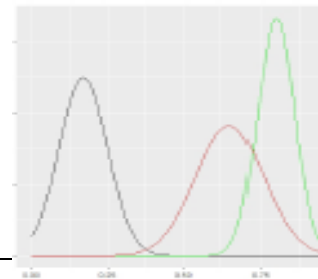


Figure 4.6: Fuzzy cognitive maps of the literature updated by the fuzzy cognitive maps created by birth companions. Dashed lines indicate a negative relationship; dash-dot-dashed lines indicate an indirect relationship identified by transitive closure

Table 4.2 provides an example of factor-level analysis across knowledge sources, comparing weights assigned to *having a Caesarean section* among recent immigrant women according to the literature, family physicians and birth companions. The literature-based weight was based on one study with an OR 1.42 (95%CI 1.03-1.96), which was subsequently normalized to a weight of 0.17 with a density of 0.01-0.32. (Gagnon et al., 2007) *Having a Caesarean section* was weighted by family physicians (mean=0.46, $\sigma^2=0.1$) and by birth companions (mean=0.8, $\sigma^2=0.06$). Updating using Bayesian analysis (Appendix 2- Additional File 4.1, Equation 4) resulted in an updated point estimate and credibility interval, accounting for variability in both the literature-based estimate and across stakeholder groups, shown in the figure embedded in Table 4.2. A comparison of updated results between original data and duplicated data is provided in Appendix 2- Additional File 4.2.

Table 4.3 provides an example of when stakeholders include factors not reported in the literature. Both family physicians and birth companions identified discrimination as an important contributor to unmet postpartum care needs among recent immigrant women. Discrimination was identified in qualitative, but not quantitative, literature. (Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; Merry et al., 2011; O'Mahony & Donnelly, 2010) Table 4.3 compares stakeholder weights and distributions, offering some insight into how each stakeholder group interpreted the importance of discrimination on unmet postpartum care needs among recent immigrant women.

Table 4.2: Original weights and updated values from the literature, family physicians and birth companions for the influence of having a Caesarean section on unmet postpartum care needs among recent immigrant women

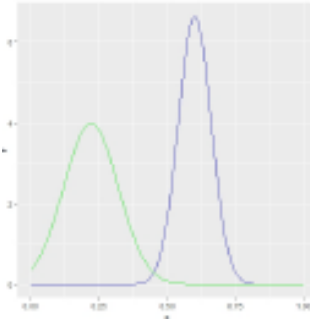
Influence of Having a Caesarean Section on Unmet Postpartum Care Needs Among Recent Immigrant Women				
Source of Estimate or Weight	Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)	
Literature	1.42	1.03	1.96	
Normalized value	0.17	0.01	0.32	
Updated by Family Physician Knowledge Average weight assigned by Family Physicians: 0.46				
Bayesian	0.39	0.17	0.61	
Updated by Birth Companion Knowledge Average weight assigned by Birth Companions: 0.8				
Bayesian Updating	0.65	0.41	0.89	

i) Values from the literature (in black), weighted by family physician (in blue), and when updated (in red).

ii) Values from the literature (in black), weighted by birth companion (in green), and when updated (in red).

Table 4.3: Original weights and updated values from the literature, family physicians and birth companions for the influence of perceived discrimination on unmet postpartum care needs among recent immigrant women

Perceived Discrimination on Unmet Postpartum Care Needs Among Recent Immigrant Women				
Source of Estimate or Weight		Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)
Literature		Not measured		
Normalized value		0		
Updated by Family Physician Knowledge				
Average weight assigned by Family Physicians: 0.6				
Bayesian Updating		0.49	0.2	0.79
Updated by Birth Companion Knowledge				
Average weight assigned by Birth Companions: 0.22				
Bayesian Updating		0.18	0.0	0.37



Weight assigned by family physician (in blue) and birth companions (in green).

Step 4: Describe explanatory processes leading to priority outcomes

General Description: This step draws on published literature, stakeholder explanations, and the analyses conducted in the previous step to develop candidate explanatory accounts. Relationships described in stakeholder cognitive maps show how stakeholders make sense of their experience in the context of evidence from the literature. (Mingers, 2005; U. Özesmi & Özesmi, 2004) Weighting by stakeholders helps prioritize factors or processes that contribute to an outcome, whether from published evidence or those added to the maps by stakeholders. If stakeholders identify novel factors contributing to the outcome, a brief literature search is done to identify relevant studies exploring these issues and relevant findings are included in the evidence base to develop explanatory accounts.

Consistent with participatory research, explanatory accounts and/or consolidated themes can be shared back with stakeholders to be adjusted to align with their own understandings. This strengthens the trustworthiness of the explanatory accounts and can be done with multiple different stakeholder groups. This is especially important when working with marginalized communities, where theories and explanations generated outside the community may reinforce erroneous stereotypes. (Tuck, 2008)

Step 4 in practice: Following the process outlined by Pearson and colleagues, the lead author generated explanatory accounts from published literature and stakeholder accounts to describe how specific factors and relationships between them may contribute to unmet postpartum care needs among recent immigrant women. (Pearson, 2015) Explanatory accounts were informed by identified literature, the relationships identified across different stakeholder groups (for practical reasons, all relationships weighted 0.2 or above in any map were included), direct or indirect relationships between two or more factors (identified as walks by transitive closure), as well as differences in weights between knowledge sources about how specific factors contribute to unmet postpartum care needs. These accounts were also informed by notes from mapping interviews (Step 2) where stakeholders verbally rationalized their selection and weighting of relationships while making the maps. (Pawson, 2008; Pearson, 2015) Ninety explanatory accounts were consolidated down to 20, guided by questions to specify the conceptual clarity of each explanatory account. (Pearson, 2015) Accounts were grouped by common mechanism to explain factors and relationships that contribute to the

outcome, and then grouped across 4 related themes. Original, consolidated explanatory accounts and overarching themes were reviewed by a senior author with experience in realist analysis (ER). Consolidated themes and explanatory accounts are shown in Table 4.4 and in the Appendix 2- Additional Files 4.3 and 4.4. Each explanatory account is attributed to a particular stakeholder group, the literature (through reference to the specific study), or a combination of these. A narrative of findings is included in Appendix 2-Additional File 4.5.

Step 5: Identify local interventions and implications for evidence syntheses

This step asks stakeholders to make recommendations to address the outcome based on the understanding facilitated by Weight of Evidence. Given the breadth of factors included in the maps, it can be helpful to draw on key outputs from Weight of Evidence, such as maps generated by stakeholders and the evidence updated by stakeholder perspectives (from Step 2 and 3 respectively) and the consolidated explanatory accounts (from Step 4). Each stakeholder group can recommend strategies that they can carry out themselves, as well as those that would be most effective in addressing the issue in both the short and long term. (Abelson et al., 2003) While this was not a step fully implemented as part of this pilot of Weight of Evidence, other applications of this procedure have contributed to evidence-based stakeholder-led recommendations for perinatal care for adolescents. (Dion & Andersson, n.d.)

Discussion

Weight of Evidence facilitates the inclusion of complex and often informal stakeholder knowledge alongside evidence from qualitative and quantitative literature in a transparent and reproducible way. Thus, informing a richer understanding of the issue at hand and giving users an opportunity to re-conceptualize a problem and its potential solutions. Weight of Evidence provides an accessible way to represent published literature to a diversity of stakeholders and draws directly on stakeholder knowledge and causal understanding to determine how to prioritize and combine different types of evidence.

Our research group developed the Weight of Evidence as a rigorous procedure to incorporate stakeholders' perspective in the design and evaluation of health services, with a focus on incorporating perspectives from marginalized populations, often under-represented in health services and biomedical literature. (Serrant-Green, 2011) The systematic and analytical

approach to integrating different understandings around a single issue are what make Weight of Evidence particularly relevant for evidence-informed decision-making, whether at national or regional levels, for policy development or institutional networks.

Recognizing that someone with different lived experience may understand and solve a problem differently can be useful information. This is not to suggest that one type of knowledge has a hierarchy over others. Rather it stems from the belief that people make better decisions when they benefit from both evidence-based perspectives, as well as context-specific understanding. (Harding, 2003; Oliver et al., 2018) Consistent with the aims of mixed methods research, Weight of Evidence offers a way to bring these different forms of knowledge together, in support of a more complete understanding of an issue. (Creswell & Clark, 2011) Few knowledge synthesis approaches preserve divergent or conflicting perspectives, often homogenizing across studies thus losing the richness within difference. By holding space for multiple ways of understanding the same issue, Weight of Evidence creates opportunities to unpack differences in order to identify how and when these differences arise and with what consequences. (Keller, 1992; Maxwell, 2012)

In this demonstration case, stakeholder-identified factors were more diverse and more actionable than factors identified in the literature. They focused less on individual risk factors of recent immigrant women (for example, high school education or specific health behaviours) and more on the contextual supports and systems around them. Stakeholder-identified factors also highlighted larger structural and organizational issues, such as resource allocation, workforce planning and social isolation, in relation to unmet postpartum care needs, demonstrating how the inclusion of relevant perspectives in problem definition can broaden the menu of possible interventions to address unmet postpartum care needs.

Contextualizing evidence is often framed as part of knowledge translation, contributing to evidence-based practice and decision-making, whereby once primary research is synthesized, it is assessed and interpreted for local relevance. Effective translation requires that evidence be understood and applied in relation to local context and practical wisdom, incorporating insights from clinical experience and patient experience to identify and define meaningful interventions. (MacDermid & Graham, 2009) Several authors have highlighted the challenges

of contextualization and stakeholder involvement in evidence synthesis more broadly, including poor operationalization and a lack of understanding of how stakeholder input influences evidence interpretation and translation. (Haddaway et al., 2017; Pollock et al., 2018) The majority of stakeholder engagement in evidence syntheses, including contextualization, has focused on those who have some understanding of research evidence and already have a seat at decision-making tables. Two recent systematic reviews of stakeholder and community engagement highlight that stakeholder involvement in evidence synthesis has focused primarily on the engagement of health professionals, academics and decision-makers with only 30% of studies including patients and communities as stakeholders. (George et al., 2017; Pollock et al., 2018)

Weight of Evidence is relevant for all types of stakeholders, though was developed to address challenge in engaging stakeholders who have not historically been involved in planning and decision-making. Weight of Evidence advances the rigour of contextualization and stakeholder engagement in evidence syntheses by introducing a systematic method to assess the legitimacy of reviews by those most affected by the issue at hand without expecting stakeholders to become highly versed in methods of evidence synthesis. (Langer, Erasmus, Tannous, & Stewart, 2017) This has important implications for accessibility and shapes who can participate in contextualization processes. By maintaining a high-level of transparency and clarity in how and where stakeholder perspectives prioritize and adapt available evidence base, Weight of Evidence presents a reliable and verifiable procedure to contextualize evidence syntheses. (Haddaway et al., 2017) Making explicit when and how we value different forms of knowledge opens up analysis and decision-making processes to greater scrutiny and discussion, facilitating a more collaborative conceptualization of priority issues. (Befani & Stedman-Bryce, 2017)

This application of Weight of Evidence also highlights potential future applications to refine and legitimate systematic reviews based on the contextualizing of evidence by those most directly affected by the issue. Identifying factors not included in the literature as well as adapting or introducing relationships between factors not previously accounted for, Weight of Evidence offers a systematic and transparent procedure to identifying what evidence matters, to whom and with what consequences. These are all critical questions that shape how evidence syntheses contribute to the translation of evidence into practice and decision-making.

(Barkham & Mellor-Clark, 2003; Booth et al., 2019; MacDermid & Graham, 2009) While our pilot application of Weight of evidence did not include stakeholders in setting the question for the evidence synthesis, subsequent application of this method included an evidence-based participatory approach to the initial problem definition. (Dion, Klevator, Nakajima, & Andersson, 2021)

Contributions to mixed methods research: Weight of Evidence presents a concrete example of how advanced statistical tools applied within a transformative participatory research perspective can contribute to innovations in mixed methods research. (Andersson, 2018) Weight of Evidence offers a way to move beyond a monolithic view of evidence and expertise and advance evidence syntheses to incorporate contextual understanding of which evidence is most relevant for a particular setting. This may be particularly relevant when the evidence base is sparse or contradictory, making it difficult to make conclusion or recommendations. (Badampudi et al., 2019) Although poor and socially marginalized groups are often very clear about how marginalization impacts their health, the issue is often poorly reflected in the available evidence bases, making Weight of Evidence particularly suited to contextualizing evidence with under-served populations. (Serrant-Green, 2011)

This paper demonstrates that people's understanding of both root causes and priority factors can be described in detailed and systematic ways, facilitating a transparent and rigorous combining with evidence. Combining cognitive maps across different perspectives operationalizes the dialectic stance described by Greene and Hall (2010), providing insights into how perspectives complement and differ from one another. This can function as an important lever to identify potentially shared priorities as well as areas of misunderstanding or difference.

Fuzzy cognitive maps provide an accessible way to represent different forms of knowledge to be understood and adapted across perspectives and paradigms. (Kosko, 1988; Popay & Williams, 1996) Making epidemiological data, or knowledge from other stakeholders, accessible through fuzzy cognitive mapping invites stakeholders to engage with the full scope of evidence often available to other decision-makers. Maps demonstrate how different knowledge is considered in the identification of priorities in consideration of, and not in

isolation, of all available evidence. Practically, fuzzy cognitive maps provide an architecture for data integration during the mapping interview (step 2) as stakeholders indicate how and with what weight qualitative data should be integrated with quantitative evidence. This process also catalyzes new data from stakeholders that is incorporated into the cognitive maps. This expands upon exiting protocols and applications of fuzzy cognitive maps by transforming qualitative data from themes (either identified from qualitative literature or identified by participants) into a relational structure together with quantitative data, led by participant expertise rather than researcher-expertise. (Fetters et al., 2013; Giles et al., 2007; U. Özesmi & Özesmi, 2004) As conceptual rather than probabilistic models, cognitive maps then reflect interdependence between factors that can serve as a decision aid in complex settings like clinical care, where artificially isolating associations within a *de facto* network can diminish the contextual understanding and relevance of decisions. (Napier et al., 2014)

Weights generated through fuzzy cognitive mapping invite stakeholders to analyze problems in context, while generating transparent and meaningful measures of influence for each factor that can be easily analyzed by stakeholder group, or ‘in conversation’ with other types of knowledge. This expands the conceptual boundaries by incorporating issues formerly rejected or seen as outside of the system of influence. (Midgley, 2000; van Bertalanffy, 1968)

Examining weights within and across stakeholder groups offers an accessible and systematic tool to address the long-standing concern in Bayesian statistics of generating meaningful and representative priors. Graphic representations and pattern matching tables encourage a meta-level comparison between knowledge sources. A factor-level analysis is possible by comparing the distribution of weights for specific relationships, visually representing a density of credible weights assigned by different stakeholder groups instead of plotting a single average value. (Kruschke, 2015)

Weight of Evidence integrates stakeholder-identified, qualitative, and quantitative data through fuzzy cognitive mapping and Bayesian updating. This integration is then leveraged in the generation of explanatory accounts (step 4) as qualitative, quantitative and stakeholder-generated evidence contribute to identify candidate causal processes. (Astbury & Leeuw, 2010; Pawson, 2008) Stakeholder involvement led to the identification of factors beyond those

identified by the original literature review, prompting a broader examination of literature to confirm, expand and refine our explanatory accounts.

Lessons and limitations: Duplicating our data skewed results towards stakeholder values and artificially reduced variance. Yet, comparing results between the original and duplicated data provided several insights. The first is that it matters how we present stakeholder perspectives. In the demonstration case, individual stakeholders each created their own map. In other applications of this procedure within our research group, a group of stakeholders collectively created one map. (Sarmiento et al., 2020) These differences have important implications for the development of the maps and ensuring that the final stakeholder generated maps are representative of differences in power and lived experience across and within stakeholder groups. (S. A. Gray, Zanre, & Gray, 2013) It also has implications for how updating occurs, as each additional stakeholder map contributes data to the updating procedure.

The second insight is that the densities of stakeholder weights are helpful representations of the extent of agreement both within and between stakeholder groups. Differences in opinion within stakeholder groups, as evidenced by broad or multi-modal densities, suggest the need for larger sample sizes, greater differentiation between stakeholder groups, or as a jumping-off point for further exploration of observed differences.

Various forms of bias may also influence how weights generated through the fuzzy cognitive mapping process represent the beliefs of stakeholders. We drew on the recommendations in the literature to generate robust priors including carefully structured elicitation procedures, drawing on multiple experts to generate an aggregated prior estimate and the opportunity for stakeholders to provide feedback and corrections to their maps. (Burgman et al., 2011) Several forms of uncertainty remain inherent to the process of generating stakeholder weights, including linguistic and epistemic uncertainty. Adaptations to the elicitation process can address these concerns, however, we did not have the opportunity to conduct sensitivity analysis around these adaptations.

That this demonstration case focused on methods development rather than implementing solutions introduced some limitations to this study and has several implications. First, since

systematic review methods are well-established and therefore not part of the methodological innovation of this procedure, the lead author independently conducted the mixed methods review. To use the tool for real time service improvement, a conventional review following established protocols would be more appropriate to provide comprehensive and robust evidence in the literature-based map.

A second important limitation of this study is that it did not involve a sufficient number or diversity of stakeholders to draw definitive conclusion about the implications of this work for community perinatal care. For researchers planning to apply *Weight of Evidence* in their work, it is recommended they follow existing sample size recommendations for fuzzy cognitive maps. (U. Özesmi & Özesmi, 2004)

Conclusions

Weight of Evidence combines context-specific stakeholder knowledge with quantitative and qualitative data from published studies, reconciling several perspectives and translating these into statistically interpretable and actionable results. It advances the concept and practice of stakeholder engagement and sets out a procedure to contextualize evidence synthesis towards more comprehensive and relevant findings. This article describes how the application of participatory methods and advanced statistics to broaden what counts as expertise contributes to richer understanding of an issue while also presenting novel approaches to data transformation and integration.

Weight of Evidence was developed to strengthen the voice of marginalized groups to inform interventions in health services. It also has broader applicability in supporting the contextualization of evidence syntheses and introducing more participatory and rigorous approaches to the design of quality improvement and evaluation initiatives. Weight of Evidence offers a transparent procedure to unpack differences, to identify how and when these differences arise and with what consequences, contributing to more comprehensive, relevant, and effective interventions and recommendations.

Table 4.4: Consolidated accounts of factors contributing to unmet postpartum care needs among recent immigrant women in Canada (MD=physician, BC=birth companion)

Processes contributing to outcomes	Source Explanatory Accounts	Primary Evidence
Theme: Economic and Social Exclusion		
Poverty's influence on health navigation and access	1,2,3,4,50, 53, 64, 69	(Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a); Munro 2014; Stakeholder (MD)
Social and Physical Isolation, Lack of Social Support	5,6,22,23,24, 37, 47, 51, 62,70, 80, 81, 82	(Gagnon et al., 2010; Ng & Newbold, 2011; O'Mahony & Donnelly, 2010); Stakeholder (MD &BC)
Theme: Building Shared Understandings of Health		
Social Understanding of Illness	7, 11, 17,18, 20,21, 44, 45, 67, 68, 72, 84, 88	(Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; Higginbottom, 2013); Stakeholder (MD&BC)
Culture as an Asset for Health	43, 57, 89	(Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; Higginbottom et al., 2014); Stakeholder (BC)
Theme: Empathetic and Respectful Communication		
Commitment to culturally safe care	9,10, 26, 38,39, 48, 65, 71, 78, 83, 85	(Vanthuyne, 2013); (Gagnon et al., 2010; Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a); Stakeholder (MD&BC)
Commitment to trauma-informed care	27,28,29, 42, 49, 55, 56, 87	(O'Mahony & Donnelly, 2010); Stakeholder (MD&BC)
Theme: Supporting Self-Determination Through Knowledge		
Access to Information	19,25, 32, 36, 52,58, 63, 79	(Gagnon et al., 2010; Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; Ng & Newbold, 2011; O'Mahony & Donnelly, 2010); Stakeholder (MD&BC)
Building Trust	8, 33, 86, 90	(Gagnon et al., 2007; Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; O'Mahony & Donnelly, 2010); Stakeholder (BC)
Health Services Organization		
Fragmentation	40, 41, 54, 61, 62, 73	Stakeholder (MD)
Centralized Decision-Making	59, 74, 76	Stakeholder (MD)
Individualization of Care Responsibilities	34, 46, 60,75, 12, 13,66	(Gagnon et al., 2010; Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013a; O'Mahony & Donnelly, 2010); Stakeholder (MD)

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Chapter 5: Evidence-based priorities of under-served pregnant and parenting adolescents: Addressing inequities through a participatory approach to contextualizing evidence syntheses (Manuscript #4)

This chapter is the first of two that describe the application of Weight of Evidence with a group of pregnant and parenting adolescents in Ottawa, Canada. Chapters 3 and 4 introduced Weight of Evidence through a pilot study where researcher identified the outcome of interest. Unmet postpartum care needs among recent immigrant women were well-suited as our outcome of interest as a clinically relevant example of the intersection of marginalization and perinatal health and that was well-described in the literature.

Consistent with the participatory underpinnings of this doctoral research, this chapter presents a participatory evidence-based priority setting process to identify areas of interest most relevant to the pregnant and parenting adolescents contributing to this research. The priority area identified through this process then guided the application of the Weight of Evidence with pregnant and parenting adolescents, described in the next chapter. By valuing the voices of pregnant and parenting young people in determining the focus of our research, we were able to focus discussions on what mattered most to participants. To ground the priority-setting process described in this chapter, I drew on outcomes and experiences identified in the literature review presented in Chapter 2, this time specific to pregnant and parenting adolescents.

I am the first author of this chapter. Dr. Neil Andersson, Dr. Amy Nakajima and I conceived of the study and contributed to its design. I worked with Aime Klevor to conduct the research and the analysis together with Dr. Andersson. I drafted this chapter and Aime Klevor, Dr. Andersson and Dr. Nakajima all contributed to its development. This manuscript is published in the International Journal for Equity in Health.

Abstract

Purpose: This study describes an interdiscursive evidence-based priority setting process with pregnant and parenting adolescents and their services providers.

Methods: A mixed methods literature review identified studies reporting on perinatal outcomes and experiences of adolescents during pregnancy to 12 months post-partum published in Canada after 2000. We also calculated relative risks for common perinatal risk factors and outcomes for adolescents compared to adult populations from 2012-2017 based on data from a provincial database of maternal and newborn outcomes. Two trained peer researchers identified outcomes most relevant to their peers. We shared syntheses results with four service providers and 13 adolescent mothers accessing services at a community service organization, who identified and prioritized their areas of concern. We repeated the process for each priority issue identified by the women and expanded upon them through semi-structured interviews.

Results: Adolescent mothers face higher rates of poverty, abuse, anxiety and depression than do adult mothers. Adolescents prioritized the *experience of judgment* in perinatal health and social services, particularly as it contributed to them being identified as a child protection risk. Secondary priorities included loss of social support and inaccessibility of community resources. The experience of judgment in adolescent perinatal health literature was summarized around: being invisible, seen as incapable and seen as a risk. Adolescent mothers adapted these categories, emphasizing organizational and social barriers.

Conclusions: Young marginalized women are disproportionately affected by inequities in perinatal outcomes, yet their perspectives are rarely centered in efforts to address these inequities. This research addresses health inequities by presenting a robust, transparent, and participatory approach to priority setting to better represent the perspectives of those who carry the greatest burden of health inequities in evidence syntheses. In our work, marginalized adolescent parents adapted published literature around the experience and consequences of social stigma on perinatal outcomes, shifting our understanding of root causes and possible solutions.

Background

Despite Canada's investment in universal and accessible health services, people living in poorer socioeconomic conditions often have poorer outcomes than those with greater access to resources and educational opportunities. (1,2) By international standards, Canada has a low pregnancy-related maternal mortality rate (7.4/100 000 births in 2013-14). (3) Adolescent women in Canada have higher risk factors and poorer outcomes. Increased risks associated with adolescent pregnancies include preterm and very preterm delivery, having infants of low birth weight and/or small for gestational age, and for neonatal and infant mortality. (4,5) Although socioeconomic and behavioural factors like smoking, alcohol and drug use, poor nutrition, and poor prenatal care are also risk factors, young maternal age remains an independent risk factor for these outcomes after adjusting for potential confounders. (6) Globally, significant resources are dedicated to reducing unplanned pregnancies in adolescence. In Canada, the age-specific birth rate among adolescents among both 15-17- and 18-19-year-olds has declined between 2009 to 2013 (from 8.2 to 5.3/100,00 live births among 15-17 year olds and from 25.8 to 18.6/100,000 live births among 18-19 year olds). (3) Some authors suggest this is due in part to improved sexual education and increased access to contraception and abortion. (4)

This paper describes our approach to contextualize available evidence in the lived experience of adolescent mothers, to identify and better to understand priority issues affecting their care as pregnant and parenting adolescents. As part of a larger initiative, this paper describes two meetings with young mothers, the first to determine the focus of the research project, and the second as an exploration of the chosen focus issue.

Methods

Engaging Peer-researchers: We hired a peer researcher to work as part of this project. Two candidates were identified by staff at our partner organization, a community-based health and social service agency for young pregnant and parenting adolescents, which includes a maternity shelter for precariously housed pregnant and parenting adolescents. Both peer researchers were young mothers who accessed services at our partner organization. Both peer researchers received 10 hours of peer researcher training, adapted, and delivered by the lead author (AD). (7) Peer-researchers were paid during their training and while contributing to the project. A

flow chart describing the overall project methods is provided in Figure 5.1 and indicates where peer researchers were actively involved.

Mixed studies review: We searched Medline, CINAHL and Web of Science for primary research describing perinatal (pregnancy to 12 months post-partum) health outcomes and experiences of adolescent women (under 23 years of age) in Canada, including all articles published in French or English after the year 2000. We included reports of clinical outcomes and those describing the experiences of adolescents through antepartum, intrapartum, and postpartum care. Where available, we also included studies describing the experience of healthcare providers caring for pregnant adolescents. We excluded clinical guidelines.

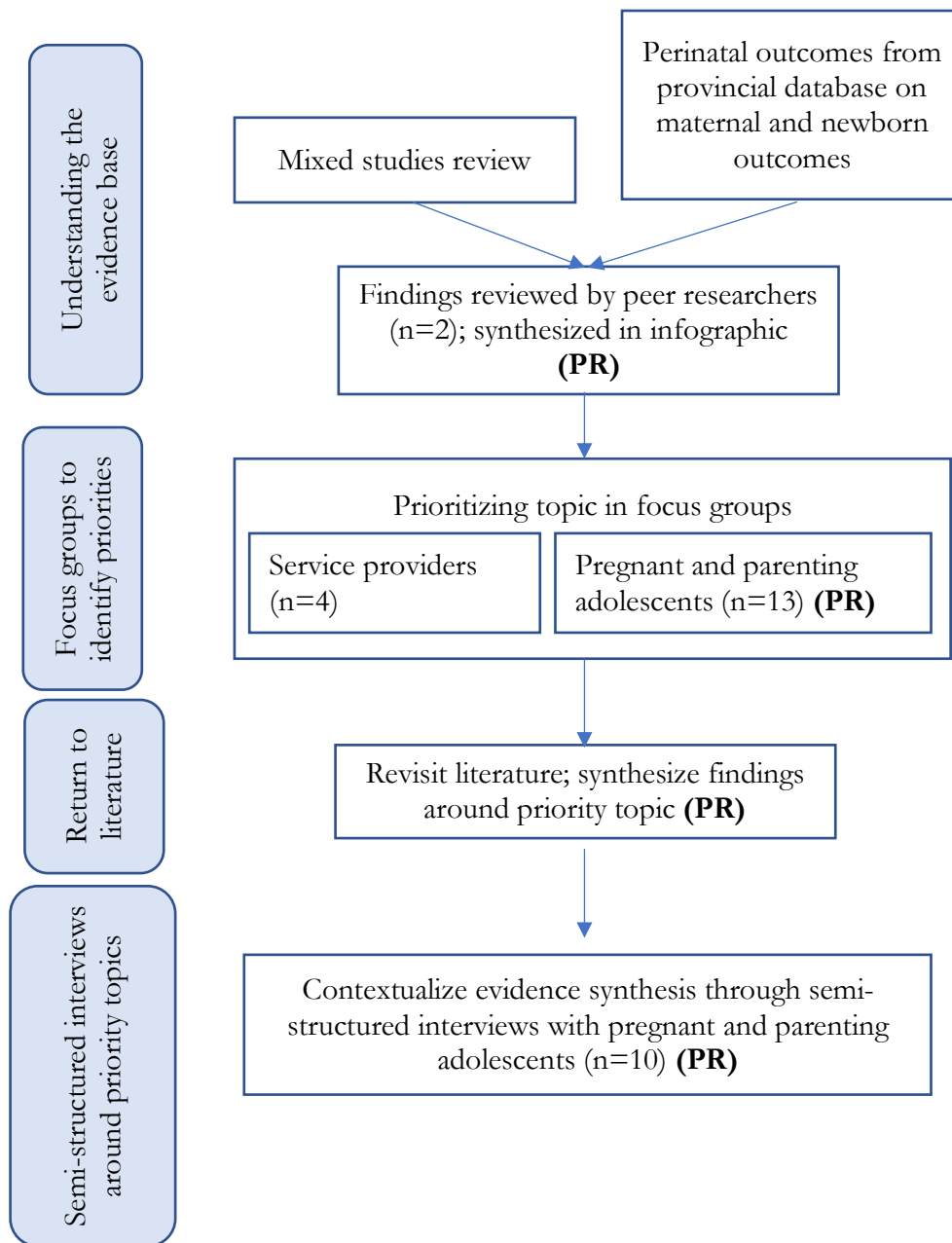


Figure 5.1: Flow chart describing the method, PR indicates where peer-researchers were directly involved

The lead author screened all abstracts, read and extracted data from all eligible articles and assessed the quality of studies using the Critical Appraisal Checklist for Qualitative Research. (8) We extracted findings using inductive thematic synthesis and descriptive statistics for quantitative data. (9-11)

Regional and provincial data on perinatal outcomes: We also analyzed data from the Better Outcomes Registry Network (BORN), a database on pregnancy, birth, and childhood outcomes for the province of Ontario. We extracted data on common perinatal health indicators (such as pregnancy rates among adolescents, preterm births, access to antenatal care, labour, and birth complications) as well as specific indicators commonly reported among adolescent pregnancies (substance use, sexually transmitted infections, mental health concerns, experience of abuse). We calculated relative risks for adolescents for each indicator by year and over the 5-year period for both the province and the relevant local health integration network from 2012-2017.

The lead author and peer-researchers reviewed statistics of outcomes and risk factors from quantitative studies along with themes, quotes and images identified from qualitative studies. We discussed which findings might be most relevant to clients accessing services at our partner agency. AD summarized selected findings in an infographic, which the peer researchers reviewed and refined.

Participant recruitment: Wherever possible, we piloted all elements of our method with peer researchers and adopted strategies to support meaningful engagement with adolescents. Adolescent women were invited to participate in the focus groups through recruitment posters, discussion with staff of our partner organization and brief presentations by the lead author and peer researchers. We adapted consent forms to ensure that language was understandable and accessible to potential participants. (12) (see Appendix 3- Additional File 5.1 for examples) We opened each meeting with a discussion of young people's rights when participating in research. Using a Charter of Rights for Children and Young People developed by Moore et al., we reviewed issues relating to participants' rights to be heard, to participate in the way they prefer, to be treated well and not be hurt or discriminated against. (13) Counseling

staff from our partner organization was also available if anyone needed additional support during or after participating in discussions.

We invited women aged 16 and above to participate in our research. Many clients of our partner organization are recognized as minors withdrawn from parental control and are legally recognized as adults when engaging with service organizations. While this often adds to their vulnerability as young parents, we felt it would be inappropriate and potentially harmful to ask potential research participants under the age of 18 to seek parental consent to participate in this research project. This consideration builds on previous research on qualitative, community-based research with adolescents on their sexual health and is supported by studies suggesting that with enough time and information, adolescents over the age of 15 years have the cognitive capacity to make informed decisions. (14)

We worked with our partner organization and peer-researchers to determine appropriate honoraria for participants. We provided childcare, bus passes and snacks during each meeting to ensure that participants could engage comfortably in discussions. We also provided \$30 gift cards for each 2-hour meeting in recognition of participants expertise. We distributed gift cards at the beginning of each meeting (after the consent process) so that participants did not feel obliged to stay if they were uncomfortable throughout the meeting. (15) Prior to engaging with young women as participants in this research project, the lead author (AD) was a respite volunteer for young mothers at our partner organization's shelter for over a year before and throughout the project. Many women knew the peer researcher (AK) as a fellow client of our partner organization. This helped to build trust with participants and create familiarity with our partner organization's activities.

Focus groups to identify priorities: We carried out two separate focus group discussions to identify priority areas to better address pregnant and parenting adolescent needs. (16) In both focus group meetings, we presented the evidence synthesis infographic and invite participants to tour nine photos and quotes selected by peer researchers from qualitative studies. We emphasized that the findings from the literature represented how perinatal health among adolescent women was discussed in published literature and that not all aspects may resonate with their own experiences.

The first focus group was with four service providers from obstetrics, mental health, nursing and social work, all involved in providing front line services to pregnant and parenting adolescents. After reviewing the summary infographic and selected extracts from qualitative studies, they individually identified priority challenges in the perinatal health and well-being of their clients on post-it notes, and then grouped common themes between them. Each provider was given five stickers to allocate to the challenge they felt was most important to young mothers' well-being, specifying that they could place more than one sticker per issue. Priority issues were summarized and included in the focus group with adolescents.

The second focus group was co-facilitated by the lead author (AD) and one of the peer researchers (AK). After reviewing the summary infographic and selected extracts from qualitative studies, we asked each participant to identify issues where they faced challenges or barriers throughout their pregnancy and early postpartum experience. We prompted participants to draw from the literature, priority issues identified by service providers in the first focus group, as well as their own experiences. Participants wrote their ideas on post-it notes. Where comfortable, participants presented their issue, briefly describing why it was important and placed it on the wall. As each subsequent participant shared their issue, they determined whether their issue could be grouped with one already posted on the wall or if it addressed a separate issue. (17) Any participants who did not want to present their issue themselves could hand their post-it notes to the two facilitators (AD and AK) as we circulated around the room. Before moving on to the next step, we asked participants to adjust any grouping or descriptions of their own topics if they felt their idea had changed or was miscategorised. We also included priority themes identified by service providers if they were not already mentioned for women to include in their evaluation.

Each participant received five voting stickers to identify the most important challenges faced by young mothers and clarified that they could place more than one sticker per issue. We then re-organized categories according to participants' priorities. We gave participants an additional two stickers each, asking them to identify among those identified in the first round, their first and second priority concerns. We finalized the priority issues through group discussion, and participants were asked to write the answers to the following two questions with respect to the

issue identified as the top priority: *Why is this important? What do we still need to know about this?* (7)

Return to literature: We reviewed the studies included in our mixed review to re-assess how these studies explored the issue identified during the focus group. The lead author (AD) identified primary and second-order themes related to the priority issue. Second-order themes are grounded in evidence from the original studies but are the result of identifying patterns or central ideas across the collection of studies. (18) These themes were further refined by the peer researcher (AK). (18)

Semi-structured interviews: We used the themes to guide individual or small group discussions with 10 young mothers, where they generated their own ideas and then arranged them around the second-order themes identified in the literature, creating new categories when needed. They subsequently incorporated primary themes from the literature that they felt were relevant to their own experience. The lead author and peer researcher independently reviewed the concept maps and notes from each of the interviews and developed a list of common themes. They compared themes and refined them to reach a final set of themes grounded in the experience of participating women.

Ethics approval was received from the McGill Faculty of Medicine Ethics Review Board (A09-B51-17A). An Advisory Board made of senior staff of our partner organization also refined and approved this research.

Results

Mixed studies review: Our search identified 771 publications. The lead author (AD) assessed all abstracts to determine eligibility and extracted data from 35 relevant articles (24 quantitative, 11 qualitative). A flow chart of our review process is shown in Figure 5.2.

Adolescents with major mental illness have a higher age-specific fertility rates than adults with major mental illness. (19) Pregnant and/or parenting adolescents were two to four times more likely ever to have experienced physical abuse, (20) were more likely to be single and were four times more likely to have a low income (less than \$40 000 a year). (21) Roughly 60% of young

mothers accessing care at a youth pregnancy outreach clinic either completed or were in the process of completing high school. (22) Pregnant adolescents were 10-47% less likely to attend prenatal care in the first trimester, often citing financial barriers, long waiting times, lack of privacy, fear of judgment and not wanting to miss school. (4)

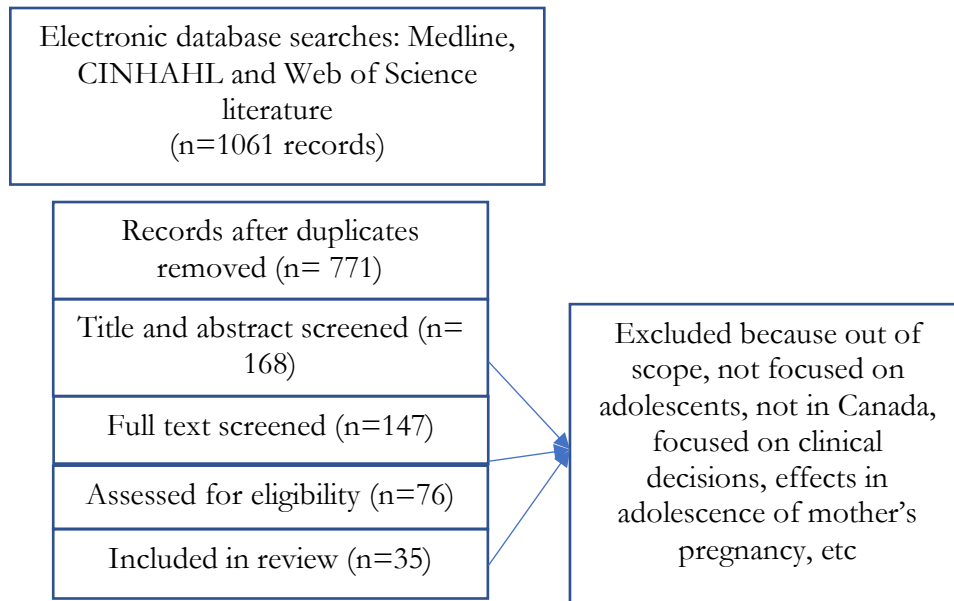


Figure 5.2: Flow chart describing the screening of articles in mixed studies review of adolescent perinatal outcomes in Canada

Themes identified in qualitative studies reflect the complexity of emotions surrounding pregnancy and motherhood. Themes and illustrative quotes are shown in Table 5.1. They include gratitude for their experience of pregnancy and their children, while also experiencing pervasive social stigma navigating education, employment and social services for themselves and their children. (23,24)

Table 5.1: Themes Identified in Qualitative Literature

Theme	Illustrative Quote
Motherhood as Transformative	<i>"I was pregnant and realized the path that I was going to bring another human being into. This was my choice – so there were two paths for me to go on. To continue going on this one and bring a child in that, not being in control of my life. And I knew that I couldn't do that to a child. So, making the choice to go the straight path and know what is coming."</i> (25)
Judgment	<i>"My social worker questioned my ability to mother properly."</i> (26)
	<i>"It bothers me what other people think. I am trying really hard not to think about what other people think about my mothering. Do you know what I mean? ... Because everyone is telling us that we can't."</i> (25)
Control	<i>"And actually, I had a friend that took something for the birth, and it showed [in a subsequent drug test] that she did drugs, when she's not that kind of person. And they instantly took that baby ... So, I didn't take anything [during labour]. It was pretty crazy. I was scared."</i> (26)
Need for Comprehensive Support	<i>"I am not ashamed of being a teen mother. However I do feel that if someone had guided me when I was going through my eating disorder, addictions, and insecurities that my life could have been different."</i> (23)
Poverty and Meeting Basic Needs	<i>"Umm, just healthy foods. I find that they're really hard to access. That ties in really huge with women's health right?"</i> (23)
	<i>"If you don't have a safe place to call home, then you're not going to be able to get any other supports for yourself in place including anything for your sexual health."</i> (23)

Data from provincial database: Ontario-specific findings were similar to those reported in the literature. Adolescent mothers in Ontario were more likely than adult mothers to have a mental health diagnosis of anxiety (relative risk (RR) =1.77, 95% CI 1.72-1.81), depression (RR=2.16, 95% CI 2.11-2.22) as well as more severe mental health disorders (RR=2.88, 95% CI 2.75-3.00). Pregnant and/or parenting adolescents were more likely to have used drugs (RR= 5.63, 95% CI 5.41-5.84) or alcohol (RR=2.33, 95% CI 2.22-2.44) during pregnancy and they were more likely to be diagnosed with a sexually transmitted infection during pregnancy (RR=2.77, 95% CI 2.62-2.93).

Evidence tables from our review as well as risks and outcomes among adolescent (under 23 years) and adult pregnancies in the Champlain Local Health Integration Network and across Ontario extracted from the BORN database are in Appendix 3- Additional File 5.2.

We finalized the evidence infographic (Figure 5.3) and peer researchers identified nine quotes and photographs from four qualitative studies that used PhotoVoice methodologies identified through our review to include in priority setting meetings with service providers and young women. (23,25,27,28)



Figure 5.3: Evidence synthesis infographic describing findings from mixed methods literature review of perinatal outcomes and experiences of adolescents in Canada from 2000-2019. Infographic was co-developed with peer researchers involved in this study.

Focus group to identify priorities: Four service providers from the fields of obstetrics, mental health, nursing, and social work, all involved in providing front line services to pregnant and parenting young people (under the age of 25) in Ottawa, contributed to identification of service priorities. They pointed to the need for access to mental health services and to the influence of stigma and fear of the consequences of being vulnerable as critical factors influencing perinatal well-being, as outlined in Table 5.2. They saw young women's on-going precarity due to poverty, housing instability and the need for independent living skills as factors contributing poorer perinatal outcomes, highlighting the need for trauma-informed and culturally informed programming.

Thirteen women aged 17-25 years participated in the second focus group. Participants' children ranged in age from one month to 4 years old, with between 1 and 4 children per woman, and women had varying levels of custody of their children. As outlined in Table 5.2, women overwhelmingly identified the experience of being judged or misunderstood as their most important challenge throughout their maternity and early motherhood experiences. Women experienced judgment in everyday experiences, such as on public transportation or when grocery shopping, which eroded their sense of confidence. Many women reported receiving negative comments, including being asked to leave public spaces while breastfeeding their infants in public.

“Young moms and moms in general are still constantly being shamed and ridiculed for breastfeeding in public...it makes me mad when I see women being shamed for it. If you don't like to see it, look the other way.”

After discussing women's experiences of judgment across multiple areas of their lives, women identified being identified as a child protection risk as their most important concern. Several women stated that their interactions with child protection workers themselves had been generally positive, but that initial reports to the Children's Aid Society's were uninformed or made without adequate investigation or understanding of their context. Women sought to be seen for their strengths as well as challenges, despite and not because of their age, and emphasized early and non-judgmental support to prevent the need for child protection involvement. This priority area was further explored with participants in subsequent meetings and described in a sister publication.

Table 5.2: Priority Areas to Support the Well-being of Pregnant and Parenting Youth, Identified by Service Providers and Young Women

Priority Areas Identified by Service Providers	Priority Areas Identified by Young Women
Mental Health • Access to mental health services • Anxiety and Depression • Untreated or undiagnosed mental health needs Judgment • Fear of being vulnerable; fear of being flagged as a risk to Child Protection Past Traumatic Experiences • Impact of childhood trauma on parenting • Impact of domestic violence; unstable relationship with child's father (or mother) Safe and Supported Living • Unstable inadequate unaffordable housing • Access cultural perspectives towards parenting and perinatal care • Lack of life skills to support independent living • Poverty's impact on accessing care Lack of coordinated services for youth	Judgment • In being identified as a child protection risk • Accessing housing • Breastfeeding • Accessing health services Lack of connection with supports • Loss of social support network/Isolation • Not knowing options and resources Navigating Care/Institutional Barriers • Access to mental health services • Expectations • Permanently labeled Influence of childhood trauma on parenting Intimate Partner Violence Poverty

Return to the literature: Upon reviewing the studies identified in our literature review, we identified three second-order themes describing how judgment is experienced by pregnant and parenting adolescents: *being seen as a risk*, *being seen as incapable* or not being seen at all (*being invisible*). First-order themes that contributed to each of these themes are shown in the left-hand column of Table 5.3.

Semi-structured interviews: Ten women participated in follow-up interviews where all but three had participated in the focus group meeting described above. We held these interviews individually or in groups of two depending on participant preference. After describing their own experiences of judgment during pregnancy and postpartum period, all participants confirmed the relevance of the second-order themes. Participants organized their own experiences and selected first-order themes from the literature under each of the second order theme and described the consequences or effects of each type of judgment. Some participants described experiences or events but were uncomfortable with formally documenting them. We supported the distilling of ideas, but participants decided how their experiences were described, represented or even included, emphasizing that participants also had the right to not share their stories. (29) We describe how participants adapted and contributed to each of the second-order themes below, summarized in Table 5.3.

Seen as A Risk

Women described feeling discounted or quickly judged by service providers who did not understand the broader context of women's experiences. Women were frustrated by experiences of surveillance and judgment rather than support when they disclosed needs around housing, low income, or other health and social concerns.

"They judge you for something you didn't even know you are doing. They make you feel like you are not capable of being a good mom....instead they should try to help you become the best mom you can be."

Table 5.3: First and second-order themes identified in the literature, with additional themes added by participants around the experience of judgment and its consequences for perinatal health

Experiences of Judgment	
Second-order theme: Seen as a Risk <i>First order themes identified in literature</i> • Blamed for things outside of control (30-33) • Pressure to show “good motherhood” (24,26,31-33) • Asking for help leads to blame (24,30,34) • Always under microscope (25)	<i>Themes added by women</i> • Using my past against me • Seen as dangerous if I stand up for myself
Second-order theme: Seen as Incapable <i>First-order themes identified in literature</i> • Assumed incompetence (25,32) • Consent not seen as necessary (30,32)	<i>Themes added by women</i> • Loss of confidence of others; affects belief in oneself
Second-order theme: Invisible <i>Primary themes identified in literature</i> • Own needs not recognized (23,34)	
Consequences of Judgment	
<i>First-order themes identified in literature</i> • Internalized blame (30,35) • Self-doubt (30,31) • Unmet needs (23,30,33,34) • No voice in decision-making (25,33)	<i>Themes added by women</i> • Anger, Frustration • Contributes to anxiety and depression • Must fight to be heard • Makes me want to give up

Women felt they did not have enough information about programs and services available to them, particularly those focused on the needs of pregnant and/or parenting adolescents. Several women reported avoiding services or not fully disclosing needs for fear of judgment. This left them with unmet needs, particularly around mental health.

“I also had to balance not saying too much. I couldn’t say what I really feel for fear that it would be seen as a risk to my child and would be reason to justify her removal or the removal of my rights”.

Women reported feeling let down or judged by those they thought could support them; in many cases, losing social support from friends, partners and sometimes family, upon learning they were pregnant. Women often spoke about isolation and harassment from friends at school or work, unsupportive teachers and/or family members who may disapprove of their pregnancy and/or their partners.

“It is judgment from the people that have meant something to me that hurts the most”

Women also described feeling permanently labeled based on their needs or events in their lives, over which they had little control. Examples included parenting with a disability, having had child protection involvement in their own childhood or by what were seen as choices to remain in abusive or violent relationships.

“I have a mild form of autism, so that brought additional judgment. They were telling me that I shouldn’t be having kids because ... neither of us will know what to do with a child”.

“We don’t need to be hovered over -- we aren’t terrible or scary people, or that we have no idea what we are doing. Some of us are in bad situations or made some poor choices along the way, but it doesn’t mean we don’t know anything”.

Women described having to counter ideas around parenting norms particularly related to the absence of partners or extended family in their lives. For them, isolation from these relationships was difficult but often necessary.

“Then she [my child’s doctor] began to be really opinionated about me needing to get back together with my son’s dad. Eventually, I told her that I didn’t want to go back to being beaten every day and she backed off... Isolation is seen as a bad thing, but when your support network isn’t good for you, sometimes it is the best thing”.

Invisible

Several women discussed the paradox of navigating health and social service systems as a young mother, where they were expected to manage the responsibilities of new motherhood as an adult, while still being a minor, from both a legal and societal perspectives. In the words of one participant *“I am old enough to have a baby.....but not old enough to give consent [for my own medical needs]?!?”*,

Seen as Incapable

Women linked experiences of social stigma with higher levels of stress, frustration and in some cases anger. They reported feeling as though they were made to feel incompetent before being given a chance.

“When I had my first child in the hospital, people just took over, with the assumption that I wasn’t going to do it myself”.

“I sneeze and it is judged; I go to the bathroom, and I wonder if it is okay....you cannot function as a human if you are always in doubt”

These experiences contributed to women feeling as if they had no voice in or control over their care, undermining their position as primary caregivers. Some women reported feeling that their consent in the care and handling of their child was not respected, with one woman limiting her sleep in the hospital both ante and post-partum for fear that decisions about her newborn’s care would be made without her.

Refusing Judgment

Women refuted judgment and its consequences by affirming their identities as mothers. They invested considerable mental and emotional energy in controlling the narrative in how they were perceived, learning to advocate for themselves and their children early on.

“You can either deal with judgment and live your life or hide away. I hid for a while but then I decided I just didn’t care what other people think, but I had to grow up fast to get there”.

Women also reported refusing support that did not meet their needs, which they felt resulted in being labelled as non-compliant.

“I wasn’t interested in participating in an arts and crafts program but had to, as well as other programming that I didn’t find helpful. I pushed back against the rules because I didn’t feel they were helpful or what I needed”.

“I am generally uncomfortable with male authority figures and didn’t want a man examining my baby, so when the male resident came to examine my daughter, I refused the exam”.

Women also emphasized the importance of supportive relationships in preventing difficult circumstances from evolving into more serious risks for themselves and their children. This often included family members and close friends, as well as health and social service providers, particularly those working within adolescent-specific services.

“For me it was my mum and grandmother - telling me that I am a good person, that I can do this. They made me believe in myself”.

“There were some good people at the hospital- they showed that they had faith in me and took the time to spend some time with me. One was a lactation consultant, who stood up for me within the hospital and with other professionals”.

Discussion

This research summarizes available published evidence around adolescent pregnancy in

Canada and describes how this evidence is prioritized and understood by adolescent mothers themselves. Adolescent mothers face higher rates of poverty, abuse, anxiety, and depression than do adult mothers. Adolescents prioritized the *experience of judgment* in perinatal health and social services, particularly as it contributed to them being identified as a child protection risk. Women's experiences of judgment around pregnancy and parenthood had important implications for mental health, their identity as mothers, and access to services. They emphasized the importance of supportive relationships and their role as advocates to counter the consequences of judgment.

Social norms around motherhood play a large role in the experience of adolescent motherhood. (36-38) Women described barriers specific to young parents that are built into the structure and organization of institutions. These barriers affected women's access to health, opportunities for education, financial support, housing and in navigating child protection issues, exacerbating existing vulnerabilities, even in the absence of individual prejudice or discrimination on the part of care providers. (39)

Experiencing repeated signals of inadequacy often leads to internalizing of negative stereotypes, and can influence people's willingness to seek care, as well as how care is acted upon and what is refused. (29,40) Fearing rejection, women guarded against or avoided potentially threatening interactions altogether. Women in our study mentioned the mental health consequences of repeatedly feeling judged, having their identity as mothers undermined or questioned, and the invisible emotional work to manage how service providers perceived them.

Women found themselves labeled as 'non-compliant' when they did not access the care system that does not adequately consider their needs. When policies and resource allocation does not align with community needs, however, providers might also lack the support of strong inter-professional collaborations to provide integrated and community-based perinatal care. (41-43) In a matched cohort study, Fleming et al. found adolescents receiving specialized multidisciplinary community-based perinatal care had significantly lower risks of low birth weight and preterm delivery, and higher rates of prenatal visits, prenatal class attendance and

group B streptococcus screening compared with adolescents across Ontario, despite higher levels of tobacco, alcohol and other substance use than the control group. (44)

These findings have several implications for research and for the provision of perinatal care for young people. Researchers, clinicians, and care providers can lessen the extent to which judgement shapes maternity and early parenthood experiences, especially among those who may face high levels of stigma. We need interventions to shift the deeply held attitudes and beliefs that lead to labelling, devaluing and discriminating and the processes that maintain these perceptions as dominant ones. (40,45) Recognizing the value of lived experience in informing service delivery can strengthen our understanding of the influence of social and organizational contexts in health interventions. (46) This is particularly important in stigmatised communities, where incorrect assumptions or representations may reinforce negative stereotypes. (47)

The interdiscursive approach we describe in this article is a systematic yet simple approach to grounding evidence in local contexts with a population that has little familiarity with conventional evidence synthesis approaches. We conducted this evidence-based priority setting exercise to determine priority areas for a subsequent stage of research, and therefore we considered the perspectives of local stakeholders as contributing contextual knowledge that was important in identifying priority topics. This does not diminish the important contributions of biomedical and other forms of research or suggest that one type of knowledge has a hierarchy over others. We suggest that people make better decisions when they benefit from both evidence-based perspectives, meaning those transferred through theoretical or statistical inferences, often developed through primary studies or syntheses, as well as context-specific understanding, based on local settings, experience and tacit understanding of practice and organizational 'know how'. (48) By valuing the voices of pregnant and parenting young people in determining the focus of our research, we were able to focus discussions on what mattered most to participants. This probably also increased engagement and participation in subsequent stages of our research. Inviting stakeholders to engage with the full scope of evidence often available to other decision-makers and subsequently identify priorities is an important mechanism to prevent the dismissal of community or informal knowledge on the grounds of not having full understanding of an issue. Our findings are particularly relevant for

local service improvements and point to additional areas to consider for future evidence syntheses.

Conclusions

Centering knowledge synthesis on adolescent women's voices changed the focus of our research. An iterative process grounded conventional evidence in young women's lived experience, deepening our understanding of the role of judgment in shaping perinatal care. Women's experiences of judgment around pregnancy and parenthood had important implications for mental health, their identity as mothers, and access to services. They emphasized the importance of supportive relationships and their role as advocates to counter the consequences of judgment.

Adolescent parents are disproportionately affected by inequities in perinatal outcomes, yet their perspectives are rarely heard in efforts to address these inequities. We used transparent and participatory methods to strengthen the voice of marginalized adolescent parents in identifying clinical and research priorities that address their needs. Without meaningfully involving those most affected by an issue, we risk leaving already marginalized groups underserved and further excluded from the benefits of care and quality improvement initiatives.

Declarations

Ethics approval and consent to participate: Ethics approval was received from the McGill Faculty of Medicine Ethics Review Board (A09-B51-17A). An Advisory Board made of senior staff of our partner organization also refined and approved this research.

Consent for publication: Not applicable as all data was anonymized and no individual identifying information is included in manuscript.

Availability of data and materials: All data generated or analysed during this study are included in this published article and its supplementary information files.

Competing interests: The authors declare that they have no competing interests.

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Author' Contributions: AD, AN and NA conceived of the study, AD and AK carried out the research, AD, AK and NA carried out the analysis. AD drafted the manuscript and AK, AN and NA made substantive revisions. All authors read and approved the final manuscript.

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Chapter 6: How adolescent mothers interpret and prioritize evidence about perinatal child protection involvement: participatory contextualization of published evidence (Manuscript #5)

This chapter describes the implementation of Weight of Evidence, as presented in previous chapters 3 and 4, focused on the prioritized concern of exposure to child protection investigations among pregnant and parenting adolescents, as identified chapter 5. As Weight of Evidence builds upon a completed evidence synthesis, in this chapter, I draw on outcomes and experiences among pregnant and parenting adolescent identified in the literature review presented in Chapter 2, as well as a more focused evidence review on the experience of child protection investigations in the postpartum year and among pregnant and parenting adolescents.

I am the first author of this chapter. Dr. Andersson and I conceived of the study, I conducted the research and completed the analysis together with Neil Andersson. I drafted this chapter and Dr. Andersson made substantive contributions. This manuscript is currently under review at the Child and Youth Services Review.

1. Introduction

Adolescent parents, mothers in particular, report significant stigma around their identity as parents and their perceived capacity to care for their infants. (1-4) Adding to the stigma of parenting at a young age, young parents in Canada are more likely than older parents to live in poverty, to have precarious housing, to be characterized as misusing substances and to live with mental health concerns. (5-7) All these factors place adolescent women and their children at higher risk for negative outcomes in pregnancy including preterm and very preterm delivery, low birth weight, and neonatal and infant mortality. These same factors also contribute to higher rates of involvement by child protection in the perinatal period. (5,8,9)

The role of child protection in prenatal care and the post-partum period is complex and emotionally charged, often having lifelong consequences for both infant and parents. (9-11) Timely identification and intervention to prevent child protection risks are critical; infants are

especially vulnerable as they are totally dependent on their caregivers. In Canada, infants are the age group most investigated for the risk of maltreatment, where caregiver functioning is the most frequent determinant of continuing provision of services upon investigation. (9,11)

Few studies describe the experience of mothers navigating child protection involvement through pregnancy and the perinatal period in Canada (12-15). We identified none from the perspectives of adolescent mothers. To improve our understanding of factors that shape child protection risks of infants of adolescent parents, we used a participatory approach to contextualize published evidence in the knowledge and experience of stakeholders. We focus on the lived experiences of young mothers exposed to child protection investigations and engaged with child protection workers specialized in pre- and post- natal risk assessment at the local Children's Aid Society. Our special concern was the experience of being identified and on the early stages of investigation of child protection risks.

2. Methods

Overview: This research was a partnership with a community-based social service organization provided health and social services to pregnant and parenting adolescents. We had the support of one peer researcher with lived experience as a young mother with housing and economic insecurity who contributed to earlier phases of this work. The peer-researcher received 10 hours of training, adapted and delivered by the primary author (AD). (16) The project paid for their training and contributions. Through an evidence-based and participatory procedure to prioritization of research questions, 13 pregnant and parenting adolescent women collectively prioritized the experience of perinatal child protection involvement. We contextualized evidence of factors that contribute to child protection investigations, first with a group of adolescent mothers involved with child protection and then with child protection workers.

We adapted the Weight of Evidence procedure, which we developed to contextualize literature with stakeholder perspectives in relation to access to perinatal care. (17) We began with a conventional literature review. We then contextualised published evidence in the lived experiences of young mothers exposed to child protection investigations and shared the contextualized perspectives with child protection workers specialized in pre- and post- natal

risk assessment at the local Children's Aid Society. We then built on young women's knowledge to co-develop potential intervention strategies.

2.1 Conventional Literature Review

A systematic mixed studies literature review collated published factors that contribute to child protection investigations among adolescent parents in Canada. With the help of a health sciences librarian, we searched Medline, CINAHL and Web of Science for primary research describing factors that contribute to child protection investigations, regardless of substantiation or further referral to services, among adolescent women (under the age of 22 years) compared with adult women in Canada. We included all articles published in French or English after the year 2000 and supplemented this with forward and backward citation analysis. The primary author (AD) screened all abstracts, read, and extracted data from all eligible articles, using inductive thematic synthesis for qualitative data and descriptive statistics for quantitative data. (18-20)

Following procedures described elsewhere, (21) we collated findings from the literature review as a fuzzy cognitive map (Figure 6.1) to facilitate the contextualization of the evidence with stakeholders. We converted all effect estimates to a common measure (odds ratios). (22) Nodes in the map represent independent variables from quantitative studies, and the strength of the arcs connecting nodes described effect estimates. "Unattached" nodes represent themes identified in by inductive thematic synthesis in qualitative studies. (23-25)

2.2 Contextualize published evidence in lived experience

2.2.1 How young mothers conceptualize child protection risk

Individual or small group mapping interviews engaged young women who experienced child protection involvement as a parent. The lead author (AD) carried out semi-structured interviews with young women, beginning with a discussion of how they felt judgment shaped their maternity care and early parenting experiences, described in more detail elsewhere. (2) Each woman independently identified what she considered important factors contributing to perinatal child protection involvement. As women identified factors, they summarized them in as few words as possible and wrote them on small, laminated magnets. We then presented the literature-derived cognitive map (created in the previous step) on a magnetic white board

and invited participants to adapt it, incorporating their own factors and removing factors they considered irrelevant. After grouping similar or synergistic factors, women assigned a weight and direction of effect (+ve or -ve, from 1 (lowest) to 5 (highest)) in assessing each factor's contribution to having child protection involvement. Appendix 4- Additional File 6.1 shows sample maps.

A mathematical algorithm (fuzzy transitive closure) identified indirect relationships between factors and the most influential pathways or 'walks' that contribute to child protection risks. Transitive closure accounts for how some factors might have a small individual influence but may also contribute to a sequence of events that have an important overall influence, effectively translating the map into a knowledge network rather than reflecting isolated factors acting independently. (24,26) We also calculated in- and out-degree centrality using social network analysis techniques to identify the most important contributing factors and potential outcomes in maps. (23) We averaged weights for each relationship across the women's maps to generate an average perspective from young women. We used an open-source software (yEd) to digitize maps and to calculate centrality measures. We then used the women's maps, a) to ground available literature in priorities and knowledge of adolescent mothers to identify gaps in the literature, and b) as a foundation to gather child protection workers' perspectives on the evidence base and women's contextualization of the evidence.

2.2.2 Ground available literature in the priorities and knowledge of adolescent mothers

We updated the strength of each relationship described in the literature with the weights assigned in the maps created by young mothers (see Appendix 4- Additional File 6.2 for description of updating procedure). (21) This calculated new weights for each relationship, increasing the weight or credibility of relationships that young women and the literature both identified as important, while decreasing the weight or credibility in areas where young women did not prioritize evidence from the literature. (28) We compared factors, weights, and pathways between the literature, from young women and from literature updated by young women's perspectives.

2.3. Contextualize maps with child protection professionals

We conducted semi-structured interviews with three child protection workers who at the time led pre- and post-natal risk assessment for the local Children's Aid Society. We shared a representation of the average map of women's perspectives of factors contributing to child protection investigations and asked child protection workers to adjust, comment on or add any factors that they felt relevant. We also asked several questions about organizational supports and challenges related to their work, and where they would prioritize interventions to prevent or reduce child protection investigations among pregnant and parenting adolescents. Detailed notes from each of the interviews were subsequently analyzed for recurring and salient themes.

2.4 Leveraging stakeholder knowledge to identify intervention strategies

Consistent with a realist analytical approach, and following that outlined by Pearson and colleagues, AD generated explanatory accounts identified in published literature, from cognitive maps created by participating adolescents, and narrative accounts from both adolescents and child protection workers to describe how factors and relationships between them may contribute to having perinatal child protection involvement. (27,28) The weighting of relationships in the maps helped to identify priority relationships. (23) Wherever possible, explanatory accounts were described using "If.....then...." statements, describing what led to outcomes and factors identified in the literature and stakeholder maps. (28) We also drew on notes from mapping interviews where stakeholders often verbally rationalized their selection and weighting of relationships while making the maps. When women identified factors not identified in the original literature review, we returned to the literature to identify any additional studies addressing these specific factors. Explanatory accounts were subsequently added or adapted based on these findings. We consolidated explanatory accounts following the questions outlined by Pearson et al. and grouped them by overall theme. (28)

We organized the consolidated themes into a conceptual roadmap, showing the connections and inter-relationships between the consolidated themes. We presented the framework back to the women that participated in the mapping interviews in individual or small group meetings, presenting each theme and the consolidated accounts that contributed to them. We asked women to 1) adapt any of the themes and consolidated accounts, including their placement within the conceptual roadmap, to better represent their own experiences and

understanding; and 2) to identify themes (or parts along the roadmap) that would make the greatest positive difference in their perinatal and early parenting experience.

Ethics approval was received from the McGill Faculty of Medicine Ethics Review Board (A09-B51-17A). An Advisory Board made of senior staff of our partner organization also refined and approved this research.

3. Results:

3.1 Conventional Literature Review

We identified 53 publications and the lead author (AD) assessed all abstracts to determine eligibility. We extracted data from 14 relevant articles (8 quantitative, 6 qualitative).

Mothers under 22 years of age were more likely than older mothers to be investigated for a future or potential infant child protection risk, despite the same rates of substantiated claims as older parents investigated for infant child protection risks. (11,29) Among child protection cases in Ontario among infants in 2008, 24.7% of mothers were under 21 years old and 41.7% of investigations were between 22-30 years old. (9) According to the Ontario Incidence Study of Reported Child Abuse and Neglect, adolescent parents are most commonly investigated for neglect, often associated with poverty and exposure to intimate partner violence. (29,30) Consistent with the literature around adolescent pregnancy, evidence suggests adolescent mothers investigated for child protection concerns have fewer social supports, more likely to report substance misuse, to have a history of foster care in their childhood and to experience more housing instability than older parents. (5,6,29) Adolescent mothers experienced similar levels of intimate partner violence and mental health concerns as older parents investigated for infant child protection risks. (29)

Secondary analysis of the 2013 Ontario Incidence Study suggested caregiver functions as the most common reason for investigations among infants, along with exposure to intimate partner violence, low social support, mental health concerns and use of substances. (11) This same analysis showed families investigated for infant child protection concerns were more likely to be lone caregivers. They were more likely to report that the household consistently ran out of money and to have moved at least once in the last 6 months. (29) The same risk

factors (lone caregiver, short of money and moving frequently) were more likely among First Nations families investigated for child welfare concerns, although this analysis did not break down rates by age of caregiver or child. (31) In an analysis of investigation rates by ethnicity, Indigenous, Black, and Asian families were over-represented among investigations for children aged 0-5 years old. (32)

We could not identify any published qualitative studies describing the experience of adolescent parents navigating child protection investigations. We drew instead on available literature describing parents of all ages navigating child protection investigations in Canada. Several themes were incorporated from our previous work with the same group of adolescents, contextualizing factors related to judgement in pregnancy, specifically factors that might contribute to child protection risks. (2) Those themes were compared with and elaborated upon based on available literature.

Studies reported that women felt that their identity as parents was undermined by a lack of recognition of their strengths and parenting efforts. Parents also felt that their needs were seen as separate from the best interests of their child. Parents reported that once flagged as having child protection involvement, this label accompanied and continued to undermine their parental identity as they accessed other health and social services. These experiences were reported in the literature and further validated by participants in our study. (10,13-15) These themes were captured as ‘damaged identity’, ‘ignores strengths’ and ‘needs seen as separate from child’s’ in the fuzzy cognitive maps.

Parents also highlighted the double bind of disclosing needs around mental health, substance use or other stigmatized needs when services may not be available. Without access to appropriate care, parents feared that disclosure may actually contribute to increasing their vulnerability to child protection involvement. (10,15) This theme was labelled as ‘disclosure vulnerability’ in the fuzzy cognitive maps.

In the literature and confirmed by participants in our research, parents reported feeling judged for circumstances outside of their control or that some concerns were inappropriately escalated. Through interviews with hospital social workers, Berrouard reported young and/or

Indigenous mothers were often reported for non-protection concerns, particularly in cases where women pushed back against practices that they saw as unhelpful. Berrouard also highlighted how perceptions of risk were shaped by poverty, as meeting expectations around accessing pre and post-natal care was difficult for low-income families. (10,15) These themes were included as 'shallow perception of risk' and 'blame outside of control' in the fuzzy cognitive map.

Women also highlighted the effort they invested in preserving a positive identity and relationships, particularly with child protection workers and health and social service professionals. Parents described frustration with a lack of transparency and support around the investigation process. (10,13,15,33) The challenge of maintaining positive relationships with professionals while feeling unsupported through the investigation process is captured as 'emotional management' in the fuzzy cognitive maps, while 'lack of transparency and support through the investigation process' is captured as a separate theme.

As a corollary, women in our study and in the literature, emphasized the importance of supportive relationships with professionals and women's social support networks. The literature described the extent to which parents sought to maintain supportive relationships and how much they were appreciated throughout their investigation experiences. (13-15,33) This is captured as 'importance of supportive relationships' in the fuzzy cognitive map.

Figure 6.1 shows the fuzzy cognitive map of the factors contributing to child protection investigations among adolescent parents as described in our literature review. We included evidence from literature on factors that affect perinatal health outcomes and experiences of adolescent mothers in Canada, completed in an earlier phase of this research. (2)

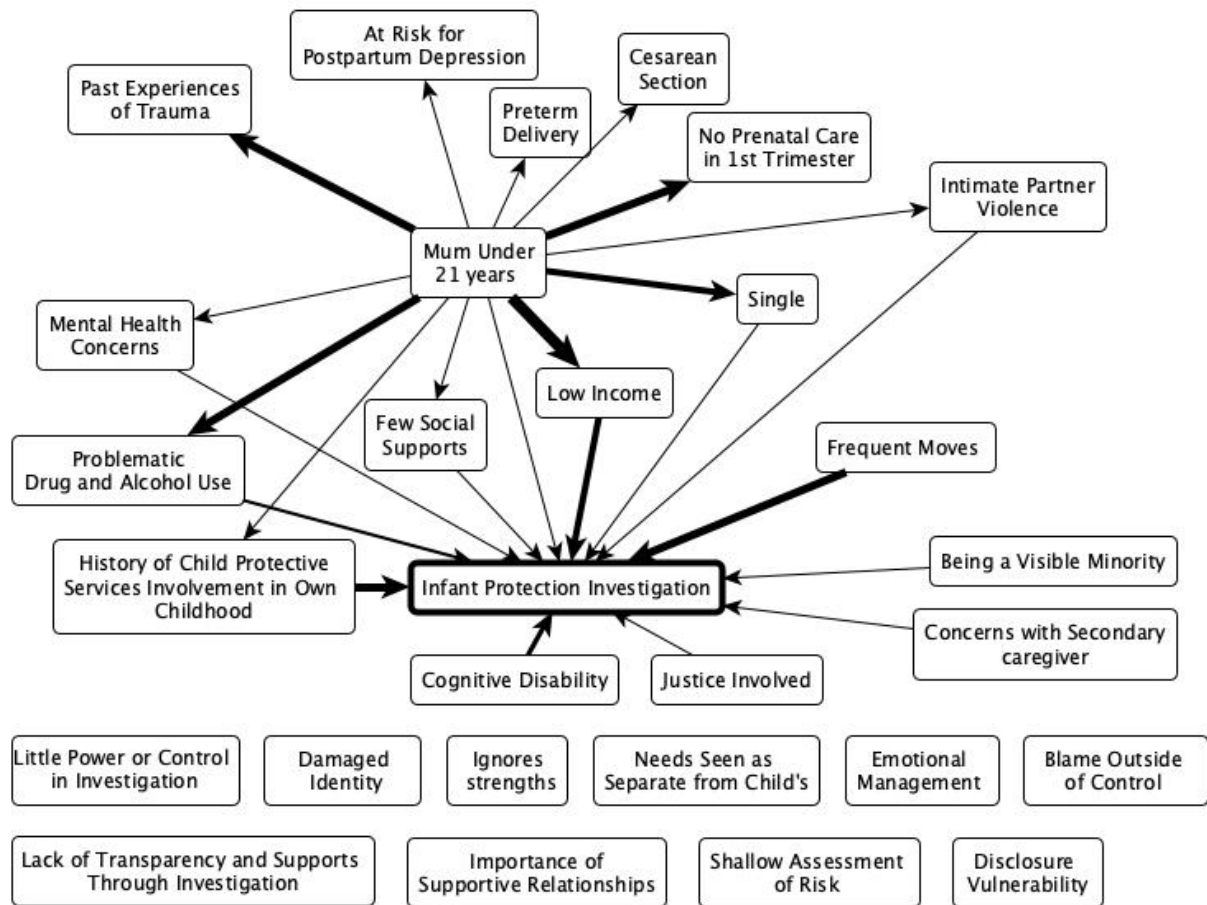


Figure 6.1: Fuzzy cognitive map of factors contributing to child protection investigations from qualitative and quantitative literature. Weights of the lines represent the strength of association as reported in the quantitative literature and themes identified in qualitative literature are listed along the bottom, unattached.

3.2 Contextualizing evidence in lived experience

3.2.1 *How young mothers conceptualize child protection risk*

3.2.1.1 *Cognitive maps*

We conducted cognitive mapping interviews with 10 women (between the ages of 18-26) individually or in pairs. Table 6.1 shows demographic characteristics of participants. Discussions distilled ideas, issues, or themes from women's experiences of navigating child protection risks. Fuzzy cognitive maps generated by women (Figure 6.2) re-weighted factors in the quantitative literature and incorporated qualitative themes according to their relative importance to other factors in the map. Most women named factors in categories already identified in the literature, many changed the weighting (or influence) of factors. Some women identified factors not in the literature.

Table 6.1: Demographic characteristics of women participating in semi-structured interviews (N=10)

Demographic Characteristic	%	Demographic Characteristic	%
Completed High School	30%	CAS involvement in own childhood	60%
Ethnicity		Experienced intimate partner violence while pregnant or parenting	80%
Black	30%		
Caucasian	50%		
Indigenous	10%		
Multi-ethnic	10%		
Receives Public Income Assistance	80%	Experienced abuse of any kind from family	70%
CAS involvement in pregnancy or parenting	80%	Experienced anxiety or depression while pregnant or parenting	50%
Youngest Child is in their custody	90%	Accessed mental health services during pregnancy or post-partum	80%
No longer has custody of older child(ren)	30%	Used illegal substances while pregnant or parenting	40%

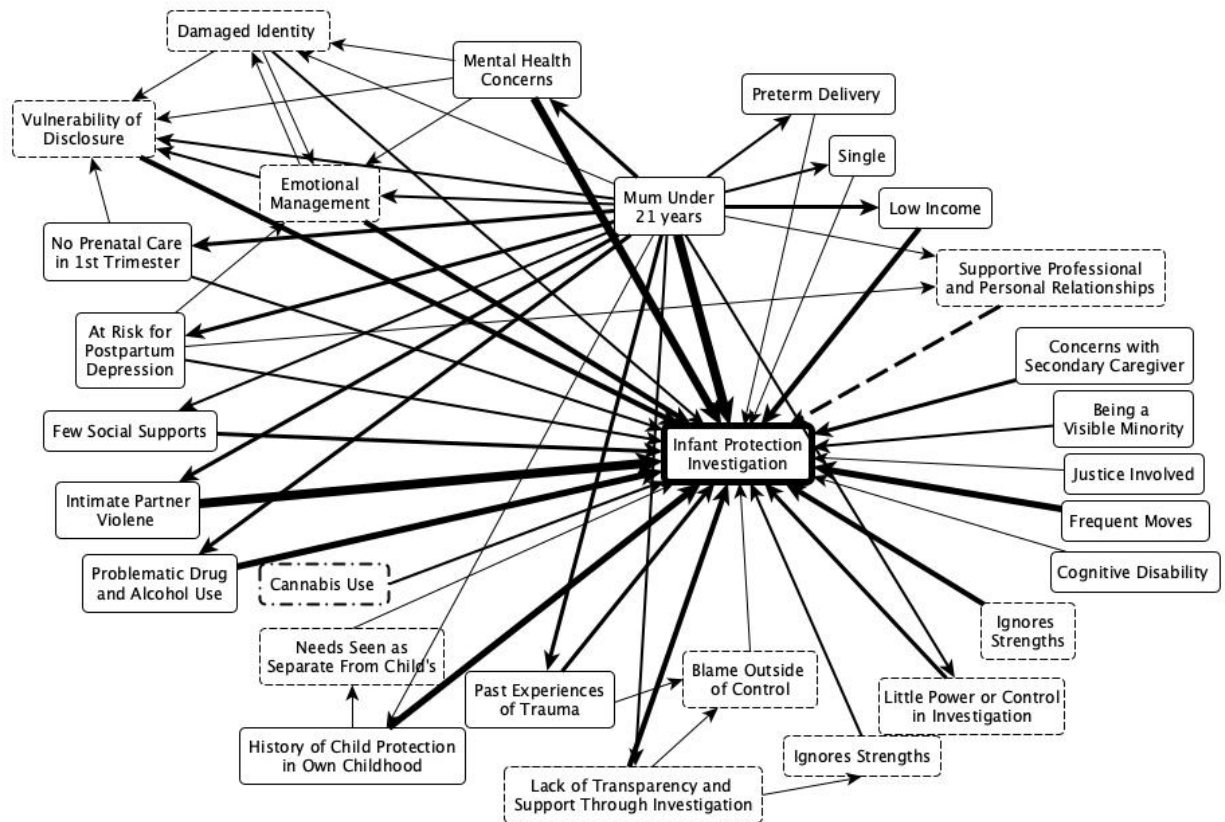


Figure 6.2: Fuzzy cognitive map of factors contributing to child protection investigations from young women’s perspectives. For readability, the map only includes factors weighted 0.1 or above. Factors selected by women from the qualitative literature have a dashed outline while those spontaneously identified by women have a dash-dot-dash outline. Reinforcing relationships are identified by a solid line between factors and inverse relationships are identified by a dashed line.

Participants attributed greater influence than did the literature to age, intimate partner violence, low social support, drug and substance use and mental health concerns. Many risk factors (such as low income, low social supports) disproportionately affect young mothers, (5) and participants identified their young age itself as contributing to their risk profile from a child protection perspective. Out-degree centrality pointed to the most influential factors for child protection involvement. After age, mental health concerns and risk of post-partum depression were the most important factors. In-degree centrality pointed to several key outcomes, beyond a child protection investigation itself, the most influential being vulnerability of disclosure, damaged identity, and emotional management. Transitive closure indicated the most influential relationship between factors contributing to how mental health concerns influence child protection concerns as between damaged identity, the vulnerability of disclosure and emotional management.

3.2.1.2. Narrative accounts

Many of the findings from the analysis of fuzzy cognitive maps resonated with participants' narrative accounts.

"I received great care for anything that directly affected my baby's health, but my mental health didn't fall into that. I also had to balance not saying too much -- I couldn't say what I really feel, because admitting feeling suicidal would be seen as a risk to my child and would be reason to justify her removal or removal of my rights".

The experience of stigma was interwoven with mothers' identities, sparse support networks, and multiple health and social needs. Women described repeated stigma contributing to high levels of stress and anxiety, often without meaningful support. Women reported that, over time, the vulnerability of disclosing their needs eroded their self-esteem and that early supports were important to avoid future risk.

"It is judgment from the people that have meant something to me that stand out"

"No one cares what we say if there isn't an authority figure to back it up. People are falling into a system where youth don't matter. When people look at me, nobody sees my future plans, just my present problems".

“We aren’t terrible or scary people or that have no idea what we are doing. Some of us are in bad situations, or made some poor choices along the way, but it doesn’t mean we don’t know anything or how to do anything”.

Past experiences of trauma also contributed to less trusting relationships with health and social service providers and perceptions that parents were investigated for experiences outside of their control. One participant reacted to the evidence in the fuzzy cognitive map suggesting that mothers with child protection involvement in their youth are more likely to experience child protection investigations as parents:

“With my first child, I was involved with [children’s aid society] as a kid, so I was automatically flagged to CAS. That in itself is messed up- there is an assumption that kids that were in CAS care as kids are less capable of being parents. I went into CAS care when I was 15 - it is not like I had been in care my whole life”

Facing repeated stigma, women prioritized their efforts in controlling their emotions for fear of being perceived as angry or aggressive. This also translated to women hiding their own health needs for fear of being seen as unable to care for their children. Women related this to feeling powerless or being seen as dangerous if they express strong opinions or do not follow a pre-defined plan set out by professional staff (captured as ‘little power or control in investigation’). Some provided examples of refusing support that did not meet their needs or examples of pushing back against investigation when they felt mischaracterized. Women also spoke of an extraordinary amount of emotional and administrative work to navigate child protection investigations, feeling they did not have access to all the information needed for informed decision-making (captured as ‘lack of transparency and supports through investigation’).

“I pushed back against the rules because I didn’t feel they were helpful or what I needed. I was threatened to be kicked out of housing if I didn’t go to counselling and programming. I decided to leave on my own and they called child protection because of concerns of me being pregnant and homeless”.

“Emotion management takes up a lot of time and energy.... that in itself isn’t seen as cause for investigation, but sometimes it is seen as aggression- and that they will see as a need for investigation. They also do not see a mum’s sacrifices, which also influences how you manage emotions. I pushed back and did all the things they tell you not to do- I yelled at my CAS worker and called her superior because she wasn’t listening. Sometimes we do need help, but the type of experience and extent of investigation shouldn’t depend on the luck of the type of worker you get”.

“My CAS worker tried to get me to sign over custody to my mother but encouraged me not to read the whole document and didn’t explain to me what signing the document would mean for me”.

Many women recognized the challenges faced by professionals, including lack of time and focus on accountability. Participants pointed to the need to better align supports to parents’ needs, including to address underlying issues and help them advocate for themselves. Women highlighted supportive relationships with friends and family as well as professionals as protective against investigations.

“Having a supportive relationship doesn’t mean they say nice things to you, but they will tell you what you need to hear... they will tell you the truth.”

3.2.2 Updating available literature in the priorities and knowledge of adolescent mothers

Updating the literature with young women’s perspectives expanded the breadth of factors considered relevant and shifted priorities according to evidence considered most important by women as shown in Figure 6.3. Table 6.2 shows factors prioritized by women compared to factors captured in our conventional evidence synthesis of elements that contribute to infant protection investigations, identified by out-degree centrality for each of the maps. Some factors were upweighted while others were adapted and contextualized from qualitative literature as contributing to the causal understanding of the issue from the perspectives of adolescent mothers.

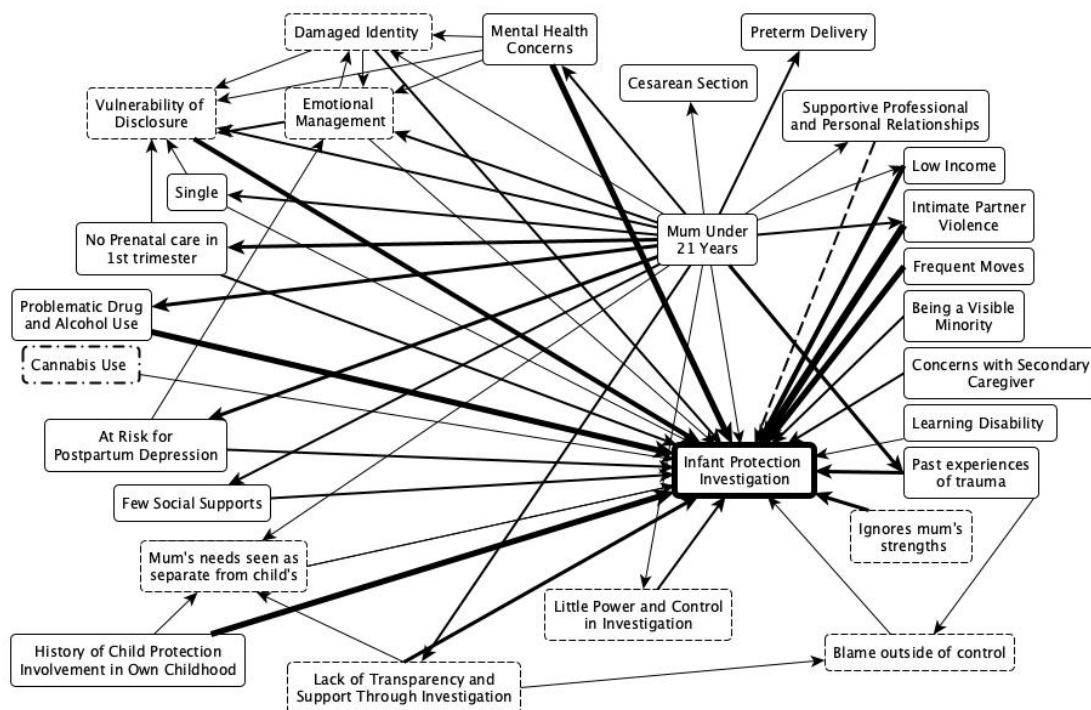


Figure 6.3: Fuzzy cognitive map of factors contributing to child protection investigations from the literature updated by young women's perspectives. For readability, the map only includes factors weighted 0.1 or above. Factors selected by women from the qualitative literature have a dashed outline while those spontaneously identified by women have a dash-dot-dash outline. Reinforcing relationships are identified by a solid line between factors and inverse relationships are identified by a dashed line.

Table 6.2: Causes contributing to infant child protection investigations among adolescents as identified through a conventional quantitative synthesis and by contextualizing evidence in lived experience of adolescent mothers. Factors are listed in decreasing importance according to each knowledge source.

Causal factors identified in conventional evidence synthesis	Causal factors identified by contextualizing evidence
Mother's young age (<21) Frequent moves Low Income History of child protection in own childhood Problematic drug and substance use Intimate partner violence Single parent Mental health concerns Few social supports	Mother's young age (<21) Mental health concerns Few supports through investigation Emotional management Damaged identity At risk for post-partum depression Lack of parent-specific supports History of child protection in own childhood No prenatal care Single parent Past experience of trauma Frequent moves Low Income Problematic drug and substance use Intimate partner violence Few social supports

3.3. Contextualize maps with additional stakeholders

We interviewed three child protection workers (two of them combining more than 75 years of experience) and a supervisor within an Ontario-based child protection agency. The lead author reviewed the evidence maps, shared how young women adapted the maps and invited child protection staff to adapt or contextualize these maps according to their understanding. We identified four main themes raised in reaction to women's cognitive maps: risk in context, isolation from community and social supports, voice and power, and institutional focus on accountability. Each of these is explored in detail below.

Risk in context

While child protection staff were not surprised by the evidence maps or the maps adapted by women, they were uncomfortable with the idea of assessing the importance of independent risk factors without considering the broader context. They suggested that risk be examined in context, considering how different factors interact to contribute to one's ability to parent. They emphasized that child protection risks are shaped by social norms about what behaviours are harmful to children, recognizing that these standards may be flawed and change over time. They saw their dual role of supporting families to find the necessary supports, while also carrying a policing role of protecting children who may be at risk, as playing an important, though often difficult, role in society.

*"If you see a child being neglected, wouldn't you want someone who is trained to do a proper assessment?
Leaving people and families isolated in that context doesn't help kids or families".*

Child protection workers described more recent efforts to 'soften' child protection interventions, citing published reports of strengths-based, family focused models that emphasize keeping children in extended family arrangements, particularly for families that have been disproportionately affected by child protection. (34-36) They also recognized the slow pace of change within institutions and that, despite policy or institutional directives, many workers may not know how to implement these shifts in practice.

They also described how differences in understanding what constitutes a risk and the role of child protection shapes how risks are identified and how parents navigate investigations. While

child protection workers reported good relationships with professionals in the community, they believed community service organizations may delay reporting infant child protection concerns, seeing child protection as a last resort, working to do all they can to mitigate risk before alerting child protection. While child protection workers understood the reasoning behind this approach, they felt it limited the opportunity for child protection workers to mitigate any concerns before they become child protection risks. They recognized hesitancy around reporting risks for fear of discouraging participation in their programming, particularly when funding models for community programs are dependent on participation. Child protection workers also highlighted that parents often have different ideas about what constitutes a risk from child protection workers, often referring to inter-generational impacts of poverty and trauma that influence how young parents were parented and how this translates to current child protection risks.

Isolation from community and social supports

Child protection staff emphasized their role in strengthening community and social supports to help mitigate risks, a gap also identified in women's maps as a lack of social supports. While protection staff emphasized building on parents' natural support structures, they also pointed to insufficient community services as challenging the mitigation of child protection risks, leading to more complex case management and limited capacity to address protection concerns. They highlighted the role of poverty in shaping access to community supports as well as reductions in outreach and engagement programs that had facilitated the engagement of the most disadvantaged families and that provided opportunities for child protection staff to support young families. Child protection staff also commented on fragmented access to community supports for young mothers, who often have needs that cross multiple service categories (e.g., for youth vs adults).

Identity and power

Child protection workers recognized the uneven power between themselves and parents facing a child protection investigation as inherent to their role within an organization charged with protecting children. Child protection workers emphasized the importance of prenatal engagement to relationship building, in a context where involvement is voluntary, and the success of developing mitigation strategies throughout pregnancy rather than addressing

accumulated risk once an infant is born. Child protection workers recognized how a child protection investigation might undermine the sense of identity and purpose that young parents often find in parenthood. They highlighted that often young parents involved with child protection have limited employment options and are often working to finish their high school education.

Child protection workers emphasized their efforts to ensure they hear parents' voices throughout investigations, to encourage support people to attend their meetings and to use accessible language with parents. Child protection professionals agreed that parents need to understand their rights in child protection as well as their accompanying responsibilities.

Institutional moves towards accountability

Child protection staff highlighted an increasing institutional focus on accountability, on opening and closing cases rather than facilitating supports for families and described a heavy burden of administrative requirements. They recognized the importance of regular and accurate reporting based on recommendations from pediatric death reviews, however suggested professional success was increasingly based on process-related statistics rather than on outcomes for families.

3.4 Leveraging stakeholder knowledge to identify intervention strategies

We returned to the literature review, young women's narrative accounts, and interviews with child protection workers to develop explanatory accounts of how different factors shape the identification of child protection investigations among young parents. Where young women identified factors or processes not addressed in our initial literature review (highlighted in Table 6.2), we returned to the literature to identify studies addressing these new factors and included them in the development of explanatory accounts. We consolidated 212 explanatory accounts, derived from the literature and our mapping interviews with young women, into 10 explanatory accounts (see Appendix 4- Additional Files 6.3 and 6.4) and organized them as an explanatory framework.

Six young women helped to refine explanatory accounts and the explanatory framework, shown in Table 6.3 and Figure 6.4, respectively. They prioritized three possible intervention

areas: 1) to reduce the stigma experienced by young mothers (by addressing explanatory account A); 2) to strengthen the role of supportive relationships (explanatory account D) , both among professionals and among young women's social support networks; and 3) to raise awareness, particularly among young parents, about parent rights, responsibilities and how to advocate for oneself in the context of child protection investigations (explanatory account G). These priorities informed our approach to knowledge translation. We used PhotoVoice, a participatory qualitative method that puts cameras into the hands of participants to help them document, reflect upon and communicate their concerns, to address the first two priorities, and is described in a forthcoming publication. (37)

Table 6.3: Consolidated Explanatory Accounts

	IF	THEN	Literature
A. DIFFICULT CIRCUMSTANCES AND TOUGH CHOICES	IF women have a partner or secondary caregiver that is seen as a risk; or have a physical or learning disability and professionals are not properly informed, or educated on how disability may (or may not) affect pregnancy, labour, and parenting; or use substances while pregnant or parenting; or have had CAS involvement as a child; or are not able to find stable and secure housing,	THEN women may need additional or tailored support that requires additional coordination and/or feel that they are judged as less capable and perceived as “risky”.	(1,12,15)
B. DISCONNECTION FROM SOCIAL SUPPORT	IF women feel they have lost their social support network because of social stigma; or do not have access to community support and trauma-informed services before or during a child protection investigation,	THEN they may feel they have no one to rely on, be unsure of where to seek help, and feel isolated and/or they are being blamed for things outside of their control.	(1,12,15,38)
C. SOCIAL EXPECTATIONS	IF women do not fit with dominant norms around motherhood,	THEN women may be seen to be incapable or risky.	(10,39,40)
D. SUPPORTIVE RELATIONSHIPS	IF women have relationships with people, they trust and that believe in them; or IF women receive trauma-informed support in early parenthood,	THEN they may be more likely to feel supported and that they can get through difficult moments. THEN they may be able to identify and understand how past trauma may affect their parenting and prevent any negative consequences.	(1,33) (1,14)
E. BARRIERS FACED BY PROFESSIONALS	IF health providers and child protection workers do not have enough time to understand their clients underlying challenges, lived experiences; or recognize the influence of	THEN they may misinterpret risk, families may not be offered services that address their true needs and women may feel unsupported or that they cannot express their needs.	(10,14,15,33,38,41)

	their own values on how they perceive what is risky in someone else's parenting,		
F. RISK AND COMPLIANCE FOCUSED	IF risk assessments do not account for the time, thought and effort required of mothers/parents to engage and keep open and accurate lines of communication and comply with child protection requirements, or are based on preset programs and/or rules	THEN professionals may have little flexibility for client-centered/tailored support, families may not be offered services that address their true needs and/or women efforts and accomplishments may go unnoticed and may be seen as uncooperative.	(15,38-40)
G. NOT KNOWING RIGHTS	IF parents do not feel they understand their rights surrounding child protection investigations; or are not given clear and full information about the child investigation; or feel like they do not have emotional, financial or structural support in navigating a child protection investigation,	THEN they may experience a sense of powerlessness and be less likely able to advocate for themselves and the needs of their families and/or may feel that they cannot safely voice their concerns and/or have a choice in professional support.	(13-15,38,39)
H. FEELING POWERLESS, WITHOUT A VOICE	IF women feel that decisions have been made without, or despite, their input, or that they continually need to fight to be heard or believed; or IF professionals voice negative opinions about a woman's choices	THEN this may shut down open communication, and/or women may feel misunderstood, powerless and lose trust in professionals to support their needs and may be less likely to seek out support.	(13,15,38-40)
I. BLAME	IF parents are responsible for issues that are outside of their control, or are unable to achieve the requirements placed on them by child protection investigations or access support for their own needs	THEN risk reduction strategies may place unrealistic goals for parents, mis-characterize family's needs and responses, and/or women may be labeled as "non-compliant" and may feel powerless and perceive CAS as unsupportive.	(38,39)
J. JUDGED AND LABELLED	IF women are seen as a risk during pregnancy, labour and delivery; or IF women are flagged for child protection risks,	THEN women may feel the need to hide their emotions for fear of appearing aggressive or angry and that they cannot openly express their needs or may learn to bury their emotions; or THEN they may feel that their role as a parent is discounted and/or that they are always observed and only seen for their current problems.	(10,13,15,38)

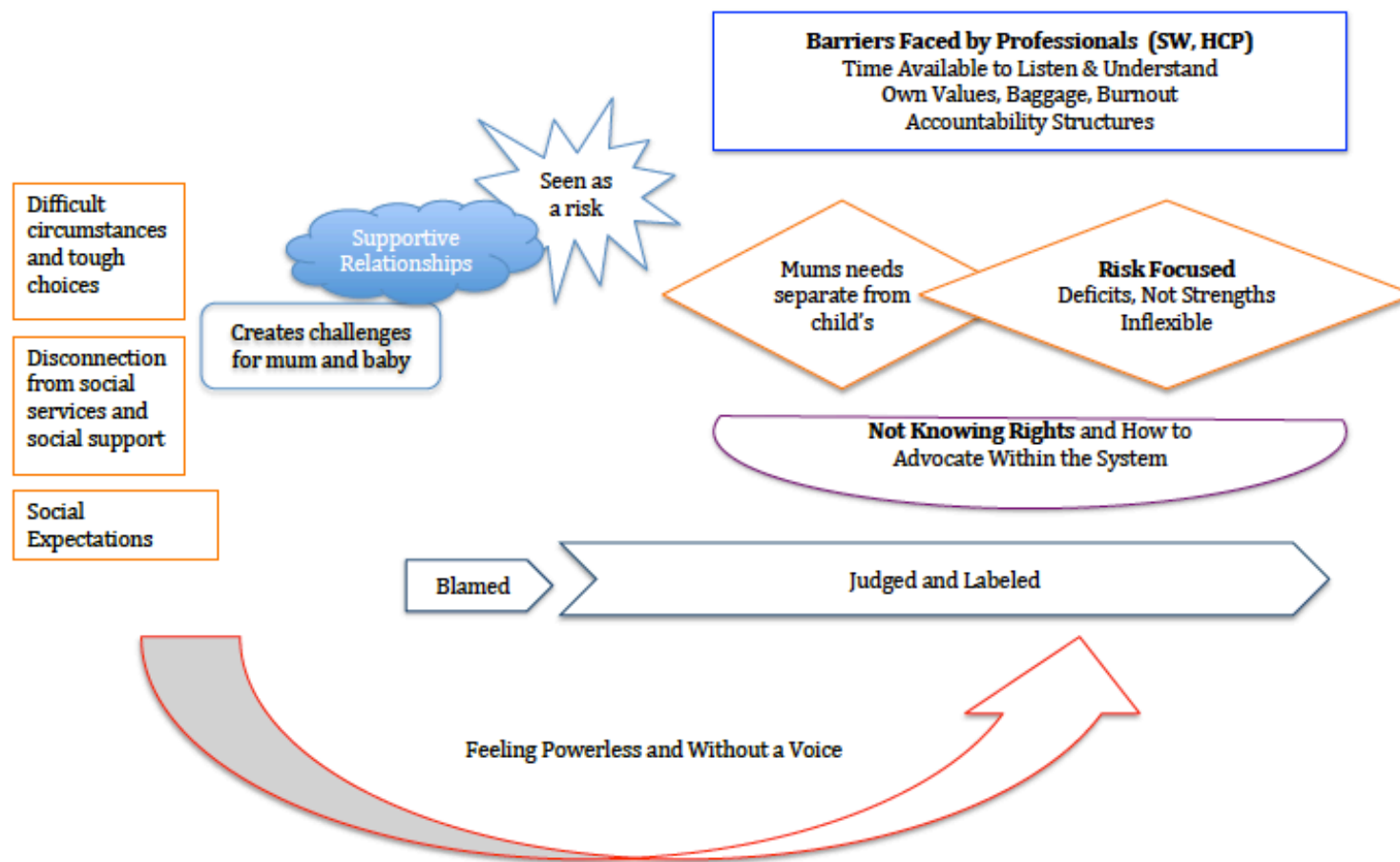


Figure 6.4: Explanatory framework developed in collaboration with pregnant and parenting adolescents, informed by published evidence and fuzzy cognitive maps created by participants

4. Discussion

This participatory procedure contributes to our understanding of child protection in the prenatal and early postpartum period in two ways. It examines upstream factors that contribute to child protection risks, to better support young parents and prevent perceived or real risks to their children. It also contextualizes published evidence with client-identified priorities. This can improve the effectiveness and safety of perinatal health and social care for a population who are disproportionately identified as living with child protection concerns, yet whose perspectives are rarely included in the evidence to address these inequities. (42) The published literature echoes many of the experiences reported by young women and by child protection workers as factors that contribute to infant child protection risks. These include experiences of powerlessness, a deep commitment to their parental identity and the fine balance of accessing needed supports while seeking to distance themselves from the far-reaching stigma of having child protection involvement. (10,14,39)

The insights shared in this article illustrate how investigations are experienced by adolescent mothers, and points to implications for both the evidence base and interventions to reduce the number of families experiencing child protection risks in the first year after birth.

Our research builds on existing qualitative and quantitative published evidence, adding how this evidence is interpreted by young mothers and child protection workers. Fuzzy cognitive maps are a medium for representing different forms of knowledge. The Weight of Evidence procedure, relying on fuzzy cognitive maps, allowed us to ground one form of knowledge in another, providing a formal and reproducible way to take account of stakeholder views in assessing the relevance of evidence.

Stakeholders identified factors beyond those in the original literature review, prompting a re-examination of how we initially understood risk factors and, consequently, how we conceptualized possible interventions. Making epidemiological data accessible to diverse stakeholder groups helps to engage stakeholders on equal terms with the full scope of evidence. This is an important mechanism to prevent the dismissal of community or informal knowledge on the grounds of not having full understanding of an issue. (14,43-45) Young

women's maps demonstrate how they assigned priorities in consideration, not in isolation, of all available evidence.

Recognizing that we understand and prioritize issues differently depending on our institutional and relational power is central to contextualizing published evidence. By inviting and holding space for multiple ways of understanding the same issue, this work demonstrates the feasibility and value of contextualizing published evidence. It also offers a path forward to make both the generation and synthesis of evidence more relevant to the needs of families. Finally, it also presents an opportunity to explore how policy and interventions align with stakeholder needs to better understand why some interventions succeed, while others fail. (46-48)

There are several practical implications of these results. Parent emphasis on the profound influence of supportive relationships points to the importance of collaborating with parents in their own context. Recognizing difficult reactions as pain-based behaviours derived from the threat of child removal plays an important role in humanizing and contextualizing parents' responses. (49) While child protection concerns need to be acted upon, building relationships and risk mitigation strategies throughout pregnancy allows for a better understanding and leveraging of parents' strengths and social context, as suggested by child protection workers in this study.

There is a lack of acknowledgment of the effect of the investigation itself may have on the immediate and long-term well-being of young mothers. Several recent studies have shown that mothers whose children have been taken into care have higher mortality rates due to avoidable deaths, including higher rates of suicide and showed significantly higher rates of anxiety and substance use disorder two years after custody loss than matched sisters who maintained custody of their children. (12,50-55) A recent study in British Columbia found that separating mothers who use substances from their children increased the incidence of unintentional overdoses. The effects of removal were compounded for Indigenous mothers, reflective of Canada's colonial child welfare policies and the over-representation of Indigenous children in the child welfare system. (30,56,57)

While not all mothers in our study had their infants taken in custody by child protection, our study suggests the investigation itself is not without harm. Women spoke of the mental health consequences of living with the stigma of having child protection involvement, with important secondary effects related to care-seeking for their own needs, challenges to their identity and self-confidence as parents and sense of connectedness with their communities.

Of our study participants, one identified as Indigenous, three as Black and one as a recent immigrant of mixed ethnicity. The remaining four participants identified as white. Race was a factor in the literature-based maps (labelled as ‘not being white’) and was inconsistently weighted by participants. The pervasive impacts of racism and identification by the child welfare system are well known and documented among communities most over-represented within the child welfare system. (57,58) While operationalized and experienced differently across communities, the dismantling of traditional systems of maternity care, parenting and family structure are part of Canada’s historical and ongoing colonial approach to child welfare and contribute to the over-representation of Indigenous and Black children in Canada’s child welfare system. (57-61)

Multiple studies confirm what mothers in our study highlighted as shouldering individual blame for risks to children that are often outside the sphere of parental influence. (10,15,62) The lack of accessible community supports was also highlighted by child protection workers as a factor complicating efforts to address the root causes of child protection risks, often leaving mothers feeling alienated from an unsupportive system rather than integrated into a responsive community. (15) This is further compounded for Indigenous families by the longstanding inequitable funding gap for health and social services, including child welfare services, for First Nations children on reserve, where Indigenous families are deprived of the same access to services as other Canadians to mitigate child protection risks. (57) It is estimated that First Nations children on reserve receive 22% less per capita in child welfare funding than other children, where this shortfall is most extreme with respect to services intended to keep children at home. (63,64) Gaps in community-specific support services are also highlighted as needed resources to better meet the needs of African Canadian families. (36)

Across Canada, there is increasing attention given to family-centered, trauma-informed approaches to perinatal care. These programs improve maternal and newborn health outcomes and decrease costs for people with complex care needs that make them more likely to have child protection involvement, such as substance use, mental health concerns, experiencing violence and living with low socio-economic support. (65-67) Interventions that focus on caregiver needs, such as poverty and limited social supports, substance misuse, mental illness and domestic abuse have a more profound effect on family interactions and the preservation of families. (9) Increasing evidence also suggests the importance of cultural continuity and community leadership in shaping perinatal care and child services in re-framing, developing, implementing and evaluating prenatal, reproductive and child health services. (36,59,68) Despite evidence of these promising approaches, many challenges remain at institutional levels, as highlighted by child protection workers in this study, as well as at funding and administrative levels. (57)

Participatory research has a significant role to play in community-led solutions to better align services with community needs. The procedure we describe here offers a way to support community-led decision-making, informed by the best available evidence, and adapted according to what might work best for a particular community context.

This work has recognizable limitations. It engaged a small group of young women accessing services at a community-based social service organization. Several of the women had lost custody of earlier children, and almost all had custody of their youngest child at the time of this study and therefore might be a special segment of the sub-population. While illustrating a more generalizable method to support client-led and evidence-informed priority setting and evaluation, the specific results of participant contextualizing and prioritizing may not be the same for other adolescent mothers in other places. Additional mapping and prioritizing with a broader and more diverse group of adolescent parents, as well as service providers, would contribute to greater representation. This would be most important among, and to be led by, communities over-represented in Ontario's child welfare system. We have also not addressed substantiation of claims nor factors contributing to the implementation of child protection plans.

The slim body of evidence describing the experience of adolescent parents and infant child protection investigations meant that much of the evidence contributing to the fuzzy cognitive maps came from cohort studies and qualitative studies in the child protection and perinatal health fields. While this makes the contextualizing of evidence all the more important, it also means that some of the relationships described in the maps were informed by a single study. This highlights the need for greater research examining risk factors for child protection risks among this population.

This study does not describe how to translate client-identified priorities into action. This was the focus of a separate knowledge translation strategy and the focus of forthcoming publications.

5. Conclusions

This work illustrates a formal and reproducible way to contextualize published literature in the lived experience of young women with perinatal child protection involvement. The young women in this study chose and prioritized different factors to those in the literature. They highlighted the mental health consequences of living with the stigma of child protection involvement, challenges to their identity and self-confidence as parents and sense of connectedness with their communities. Child protection workers added further value to this evidence, highlighting the need to examine risk in context and the challenge of supporting young families isolated from kin and community support networks. The inputs of young women and service providers precipitated a reconceptualization of risk and ideas of how to support greater agency and self-determination among young parents experiencing child protection investigations.

This research presents a new method to contextualize, and update published evidence in the experience and wisdom of those with most at stake in the outcome. It combines context-specific stakeholder knowledge with quantitative and qualitative data from published studies, reconciling several perspectives and translating these into actionable results. Together with young mothers, we co-developed priority areas to mitigate child protection risks and better to support young parents.

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Chapter 7. Discussion: Weight of Evidence contributions and future directions

The central hypothesis of my thesis is that published literature on the perinatal care of under-served women in Canada does not adequately reflect the perspectives of under-served women or the challenges faced by providers and policy and program advisors in delivering care to this population. My research questions explored how perspectives of the factors contributing to poor perinatal outcomes differ between stakeholder groups and from published literature, and how under-served populations prioritize evidence and interventions to improve perinatal care outcomes and experiences. I answered these questions by addressing my three research objectives, making methodological and substantive contributions to inform perinatal health and social services for under-served populations in Canada.

My first thesis objective was to identify patterns in outcomes and experiences among people that face a common experience of navigating Canada's perinatal health and social services living with multiple forms of exclusion. I conducted an integrative review focused on identifying patterns in outcomes and experiences among under-served populations to identify how upstream social and structural determinants may shape perinatal health.

This review highlighted the importance of examining how social and organizational factors influence perinatal health, as well as how epistemological assumptions shape the questions that receive sustained research attention and the perceived best ways to answer them. (Katz et al., 2020) Much of perinatal health literature focuses on factors that shape perinatal health at the clinical level. Poor and socially marginalized groups are often very clear about how marginalization impacts their health, but their perspectives are poorly reflected in the available evidence bases. (Serrant-Green, 2011) What comes to the fore and what remains silent is shaped by social and scientific norms about whose knowledge is important in a particular context. (Guidry-Grimes & Victor, 2012; Johnson et al., 2004; Serrant-Green, 2011) Findings from this review further focused my doctoral research around the challenge of integrating perspectives of socially excluded populations with the best available evidence, motivated by the desire to contribute to more respectful and useful services for under-served populations. (Smith, 2012)

My second thesis objective was to develop a systematic approach to contextualize published evidence in stakeholder experience. Several authors have highlighted the challenges of stakeholder involvement in evidence synthesis more broadly, including poor operationalization and a lack of understanding of how stakeholder input influences evidence interpretation and translation. (A. George et al., 2017; Pollock et al., 2018) Weight of Evidence introduced a formal procedure to contextualize evidence in stakeholder knowledge to support diverse engagement in local quality improvement.

My third thesis objective was to apply Weight of Evidence to contextualize published evidence on perinatal health in the perspectives of under-served populations and providers delivering their care. Drawing on adolescent-specific findings from the review completed as part of the first research objective, pregnant and parenting adolescents identified priority topics through a participatory evidence-based priority setting procedure. The adolescents I worked with prioritized judgment experienced while accessing perinatal health and social services, particularly as it contributed to identification as a child protection risk. I used Weight of Evidence to contextualize evidence of what contributed to child protection risks in the knowledge and experience of young mothers exposed to child protection investigations and child protection workers specialized in pre- and post- natal risk assessment at the local Children's Aid Society.

Through the development and application of Weight of Evidence, this thesis presented two methodological contributions: 1) developing an accessible, transparent, and systematic procedure to contextualize published evidence in stakeholder knowledge; and 2) advancing participatory research approaches.

The first methodological contribution of my doctoral research was the development of Weight of Evidence as an accessible, transparent, and reproducible procedure to contextualize evidence syntheses. Stakeholders participated without requiring training or expertise in evidence synthesis methods, having important implications for accessibility and who can participate in contextualization and knowledge translation. Assigning weights through fuzzy cognitive mapping invited stakeholders to analyze problems in context, while generating

transparent and meaningful measures of influence for each factor. When combined across a stakeholder group, the average weight, and the associated variation (or uncertainty) was represented as a prior distribution. Bayesian updating calculated the influence of the prior distribution, in this case stakeholder knowledge, on what was known from the literature, while explicitly accounting for the uncertainty in each measure. (Goldstein, 2006) The use of fuzzy cognitive maps to generate an informative prior provided a formal way to benefit from stakeholder insights to contextualize available evidence. This procedure may have relevance beyond Weight of Evidence. Weight of Evidence made explicit when and how stakeholder input influenced evidence interpretation and translation. (Haddaway et al., 2017) This opened analysis and decision-making to greater discussion, facilitating more collaborative conceptualization of priorities by those most affected. (Befani & Stedman-Bryce, 2017)

Advances to participatory research define the second methodological contribution of my doctoral research. Weight of Evidence invited participants to redefine how risks were conceptualized while also considering community strengths and how these can be better supported. (Guishard, 2009; Tuck, 2009) Doing so can increase participants' sense of agency, dignity and connectedness, elements shown to make important contributions to perinatal and other health outcomes. (Lyerly, 2006) In my research, pregnant and parenting adolescents emphasized their own role as advocates and the importance of supportive relationships, both among professionals and their social support networks, as critical to reducing perinatal child protection risks. Both areas were the focus of knowledge translation efforts with pregnant and parenting adolescents (described in the appendices). Interpretation and contextualization of the evidence base, drawing on fuzzy cognitive maps, Bayesian updating and realist methods, examined risk factors in context while identifying community strengths as a starting place to influence change.

My use of fuzzy cognitive maps to make epidemiological data, or knowledge from other stakeholders, accessible to diverse groups, invited stakeholders to engage with the full scope of evidence often available to other decision-makers. This expanded upon existing protocols and applications of fuzzy cognitive maps by transforming qualitative data from themes (either identified from qualitative literature or identified by participants) into a weighted relational

structure together with quantitative data, led by participant expertise rather than researcher-expertise. (Fetters, Curry, & Creswell, 2013; Giles et al., 2007; U. Özesmi & Özesmi, 2004)

Through the combined use of fuzzy cognitive mapping with Bayesian updating, Weight of Evidence introduced a transparent and analytically precise tool relevant to participatory research. Grounding published literature in stakeholder perspectives identified how different and differences across stakeholder perspectives influenced both what were considered important factors and the interdependence between them. This procedure has broad applicability within participatory research to better understand the implications of the collaborative generation of knowledge.

Fuzzy cognitive maps acted as a platform where stakeholders named and situated many potential mechanisms and social and structural influences in relation to outcomes. (Pawson, 2008) Stakeholders interpreted the evidence base, refined explanatory accounts and their implications, and prioritized intervention areas. Combining participatory research approaches within critical realist methods constitutes a modest if underdeveloped contribution of this research. Stakeholder involvement in generating explanatory accounts and anticipating their implications is especially important when working with under-served communities, where theories and explanations generated outside the community may inadvertently reinforce erroneous stereotypes. (Tuck, 2008)

This doctoral thesis also made substantive contributions to inform perinatal care of under-served populations in Canada by 1) identifying how social and economic exclusion may contribute to perinatal health outcomes and experiences; and 2) demonstrating how pregnant and parenting adolescents conceptualize risk reduction in relation to child protection involvement throughout the perinatal period.

Through the literature review completed as part of the first objective, I identified higher rates of poor maternal and newborn outcomes in populations living with social and economic exclusion than among comparator populations. I identified common experiences of economic and social exclusion, stigmatized identity, and a lack of community and organizational supports as influencing perinatal experiences. Understanding the structural, policy and organizational

factors that limit access and people's ability to benefit from curative and preventive services may help services to be more accessible and responsive to under-served populations. (Galabuzi, 2012) That pregnant and parenting adolescents prioritized factors relating to stigma and social and economic exclusion reinforced the findings from the literature review, arguing for policies and interventions that address social and structural barriers to perinatal care. (Wolfson, Schmidt, Stinson, & Poole, 2021)

I used Weight of Evidence to contextualize evidence on prenatal child protection risks among pregnant and parenting adolescents, prompting a re-examination of risks. Adolescents echoed many of the experiences reported in the literature as contributing to infant child protection risks, including experiences of powerlessness and the stigma of having child protection involvement. (Berrouard, 2017; Dumbrill, 2010; Sykes, 2011) Adolescents also identified factors beyond the literature, including the mental health consequences of protection investigations, with important secondary effects related to care-seeking for their own needs. These findings suggest that protection investigations are not without harm, as adolescents reported shouldering individual blame for risks to children often outside the sphere of parental influence, including poverty and lack of kin and community-based supports. (Berrouard, 2017; Blackstock, 2009; D. Brown, 2006) Adolescents assigned greater importance to upstream factors that may offer greater opportunities to prevent child protection risks than factors identified at the time of investigation.

These findings have relevance for primary care providers as they are optimally positioned to provide community-based perinatal care. Most people will see family physicians and other primary care providers for health care once they are aware of a pregnancy, making pregnancy a window of opportunity to coordinate care, particularly for populations that may require care from specialized services across multiple sites and provider types. (Ordean et al., 2013) Pregnancy is an ideal period to address child protection risks as people are more likely to access services and change their behaviours for the sake of their infant's health. (Wong, Ordean, & Kahan, 2011) In the absence of comprehensive trauma-informed health and social services, however, child protection surveillance is more likely to lead to apprehension of children than addressing the underlying factors most likely to contribute to child protection risks for a newborn. (Terplan, Kennedy-Hendricks, & Chisolm, 2016)

Client-centered, trauma-informed and integrated services can improve outcomes for populations most at-risk for poor perinatal outcomes. (Benoit, Carroll, & Chaudhry, 2003; Fleming et al., 2012; Nathoo et al., 2015; Ordean et al., 2013; Ordean & Kahan, 2011) Many of these programs shift away from deeply held attitudes and beliefs that lead to individualizing risk, labelling, and discriminating while also re-designing care to reorient the processes that maintain these perceptions as dominant ones, placing clients in control over the services they receive. (Geronimus, Hicken, Keene, & Bound, 2006; Ordean et al., 2013; Phelan, Lucas, Ridgeway, & Taylor, 2014) That client-centered and comprehensive care programs are able to overcome systemic and individual barriers and contribute to improved outcomes suggests that both re-considering evidence and care delivery in the context of knowledge and expertise of clients can have an important influence on perinatal care outcomes. (Ordean et al., 2013)

Limitations and Future Directions

My doctoral research has recognizable limitations. The purpose of Weight of Evidence was to contextualize findings of an evidence synthesis to local settings. In the pilot (in chapter 4) and application of Weight of Evidence with pregnant and parenting adolescents (in chapter 5 and 6), the selection of included participants set the terms for generalizability of this work for community perinatal care. My application of Weight of Evidence engaged a small group of adolescents accessing services at a community-based social service organization so represent only a segment of the sub-population. While my doctoral research contributions include a generalizable procedure to support client-led evaluation and interpretation of evidence, the specific results of participant contextualizing, and prioritizing may not be the same for other pregnant and parenting adolescents. Additional mapping and prioritizing with a broader and more diverse group of adolescent parents, as well as service providers, would contribute to greater generalizability. Despite this limitation, the process used to generate explanatory accounts, informed by a comprehensive literature search and that incorporates priority factors identified by stakeholders, is consistent with a realist approach to identifying evidence-based and testable hypotheses to inform intervention strategies. That these explanatory accounts draw on contextual factors common across under-served populations may lend generalizability to the accounts developed through my research. (Maxwell & Mittapalli, 2010)

I am also aware of potential researcher bias. I conducted the evidence synthesis, including screening and reviewing articles, extracting data for the integrative review, and I generated and consolidated the preliminary explanatory accounts on the pilot and application of Weight of Evidence. I collaborated with peer researchers and/or participants to validate and refine findings throughout this process. That I was the sole researcher leading these activities may have introduced bias that contributions of peer researchers might not have balanced.

The use of subjective accounts from stakeholders might, in some views, bias the evidence base. A robust Bayesian prior is one that accurately represents the views of relevant stakeholders. (Burgman et al., 2011) Relevance and accuracy are often tied to expertise, conventionally defined by professional qualifications, track record, and experience. (Burgman et al., 2011) These requirements can sometimes exclude people with useful knowledge, while also extend legitimacy to experts beyond their field of expertise. (Burgman et al., 2011) People living with the everyday effects of being made vulnerable are the most relevant voices to speak about how this vulnerability intersects with perinatal care, and ultimately influences their own and their family's health and well-being. (Collins, 1986; Harding, 2003) Considering these stakeholders as experts does not mean they have the only voice, nor does it displace scientific evidence or expertise. Weight of Evidence incorporates stakeholder perspectives with published evidence in a transparent way that does not diminish distinct contributions by different types of knowledge but examines the implications of their interactions.

A third limitation of my doctoral research is that I was not able, within the constraints of a doctoral program, to translate all findings from the Weight of Evidence procedure into service-related decisions. Through my partnership with a community-based health and social service organization, I applied PhotoVoice as a knowledge translation initiative and as part of the organization's programming to support self-efficacy among adolescents. This contributed to identifying priority areas for future interventions. Without additional time and financial support, I was not able to implement and evaluate suggested intervention strategies. Outside of my doctoral program I am contributing to an evaluation of perinatal care for people vulnerable to custodial loss in the Ottawa area. In this role, I draw directly on the findings from this doctoral research, particularly around the determinants of child protection risk in the perinatal period.

I introduced and tested Weight of Evidence as a rigorous participatory procedure to contextualize evidence for decision-making. Further applications of Weight of Evidence will anchor and expand its relevance for evidence contextualization and beyond. This work is already underway as doctoral students within the Department of Family Medicine are adopting and adapting Weight of Evidence, focusing on cultural safety in perinatal care in Indigenous communities in Mexico and with Inuit-populations evacuated to Montreal for maternity care. I am also leading the application of Weight of Evidence to identify support needs for academic achievement of high school students diagnosed with learning disabilities in the Montreal area. These applications and extensions will solidify Weight of Evidence as participatory procedure to contextualize evidence for decision-making and demonstrate its flexibility across diverse contexts.

My doctoral research identified several future research directions. From a methodological perspective, continued adaptation of Weight of Evidence, accompanied by sensitivity analysis, will expand the applicability of this procedure. This might be most useful in engagement and elicitation procedures to best represent and translate stakeholder perspectives in fuzzy cognitive maps and in updating evidence. In adapting Weight of Evidence to different settings, there may be contexts where it is appropriate to upweight the contributions of a particular knowledge source. For example, if a perspective has been systematically marginalized, it may be of interest to examine how this perspective changes our understanding when up weighted to count for more than other perspectives (called network weighting). There are other contexts when stakeholders hold expertise about one aspect of a problem or issue but are not able to contribute as an expert on other aspects. For example, when determining risk factors influencing the use of obstetric interventions, it may be appropriate to selectively upweight obstetrician perspectives (called factor weighting). Obstetricians, however, may be less able to fully describe how stigma and discrimination influence access to health and social services, and therefore upweighting their perspectives on this issue may not be justified. Exploring implications of differentially weighting either stakeholder perspectives or specific elements of larger network are a focus of future methodological development.

Weight of Evidence may also have relevance in other contexts where stakeholders contribute to priority setting, problem definition and causal reasoning. This includes exploring how Weight of Evidence might contribute to greater stakeholder involvement in systematic reviews by stream-lining the steps introduced by Weight of Evidence with systematic review protocols (preliminarily framed as a Weight of Evidence review). This could include stakeholder-led priority-setting to define the review's focus, contributing to the synthesis of evidence (using the approach described in Chapter 5) and contextualizing of evidence to develop an expanded and stakeholder-weighted systematic review (using the approach described in Chapter 6). This is a promising future application of the Weight of Evidence that could contribute to more responsive and relevant evidence synthesis and guidance, particularly when there is a limited evidence base to inform decision-making. (Badampudi & Wohlin, 2016)

In my Weight of Evidence example, stakeholders consistently identified factors and inter-dependence between factors not identified in the literature. This suggests a significant role for rigorous and transparent participatory research to better align research and the provision of services with community needs. This may be of particular benefit for families living with multiple forms of exclusion and vulnerable to custody loss in the perinatal and postpartum period. Integrating diverse perspectives, while centering the needs of families vulnerable to custody loss, can contribute to better understanding of immediate and more upstream determinants of risk, and how to best mitigate risk in the perinatal period. Advancing evidence-based and community-led approaches to perinatal risk reduction is an area well-suited to participatory research approaches. Future areas of research include adapting Weight of Evidence to contextualize administrative data and to develop community-led approaches to quality assessment and risk reduction with populations most at risk of custodial loss.

Chapter 8: Conclusion

This doctoral research grew out of a concern that published literature on the perinatal care of under-served populations in Canada does not adequately reflect the perspectives of under-served populations or the challenges faced by providers and policy and program advisors in delivering their care. I first identified how the literature describes perinatal outcomes and experiences of under-served populations. I then developed, piloted, and applied Weight of Evidence as a procedure to contextualize this evidence in stakeholder perspectives. A pilot study examined how family physicians and community doulas adapt and prioritize published evidence around factors contributing to unmet postpartum care needs among recent immigrant women in Canada. Applying this procedure in partnership with a community-based health and social service organization, pregnant and parenting adolescents prioritized the concern of being investigated for child protection concerns. Using fuzzy cognitive maps and Bayesian updating as integral to Weight of Evidence, I answered my first research question by demonstrating how perspectives differ between stakeholder groups and with published literature, both in the factors included and interdependence between them. Evidence contextualized in stakeholder perspectives helped identify priority factors and explanatory accounts to inform strategies to improve perinatal health among people living with social and economic exclusion, the focus of my second research question.

Addressing my first thesis objective to **identify patterns in perinatal outcomes and experiences among under-served populations in Canada**, I demonstrated that most published literature examining perinatal health of under-served populations in Canada focused on populations defined by socio-demographic risks. The locus of change centered on individual behaviour, either by under-served populations or by providers. (Carson et al., 2016; Pevalin, Wade, Brannigan, & Sauve, 2001) Identifying maternal and newborn outcomes and experiences across populations that face a common experience of social and economic exclusion, my analysis shifted the locus of change to address social and structural barriers to perinatal care. This included the influence of poverty, stigma, and a lack of institutional and community support for perinatal care.

This review also highlighted how research systems may contribute to maintaining (or not

actively addressing) perinatal inequities in Canada. The first is through the absence of regularly collected data on both outcomes and experiences of under-served populations, including among Métis and non-status First Nations people, people with physical disabilities and trans communities, among others. (Allan & Smylie, 2015; Smylie, Fell, Ohlsson, & System, 2010) These absences limit the relevance of available primary evidence, then carried through to evidence syntheses and when translated into interventions and evidence-based practice. Under-representation or a sole focus on identifying risk or deficits in under-served populations limits the visibility, attention, and voice of under-served populations in research about themselves. The exclusion of communities in determining what questions receive sustained attention within research as well as what are seen as the most appropriate ways to answer them point to the importance of co-created and participatory research. (Greenhalgh et al., 2016; Katz et al., 2020; Macaulay et al., 2007) Populations carrying the greatest burden of health inequities need a stronger voice in research intended to benefit them. While my focus was on perinatal care and child protection research, grappling with epistemic questions within research around what counts as valid knowledge and appropriate research practices is relevant to addressing health inequities more broadly. (Smith, 2012)

My second thesis objective was **to develop a systematic approach to contextualize published evidence in stakeholder experience, with a focus on engaging historically under-served populations** to better incorporate their perspectives in research intended to benefit them. Through Weight of Evidence, I developed and piloted a transparent and reproducible procedure to contextualize published evidence in stakeholder knowledge. The development and testing of this procedure advances the meaningful engagement of stakeholders in contextualizing evidence through a novel application of fuzzy cognitive mapping and Bayesian updating, and contributes to advancing participatory research.

Weight of Evidence does not require stakeholders to become highly versed in evidence synthesis methods yet maintains a rigorous and transparent procedure to contextualize evidence, with important implications for accessibility. This broadens who may have the opportunity to participate in contextualization and knowledge translation processes, particularly relevant for the translation of evidence with under-served populations. The use of fuzzy cognitive maps as a medium to represent epidemiological data invites stakeholders to

engage with the full scope of evidence, while weighting procedures generate an informative prior as a formal way to benefit from stakeholder insights in contextualizing available evidence. Weight of Evidence contributes to participatory research by lending transparency and analytical precision inherent to Bayesian statistics to the collaborative generation of knowledge. Weight of Evidence demonstrated the implications of stakeholder priorities, including from people living with the everyday effects of being made vulnerable, in consideration of, and not in isolation, of all available evidence.

Weight of Evidence invited participants to redefine how risks were conceptualized while also considering community strengths and how these can be better supported. (Guishard, 2009; Tuck, 2009) This procedure has broad applicability beyond perinatal care, including in patient engagement and patient-oriented research. Meaningful stakeholder engagement strengthens the relevance of research, improves its translation into policy and practice, and contributes to improved patient outcomes and reduced healthcare costs. (Carman et al., 2013; Gee & Corry, 2012) Weight of Evidence is a participatory and flexible procedure to engaging patients, providers and other health system actors in research, recognizing experiential knowledge as critical to improving patient outcomes. (Callan, 2014) This procedure may be particularly suited to engagement with communities that face multiple barriers to social participation as perspectives can be represented through maps and be easily shared with other stakeholders.

I applied **Weight of Evidence to contextualize published evidence on perinatal health outcomes and experiences in the perspectives of under-served populations and those delivering their care** as my third thesis objective. This prompted a re-examination of factors contributing to child protection risks and, consequently, interventions. By incorporating pregnant and parenting adolescents' perspectives on how judgement influences perinatal outcomes and experiences, this work highlighted the influence of stigma as a barrier to accessing and benefiting from health and social care throughout the perinatal period. The inputs of young women and service providers precipitated a reconceptualization of risk, identifying the investigation process itself as not without harm, and emphasizing upstream factors that contribute to child protection risks.

Client-centered risk reduction in relation to child protection involvement can improve the effectiveness and safety of perinatal health and social care for populations disproportionately identified as living with child protection concerns, yet whose perspectives are rarely included in the evidence to address these inequities. (Serrant-Green, 2011) Programs and services that centre the upstream factors that contribute to child protection risks, such as poverty and limited social supports, have a more profound effect on family interactions and the preservation of families. (Fallon, Ma, Black, & Wekerle, 2011) Grounded in the perspectives of pregnant and parenting adolescents, this research demonstrated the need for and described a process to support more collaborative approaches to perinatal risk reduction and offered several recommendations to mitigate child protection risks. This is especially important among populations who are pregnant and parenting outside of prevailing norms around motherhood, who often face increased stigma and surveillance in their parenting role. (Berrouard, 2017; Greaves et al., 2002; Krane & Davies, 2000)

I identified several areas for future research. Parallel to adaptations and extensions of the Weight of Evidence, sensitivity analysis will contribute to understanding their added value and applicability across different contexts. A promising extension of Weight of Evidence is to support greater stakeholder involvement in systematic reviews by stream-lining the steps introduced by Weight of Evidence with systematic review protocols. This could include stakeholder-led priority-setting to define the review's focus, contributing to the synthesis of evidence and contextualizing of evidence to develop an expanded and stakeholder-weighted systematic review. The application of Weight of Evidence to new and diverse settings will also contribute to refining training and support materials, contributing to the broader application of Weight of Evidence (see Appendices 5A and 5B, 6 and 7).

Through Weight of Evidence, stakeholders consistently identified factors and relationships not identified in the literature. This points to the importance of rigorous and transparent participatory research to better align research and the provision of services with community needs. This may be of particular benefit for families living with multiple forms of exclusion and who may be vulnerable to custody loss in the perinatal and postpartum period. Strategies that are evidence-based and community-led can contribute to reconceptualize risk and reduce vulnerability to child protection involvement in the perinatal period.

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Shifting what counts as expertise in perinatal health of under-served populations in Canada: using participatory methods and Bayesian updating to contextualize evidence synthesis in stakeholders' knowledge

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THESIS APPENDICES

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Appendix 1: Additional files for Chapter 2: The influence of social and economic exclusion on perinatal health outcomes and care experiences in Canada: An integrative review

Additional File 2.1: Sample search strategy (Medline)

Additional File 2.2: data extraction tables for quantitative findings

Additional File 2.1: Sample search strategy (Medline)

1. exp Canada/
2. Poverty Areas/ or Poverty/ or Low income.mp. or social assistance.mp. or welfare.mp
3. Vulnerable Populations/ or disadvantage*.mp.
4. ((Marginaliz*.mp. or Health Services Accessibility/ or Health Services Needs.mp.) and Demands/) or Attitude of Health Personnel/ or Ethnic Groups/ or Prejudice/ or Socioeconomic Factors/ or Social Marginalization.mp.
5. "Outcome Assessment (Health Care)" or "Quality of Health Care" or Health Status/ or Patient Satisfaction.mp.
6. "Emigrants and Immigrants"/
7. Refugees/
8. Adolescent/
9. indigenous.mp. or Health Services, Indigenous/ or Inuits/ or Indians, North American/ or First Nations.mp.
10. (Insurance, Disability/ or Disabled Persons/ or Disability Evaluation/ or "International Classification of Functioning, Disability and Health" or Intellectual Disability/ or mothers with disabilities.mp. or intellectual disability.mp. or developmental disability.mp. or intellectual.mp.) and developmental disabilities.mp
11. Homeless Persons/ or insecure housing.mp. or housing instability.mp. or street-involved.mp.
12. substance abuse.mp. or Substance-Related Disorders/ or drugs.mp. or harm reduction.mp. or drug-using pregnant women.mp. or addiction.mp. or drug addiction.mp. or neonatal abstinence syndrome.mp. or neonatal withdrawal.mp. or buprenorphine.mp. or methadone.mp. or substance-related disorders.mp. or injection drug.mp. OR (alcohol or fetal alcohol spectrum disorder or FASD or binge drinking or alcohol consumption or fetal alcohol syndrome or prenatal alcohol exposure).mp.
13. . Schizophrenia/ or Mental Disorders/ or addiction.mp. or serious mental health.mp.
14. Child Abuse/ or Child Welfare/ or Jurisprudence/ or Foster Home Care/ or youth in care.mp. or foster care.mp.
15. Prisons/ or Prisoners/ or incarceration.mp. or Incarcerated.mp. or prisoners.mp. or justice-involved.mp. or jail.mp.
16. Transgender Persons/ or Bisexuality/ or Homosexuality/ or LGBTQ.mp. or "Sexual and Gender Minorities"/
17. Obesity, Morbid/ or Obesity/ or obes*.mp.
18. Domestic Violence/ or Intimate Partner Violence/ or Gender-Based Violence/ or trauma.mp. or interpersonal violence.mp. or physical abuse.mp. or sexual abuse.mp. or emotional abuse.mp.
19. Maternal Health Services/ or Maternal-Child Centres/ or Maternal-Child Nursing/ or Maternal Deprivation/ or Maternal Mortality/ or Maternal Serum Screening Tests/ or Maternal Death/ or Maternal Nutritional Physiological Phenomena/ or Maternal Behavior/ or Maternal Exposure/ or Maternal Welfare/ or Reproductive Health/ or Reproductive Health Services/ or maternal.mp.
health behaviour, pregnancy and early parenting women (Benoit 2014)
patient satisfaction (Lefebvre 2010)
cultural safety (Nathoo 2013)
20. 1 and 2 and 19
21. 1 and 3 and 19
21. 1 and 4 and 19
23. 1 and 5 and 19
23. 1 and 6 and 19
25. 1 and 7 and 19
26. 1 and 8 and 19
27. 1 and 9 and 19
28. 1 and 10 and 19
29. 1 and 11 and 19
30. 1 and 12 and 19
31. 1 and 13 and 19

32. 1 and 14 and 19
33. 1 and 15 and 19
34. 1 and 16 and 19
35. 1 and 17 and 19
36. Rural Health/ or Rural Population/ or Hospitals, Rural/ or Rural Nursing/ or Rural Health Services/ or rural.mp.
37. 1 and 19 and 36
38. exp Pregnancy/ or pregnan*.mp. or early parenting women
39. 1 and 2 and 38
40. 1 and 3 and 38
41. 1 and 4 and 38
42. 1 and 5 and 38
43. 1 and 6 and 38
44. 1 and 7 and 38
45. 1 and 8 and 38
46. 1 and 9 and 38
47. 1 and 10 and 38
48. 1 and 11 and 38
49. 1 and 12 and 38
50. 1 and 13 and 38
51. 1 and 14 and 38
52. 1 and 35 and 38
53. 1 and 15 and 38
54. 1 and 16 and 38
55. 1 and 17 and 38
56. Infant, Newborn/ or Child Health Services/ or Infant Welfare/ or Infant Care/ or Infant Mortality/
57. 1 and 2 and 56
58. 1 and 3 and 56
59. 1 and 4 and 56
60. 1 and 5 and 56
61. 1 and 6 and 56
62. 1 and 7 and 56
63. 1 and 8 and 56
64. 1 and 9 and 56
65. 1 and 10 and 56
66. 1 and 11 and 56
67. 1 and 12 and 56
68. 1 and 13 and 56
69. 1 and 14 and 56
70. 1 and 35 and 56
71. 1 and 15 and 56
72. 1 and 16 and 56

Additional File 2.2: data extraction tables for quantitative findings

Data extraction table from studies on perinatal risks among adolescent pregnancies (best viewed at 500% magnification)

Risk Factors in Adolescent Pregnancy																				
Author	Study Type	Location	Year	Main Objectives	Inclusion Criteria	Comparison	N	Previous Mental Health diagnosis (depression, anxiety)	Income (less than \$5000)	Previous past physical abuse	past sexual abuse	past emotional neglect/abuse	History of Substance Abuse	Any smoking during pregnancy	Alcohol use during pregnancy	Not having appropriate education	Not having appropriate education	Living Arrangements @ delivery	Child involvement in Own Childhood	
Al-Shabab, 2015	Cross-sectional study	Canada	2005-2006	To examine the prevalence and characteristics of adolescent mothers throughout the provinces of Canada.	Mothers who were at least 15 years of age, who gave birth in Canada to singleton infants and who were living with their infants at the time of the interview (6421 women in total; 107 adolescents)	Average-aged mothers (mean age 38.3 yrs) compared to adolescent mothers (mean age 18.3 yrs)	6212 (of which n=288 are teen mothers)		OR=4.66 (2.96-7.46)	OR=2.34 (1.53-3.29)				OR=1.12 (0.72-1.72)	OR=0.54 (0.27-1.08)		OR=2.66 (1.69-4.18)			
Kim, 2015	Cross-sectional study (METS study)	Canada		To study the association of social support received during pregnancy and after childbirth on teen mothers (15-19 years) than to adult mothers (20+ years).	Adolescent women (younger than 20 years) who were living with their infants at the time of the interview (6421 women in total; 107 adolescents)		22033										teen mothers: 48.2% (n=881); adult mothers: 25.9% (n=603)	teen mothers: 48.2% (n=131); adult mothers: 21.1% (n=427)		
Leclair, 2014	Retrospective cohort study	Ontario	2006-2012	To determine the association between adolescent mothers and their infants who were born to adolescent mothers (younger than 20 years) with a history of mental health problems during pregnancy (37 weeks or greater) from the BORN registry.	Adolescent women (younger than 20 years) with a singleton live-born infant at term (37 weeks or greater) from the BORN registry								7.50%	38.80%						
								3.8% of births were to women diagnosed with major mental illness- 60228 person years (1.13%-1.4% of the total sample and none); ASPT (1999-2009) with major mental illness- 44.6/1000 (4.3-46.7); compared to 15.2 per 1000 w/out major MA (15.1-15.3) (rate ratio of 2.95 (2.84-3.07)	22% in lowest income (same between major MA and none); ASPT (1999-2009) with major mental illness- 44.6/1000 (4.3-46.7); w/out major MA (15.1-15.3) (rate ratio of 2.95 (2.84-3.07)											
Ngard, 2014	Repeated annual cross-sectional study	Ontario	1999-2009	To examine temporal trends in fertility rates among adolescent girls with major mental illness.	girls aged 15 to 19 years in Ontario, Canada (1999-2009) with major mental illness (psychotic, bipolar, or major depressive disorder) within 5 years preceding pregnancy	girls aged 15 to 19 years in Ontario, Canada (1999-2009) within 5 years preceding pregnancy with no mental illness														
Reinson, 2014	Cross-sectional study	Canada	2006	Compare the maternity experience, knowledge and behaviors of Canadian adolescent (15-19), young adult(20-24) and adult women (25-39s)	Mothers who were at least 15 years of age, who gave birth in Canada to singleton infants and who were living with their infants at the time of the interview (6421 women in total; 107 adolescents)	young adult(20-24) and adult women (25-39s)	77397													
References: Coleman, 2006; 26-834; Adolescents																				
Shih, 2015	Cohort	Toronto	2011-2014	Establish a dynamic patient database allowing demographic data and outcome measures to be evaluated.	High-risk adolescent mothers and infants receiving care through Young Families Program through Six Kids	N/A	90													
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Data extraction table from studies on perinatal risks among First Nations populations (best viewed at 500% magnification)

Risk Factors - First Nations																								
Author	Date	Study Type	Location	Year	Main Objectives	Inclusion Criteria	N	No prenatal care	Inadequate prenatal care	Received early QIS	Screening at or after term	Gestational Hypertension	Gestational Diabetes	Anemia	Infection	Living in poor neighborhood	Living in Community less than 10000	More than 200 km to nearest hospital	Maternal Age (under 20)	Single	Education (less than 11 years)	Income less than \$12k	Primiparous	
Reine, 2007		Cross-sectional study from a national database of 17 tertiary level regional NICUs across the country	Canada	January 1996-October 1997	Examine whether there are differences in selected NICU treatments between Aboriginal and white infants and whether these potential differences can be explained by maternal, infant or hospital characteristics.	Infants admitted for at least 24h or death, or who were transferred to another NICU within 24h.	Aboriginal (N=148); non-Aboriginal (N=320)	A: 7.2% (53); non-A: 1.6% (143)				A: 11.1% (80); non-A: 12.3% (1110)			A: 1.3% (60); (333); non-A: 20.1% (1631)	A: 52.3% (333); non-A: 44.0% (1691)	A: 59.5% (333); non-A: 44.0% (1691)							
Lu, 2010		China Study of 823 216 births	Quebec	1991-2000	To assess birth outcomes and infant mortality among First Nations, Inuit and non-Indigenous women by northern vs. southern residence	All births at gestational age ≥20 wks or greater and birth weight ≥500g or heavier	Non-Indigenous (N=206); non-Indigenous-Aboriginal (N=206); Southern (FN= 245); Inuit-Indigenous (N=206)																	
Lu, 2012		Retrospective cohort study	Ontario	2002-2010	To compare the prevalence of diabetes in pregnant, and evaluate differences in obstetric care between First Nations women and non-FN women	In All live singleton Ontario hospital pregnancies, and evaluate differences in obstetric care between April 2002-March 2010, between First Nations women and non-FN women with diabetes	FN women with diabetes: 253 (FN=197) 204(81%); non-FN women with diabetes: 28863	FN=13.8%; non-FN=5.6% (OR=2.71 (1.89-3.88)																
Riddell, 2015		Retrospective cohort study	British Columbia	1999-2001	To compare the quality and level of obstetric care between First Nations mothers and mothers in the general population of British Columbia. Our secondary objective was to examine differences in the use of obstetric interventions during labor and delivery, such as induction of labor or cesarean delivery, between these mothers;	First-time mothers who delivered singleton babies either at home w/ midwife or in hospital in BC between April 1999-March 2011, Nulliparous.	FN= 206841																	
Wernim, 2004		Prospective cohort study	Edmonton	July 1994-June 1995	To determine recent trends in birth outcomes, prenatal and postnatal mortality rates among First Nations, Inuit vs. non-Aboriginal populations in Quebec, using multiple sources of information to identify Aboriginal births.	All pregnant women seen for a first visit before 20 weeks' gestation at each of the 4 obstetric offices associated with UHl were eligible for the study.	FN= 25 (Males: FN=45; FN; N=74); non-Aboriginal																	
Chen, 2015		Retrospective cohort study	Quebec	1996-2010	To measure stillbirth and infant mortality rates of Aboriginal people in Quebec, in particular, First Nations people living on reserves, and compares them with rates for non-Aboriginal people in the province.	All singleton births to Quebec residents in 1996-2010. The	20190 First Nations; 4260 Inuit;	229660 non-Aboriginal singleton births																
Gilbert, 2015		Retrospective cohort study	Quebec	1989-2008																				
He, 2017		Retrospective cohort study	Quebec	1996-2010	disparities in infant morbidities experienced by indigenous populations in Canada.		20190 FN; 4260 Inuit; 229660 non-Indigenous																	

Appendix 2: Additional files for Chapter 4: Weight of Evidence: using participatory methods and Bayesian updating to contextualize evidence synthesis in stakeholders' knowledge

Additional File 4.1: Mathematical Description of Bayesian Updating

Additional File 4.2: Comparison of updating results between original data and duplicated data

Additional File 4.3: Original explanatory accounts

Additional File 4.4: Consolidated explanatory accounts

Additional File 4.5: Narrative of findings relevant to perinatal health

Additional File 4.1: Mathematical Description of Bayesian Updating

We used three different approaches to combining published literature with stakeholder perspectives around factors contributing to unmet postpartum care needs. The first approach was a simple averaging (reconciling) between two mean point estimates, where each weight value has equal influence:

$$AVG = \frac{\mu_{lit} + \mu_{st}}{2}, \quad (\text{Eq2})$$

where μ_{lit} is the normalized effect estimate from the literature and μ_{st} is the average weight assigned to a relationship by a stakeholder group.

The second approach was a weighted average (AVG_w) according to equation (3), such that:

$$AVG_w = \mu_{lit} \left(\frac{n_{lit}}{N} \right) + \mu_{st} \left(\frac{n_{st}}{N} \right), \text{ where } n_{lit} + n_{st} = N \quad (\text{Eq3})$$

where μ_{st} forms the “prior” to update the data μ_{lit} in this simplified updating model, where the prior will take on increasing weight with greater stakeholder input.

The third approach is the calculation of posterior distributions (or moments) following Bayes’ Rule, where weights from stakeholder and published evidence are represented as distributions. We described what is *known* by a stakeholder group by calculating an average weight and standard deviation to represent the variation in weights across a stakeholder group for each relationship, θ , identified in stakeholder maps. These were described as normal *prior distributions*, $f(\theta)$, where $f(\theta) \sim (\mu_s, \sigma_{st}^2)$.

Similarly, we described what evidence was available about that same relationship, θ , in peer-reviewed literature as the normalized odds ratio (eg. represented on a scale of 0-1) together with its standard deviation (also on a scale of 0-1). This was used to characterize the normal likelihood function, $f(x|\theta) \sim f(x|\mu_{lit}, \sigma_{lit}^2)$. (1) Bayesian analysis then combines what is known about a relationship, using the *prior*, $(f(\theta))$, with observed data about that relationship, using the likelihood function, $(f(x|\theta))$, by calculating a posterior distribution, $f(\theta|x)$, using Bayes’ Rule (2):

$$\begin{aligned} \text{posterior distribution} &= \frac{\text{likelihood of the data x prior distribution}}{\text{marginal likelihood of the data}} \\ \text{or } f(\theta|x) &= \frac{f(x|\theta) \times f(\theta)}{f(x)} \end{aligned} \quad (\text{Eq4})$$

References

1. Joseph L. Introduction to Biostatistics: Describing and Drawing Inferences from Data. In: Rosenberg L, Joseph L, Barkun A, editors. Surgical Arithmetic. 1st ed. Landes Bioscience; 2000. pp. 14–62.
2. Kruschke JK. Chapter 5: Bayes' Rule. In: Doing Bayesian Data Analysis. 2nd ed. Waltham, MA: Elsevier Inc; 2015. pp. 99–120.

Additional File 4.2: Comparison of updating results between original data and duplicated data

A. Influence of Having a Cesarean Section on Unmet Postpartum Care Needs Among Recent Immigrant Women							
Source of Estimate or Weight	Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)				
Literature	1.42	1.03	1.96				
Normalized value	0.17	0.01	0.32				
Updated by Family Physician Knowledge: Average weight assigned by Family Physicians: 0.46							
Original Data				Duplicated Data			
	Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)		Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)
Simple Averaging				Simple Averaging	0.31		
Weighted Average	0.39			Weighted Average	0.43		
Bayesian Updating	0.31	-0.24	0.85	Bayesian Updating	0.39	0.17	0.61
Updated by Birth Companion Knowledge: Average weight assigned by Birth Companions: 0.8							
	Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)		Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)
Simple Averaging				Simple Averaging	0.48		
Weighted Average	0.59			Weighted Average	0.74		
Bayesian Updating	0.44	-0.71	1.59	Bayesian Updating	0.65	0.41	0.89

Additional File 4.3: Original explanatory accounts

	Theme or Issue	Source of Explanatory Account	Explanatory Account	Whose Explanatory Account is it	Notes/Quotes from Source of Explanatory Account
1	Poverty	Munro 2012	If "patients were too impoverished to pay to... fill needed prescriptions" then they will not receive the recommended care and is seen as "was seen to act as an insurmountable barrier to care for most patients."	Academic- from MD perspective	This paper addresses unmet care needs from uninsured immigrant women. Limited EAs to those that would likely also apply to insured immigrant women.
2	Poverty	Additional care consideration for vulnerable patients	If "patients were too impoverished to pay to... fill needed prescriptions" or other necessary tests then physicians may "try and think about ways that I can save you money, but then I am not doing what I would normally do. I am altering my standard of care and the reason that I do all those tests is that hopefully because... not because it is expensive, but because I think that that is what I should be ordering based on good evidence. (MDS)"	Academic- from MD perspective	
3	Poverty	Gagnon Carnavale 2013	If women live in poverty, then the cost of attending pre and post-natal appointments with their children may be a barrier.	Academic- from women's perspective	"For the transportation, it is ok with one child, but when you have two or three, it's difficult"
4		Gagnon Carnavale 2013	If women perceive transportation barriers as insurmountable (because of costs, having accompanying children, weather, etc), then she may delay accessing or not access care at all.	Academic- from women's perspective	"In this country, it depends of the season when we give birth. If it's in winter, its imprisonment, we cannot go out..."
5	Low Social support	Gagnon Carnavale 2013	If women have supports from "family, peers, schools, community, social supports and supportive social policy" then they will be better able to protect themselves from unfavourable or negative environments (and be more resilient).	Academic- from women's perspective	
6	Social Structures/Policy	Gagnon Carnavale 2013	If women are frequently exposed to unfavourable/unsupportive environments, then they are more likely to make vulnerable and suffer negative consequences.	Academic- from women's perspective	If "relatively resilient mothers can be made vulnerable by unfavorable environments."
7	Conceptions of disease	Medicalization/in dualizing blame	If providers tend to "medicalize" issues that might fall more comfortably in the realm of 'social' or 'spiritual' issues for migrant women, then women may not feel supported and/or have confidence in or trust their providers, resulting in missed opportunities for care and poorer health outcomes.	Academic- from women's perspective	"referrals for 'depression' were frequently seen as offensive." "Would seek attention if sick but not if upset?" "it's a problem that will resolve itself, there is no need to see a doctor..."
8	Health Knowledge	Gagnon Carnavale 2013	If women receive conflicting information from different providers/sources, then they may be unsure of the safest/best options for their care, leading to selective adherence, aka of confidence in their providers or inaction in accessing care.	Academic- from women's perspective	"But in China, the doctors don't advice me eat the medicine. You know, they afraid of medicine maybe hurt my baby"
9	Trust in Provider/System	Gagnon Carnavale 2013	If women do not feel welcome" (due to time or communication style), then they may "prefer not to say anything"	Academic- from women's perspective	"I lied. I said everything is ok but in reality, I needed help"
10	Othered	Gagnon Carnavale 2013	If women perceive that they are being treated unfairly or discriminated against, then they do not feel welcome and may not access care or not trust in the provider and share limited information with them.	Academic- from women's perspective	"Because of language some Drs would not take them (as patients)" "Once, I went with one child to the Dr. I took the child with me because hard to find a babysitter. But at Dr's place, they asked: "why did you bring your child, it's clean here, your child did not take out his shoes". I did not like that."
11	Conceptions of disease	Medicalization/in dualizing blame	If providers tend to "medicalize" issues that might fall more comfortably in the realm of 'social' or 'spiritual' issues for migrant women, then providers mis-characterize their patient's needs and response to their recommendations	Academic- from women's perspective	"The idea of 'medicalizing' issues that might fall more comfortably in the realm of 'social' or 'spiritual' issues for migrant women suggests that health care providers re-consider the interpretation of the issue at hand from the perspective of the migrant mother."
12	Individualization of care	Gagnon Carnavale 2013	If hospitals have short postpartum hospital stays and women do not have strong community or social support systems in place, then women may feel isolated and without adequate support in the postpartum period.	Academic- from women's perspective	"Childbirth in some countries, such as Canada, means short postpartum hospital stays with a vision of greater care being given in the community. Benoit et al (2015) highlight the implications of shorter postpartum stay particularly for marginalized women."
13	Individualization of care	Gagnon Carnavale 2013	If the "responsibility for following through with any referrals made by contacting health or social service professionals may rest in the hands of the women being referred and their families" and women are not familiar with or know how to access community support services then women may not access the care they need.	Academic- from women's perspective	
14	Practical Aspects of Care- Information	Gagnon Carnavale 2013	If women and their families are having trouble navigating access to health and social services, such as not knowing "how to make appointments, outdated professional lists, complicated phone systems, and inflexible scheduling", then they may not follow up on a referral or access the care they need.	Academic- from women's perspective	
15	Isolation	Gagnon Carnavale 2013	If appointments are inflexible and/or re-scheduling is complicated (due to system or language differences) and do not fit with women's other responsibilities, then she may miss her opportunity to access care.	Academic- from women's perspective	"Another time, the appointment was taken by the CLSC [community health centre], husband couldn't go so I didn't go..."
16	Practical Aspects of Care- language	Assuming universal adaptation to the norm	If health and support services are not offered in multiple languages, then women may know about services available but may not be able to use them.	Academic- from women's perspective	"If there is something wrong, you do not know what you can do for her. There is a phone line opened 7 days and 24 hours but if you do not speak French" "But for a psychologist you have to know very well French! What can you do there?" "Every time the language is the problem. If you just arrived and gave birth, you can't do nothing. You stay home and you cry"
17	Conceptions of disease	Higginbottom-sudnese	If "signs and symptoms may be interpreted differently by physicians and patients" then women may not receive the care they believe they need (and they may lose trust in their provider)	Academic- from women's perspective	
18	Conceptions of disease	Medicalization-Categorization	If providers are not "familiar with their client's cultural background" then the "lack of obvious signals related to pain and distress may be misleading for some health care providers" and women's needs may not be recognized or seen as valid.	Academic- from women's perspective	"The lack of obvious signals related to pain and distress may be misleading for some health care providers who are not familiar with their client's cultural background."
19	Practical Aspects of Care- language	Assuming universal adaptation to the norm	If women do not have access "to culturally and linguistically appropriate information" about postpartum care, then they may not know when, how or where to access services.	Academic- from women's perspective	"Two other factors serving as barriers to seeking health care among immigrant women are weak social support and limited access to culturally and linguistically appropriate information"
20	Socio-cultural construction of disease	Higginbottom-sudnese	If women conceptualize specific practices in pregnancy, labour, delivery and postpartum as healthy, then they may resist provider suggestions to deviate from those.	Academic- from women's perspective	"These conceptualizations may allow them to resist practices which they interpret as abnormal or unnatural, such as analgesia and delivery instrumentation" "Our people, they stay for a while because they say if you rush to the hospital they're going to do for you c-section. We have that idea in our community. You have to wait until sometimes you deliver in the car or in the [ambulances]" "Participants tend to follow their beliefs, even when they contradict evidence-based medicine recommended by Canadian health practitioners." "It's my tradition. I believe in it, you know... I have to do what I believe."
21	Conceptions of disease	Medicalization/in dualizing	If "signs and symptoms may be interpreted differently by physicians and patients" then providers may view women as "non-compliant" and may believe that they have done all they can for their patients	Academic- from women's perspective	
22	Low Social support	Isolation	If women have appropriate levels of social support, then this decrease the impact of stressful life events, facilitate healthy childbirth transition and are linked to postpartum women's health status	Academic- from women's perspective	
23	Low Social support	Isolation	If "childbearing lack adequate support" then they "are at higher risk for mental health challenges and report poorer overall health [6,25,27]"	Academic- from women's perspective	
24	Low Social support	Isolation	If immigrant women have children "during the early years in Canada" and "experience low levels of social support (including access to financial support) and have smaller social networks than women born in Canada [6,7,25], then they may be "at higher risk for poor health outcomes than women born in Canada"	Academic- from women's perspective	
25		Lee- chinese experience	If women do not have access "to culturally and linguistically appropriate information" about care, then they may not express or ask their more personal or complicated concerns and/or questions.	Academic- from women's perspective	One of these participants shared that although her English was good enough to communicate with her obstetrician, she still felt a communication barrier existed between her and her obstetrician. She stated that she only asked simple questions and if the obstetrician were Chinese, she would have asked much deeper questions.
26		Assuming universal adaptation to the norm	If women feel that intra and/or post partum care was culturally insensitive, they may be less likely to return to their provider to seek care.	Academic- from women's perspective	"Several women complained about the cultural insensitivity of intrapartum and postpartum hospital maternity care."
27		Omahoney 2012	If "health care providers appeared uninterested, asking few questions, and the health care provider probed too intrusively into their vulnerable situations" then women often felt that "superficial help was received, feelings were minimized, participant was let down by the physician, insufficient time was provided to talk to the health care provider, and had the perception of being unsupported."	Academic- from women's perspective	
28	Trust	Omahoney 2012	If women do not feel welcome" (due to time or communication style), then they may "prefer not to say anything"	Academic- from women's perspective	
29	Trust	Omahoney 2012	If women do not feel listened to (due to time or communication style), then they may feel disrespected or unheard, and may be less comfortable trusting or confiding in provider.	Academic- from women's perspective	"I was in the middle of all these problems and she treated me like I was stupid... they were attacking me because they said, "You have to do your part. You have to call [for community resources] because I have so many clients and you're not my only client." I know I'm not stupid but they made me feel stupid."
30	Confidence	Knowledge	If women do not know how to navigate community support services, then they may be perceived as helpless and/or "non-compliant" by providers.	Academic- from women's perspective	"You have to do your part. You have to call [for community resources] because I have so many clients and you're not my only client."
31	Access	Poverty, Community Knowledge	If women have trouble accessing health services, then they may not pursue help for their postpartum depression	Academic- from women's perspective	
32	Access	Health Knowledge	If women do not have enough information about postpartum depression, then they may not pursue help.	Academic- from women's perspective	"Some women don't ask for help, mostly because they don't know there is help. Others are ashamed or not used to asking for help. I knew a person who was inside her home all day. She didn't know the language and she didn't go out at all until somebody told her, you cannot survive without getting help..." Participants reported that they were unfamiliar with, and in some cases unaware of, available services that could help them cope with PPD."
33	Trust in Provider/System	Omahoney 2012	If women have a poor relationship with the provider, then they may not have confidence in their diagnosis and/or referral and not pursue help for their postpartum depression.	Academic- from women's perspective	"A positive relationship with the health care provider determined whether immigrant and refugee women would seek and accept help"
34	Trust	Connectedness, Dignity	If hospital and/or clinic policies do not support women and family-centered care, then women may feel unsupported and unheard (resulting in poorer health outcomes)	Academic- from women's perspective	"Some of the nurses were really good, but they did not allow my husband to stay at night. I was very upset. If you are not ready to do service, I understand. But because you have so many patients at least let my people who love me, stay and help me. The reason they gave me was "we want one of the spouses to have good sleep." Okay, it is understandable. So let my mom stay... They said "no, the policies won't agree with that."
35	Support	Connectedness, Dignity	If women do not have support and/or time to be comfortable navigating perinatal care in Canada, then they may experience additional (unnecessary) stress through pregnancy, delivery and postpartum.	Academic- from women's perspective	The biggest problem that I faced was arriving late in my pregnancy and didn't have a specialist. So when it's time for delivery they said go to the ER... I was so stressed the words were gone and was unable to speak. Everything is new... you are alone and not with your family and don't know their system, so this is scary..."
36	Practical Aspects of Care- language	Assuming universal adaptation to the norm	If women do not have access "to culturally and linguistically appropriate information" about care, then they may not know when, how or where to access services.	Academic- from women's perspective	Some women don't ask for help, mostly because they don't know there is help. Others are ashamed or not used to asking for help. I knew a person who was inside her home all day. She didn't know the language and she didn't go out at all until somebody told her, you cannot survive without getting help..."
37	Isolation	Vulnerability	If women do not have family members, social relationships, and lack of connectedness within their social network, as well as loss of emotional and informational support, then they will be more vulnerable and may face more challenges in identifying needs and services as well as accessing care.	Academic- from women's perspective	"The absence of family members, lack of social relationships, and lack of connectedness within the social network, as well as loss of emotional and informational support were challenging" "Reference 7: 0.14% coverage Women in this study agreed that a supportive partner could make a significant difference in their ability to cope with PPD and related difficulties within the family setting"
38	Othering	Omahoney 2012	If women perceive that they are being treated unfairly or discriminated against, then they do not feel welcome and may not access care or not trust in the provider and share limited information with them.	Academic- from women's perspective	"It was difficult, mainly because for the fact of being immigrant and to find a doctor for the baby. When I tried to find a doctor, they asked me where I was from and when I said "from Mexico" I noticed a change from them... there might be some racism. I don't know. I wanted to run. I felt helpless"
39	Othering	Vanthuyne	If support staff, providers or people in general feel that they are "bearing more than one's share of the tax burden as a result of precarious status immigrants' free access to health services" then they may be less responsive to the needs of recent immigrant women.	Academic- from provider perspective	"Feelings of bearing more than one's share of the tax burden as a result of precarious status immigrants' free access to health services also abounded, especially among respondents who identified as support staff."

	Theme or Issue	Source of Explanatory Account	Explanatory Account	Whose Explanatory Account is it	Notes/Quotes from Source of Explanatory Account
40	Structure	MD1	If providers do not work in integrated care teams, then they "bear the burden" of ensuring their patient accesses adequate care, their patients may have less continuity of care and greater difficulty in ensuring patients receive and flag on referrals, and women may not receive the care they need.	Stakeholder map	
41	structure-collaboration	MD1	If providers do not have strong and open communication as well as clear and specific roles between different health and community service organizations, then responsibilities for continuity of care and patient follow-up may fall through cracks between different organizations/care teams.	Stakeholder map	
42	Training/Education	MD1	If providers do not consider that recent immigrant women may have had traumatic experiences associated with the migration experience and adjust their care accordingly, then they may not address patient's underlying needs and/or gain their patient's trust.	Stakeholder map	
43	Culture as a strength	Patient as driver MD1	If providers do not use women's cultural, spiritual and social practices around pregnancy and early motherhood as a complement to clinical care, then they may not be maximizing women's health or building on their patient's strengths and resources.	Stakeholder map	
44	Culture as a strength	MD1	If perinatal care, labour and delivery is overly medicalized, then women may feel that they were unable to respect their cultural and social practices and may be unlikely to return to access care, and/or have a trusting relationship with providers.	Stakeholder map	
45	Cultural and Social Norms	MD1	If family and social norms have a strong influence over women's care, then the provider may find themselves with cultural clashes with family members, affecting trust, open communication with patients.	Stakeholder map	
46	Connection, dignity	MD1	If institutional mandates focus primarily on efficiency (for example by limiting the time of clinic visits), then providers will not be able to "take the time to care as prevention" or "get into the pain" and they may not address patient's underlying needs and/or gain their patient's trust.	Stakeholder map	
47		MD1	If women have supports from "family, peers, schools, community, social supports and supportive social policy" then they will be better able to protect themselves from unfavourable or negative environments (and be more resilient).	Stakeholder map	
48	Othering	MD1, van Ryn, Johnson	If providers do not actively work against implicit bias, then they may inadvertently base their care on stereotypes or false beliefs about a patient's social, religious, ethnic, economic group or class.	Stakeholder map	van Ryn, others
49	Medicalization	MD1	If providers do not actively work to lessen the power imbalance between themselves and their patients by listening, "taking the time to care as prevention" or "get into the pain" with their patients, then they may not address patient's underlying needs and/or gain their patient's trust.	Stakeholder map	
50		MD1	If "patients were too impoverished to pay to access care, then they will not access care and/or receive the recommended care.	Stakeholder map	
51	Isolation	MD2	If recent immigrant women feel that they "don't have a village, don't have a community, don't have a friend, don't have a neighbour", then they may lack information and support to access services.	Stakeholder map	
52	Matching needs with services- navigation	MD2	If recent immigrant women have a poor understanding of services that are available, they may not access the appropriate services at the right time (eg. MD, nurse, Social Workers, midwife, and educator - first contact doesn't always have to be a physician).	Stakeholder map	
53	Compounded vulnerability	Assuming universal adaptation to the norm MD2	If recent immigrant women are living with high housing instability (frequent moves, no telephone) then they may be difficult to reach for follow-up and miss an opportunity to access care and support services.	Stakeholder map	
54		MD2	If providers are not working within a system with effective inter-professional collaboration infrastructure and if they are willing/interested in doing so, then they may not be able to follow-up on patients that have been lost to their care.	Stakeholder map	"It is an imperfect safety net- the system isn't working. Patients often get referrals but there is no counter-referral so people fall through the cracks."
55	Connection, supported	MD2	If providers are willing to "go the extra mile to overcome patient hesitancy to access services (particularly around access to mental health), then patients may feel more comfortable and/or face less barriers in accessing care.	Stakeholder map	
56	Individualization	MD2	If providers do not consider that recent immigrant women may have had traumatic experiences associated with the migration experience and adjust their care accordingly, then they may not address patient's underlying needs and/or gain their patient's trust.	Stakeholder map	
57	Culture as Resource	MD2	If providers do not use women's cultural, spiritual and social practices around pregnancy and early motherhood as a complement to clinical care, then they are not working with all of their patient's strengths and resources.	Stakeholder map	
58	Knowledge-Health and Navigation	MD2	If recent immigrant women do not receive adequate prenatal education that is tailored to their needs, then they may not be aware of their rights, opportunities to advocate for themselves and may be more likely to be disappointed by the difference between their expectations of care and their actual experiences/outcomes.	Stakeholder map	
59		MD2	If health and other policies do not allow for flexibility and local leadership in health and social care provision, then providers may feel that they have no voice in how care is delivered and feel frustrated with the constraints of their practice.	Stakeholder map	
60	Political priorities	MD2	If health and other policies do not focus on addressing social disadvantage, then it can become frustrating and demoralizing for providers who are limited in what they can do ("work with the diagnosis that you have").	Stakeholder map	
61	Matching needs with services- Knowledge-Health and Navigation	MD2	If there was better coordination between different services and "providers were practising within their license", then there would be a more appropriate use of resources, greater inter-professional collaboration and patient's needs would be more appropriately addressed.	Stakeholder map	
62	Navigation	Organization MD3	If women knew about and had greater access to primary care (such as family medicine teams, midwives), then care providers would be more likely to work within their license, and have access to the infrastructure that best meets those skills.	Stakeholder map	
63	Language	MD3	If the provider pool were more diverse, and if high quality interpreters were more accessible, then patients and providers would be able to better communicate around concerns, care plans and challenges.	Stakeholder map	
64	privatization	Individualization of care MD3	If parts of perinatal and reproductive care are not covered by public insurance (OUI, some vaccinations, counselling) and recent immigrant women are living in poverty, then they will not be able to access these services.	Stakeholder map	
65	bias, othering	MD3	If providers do not actively work against implicit bias, then they may inadvertently base their care on stereotypes or false beliefs about a patient's social, religious, ethnic, economic group or class.	Stakeholder map	
66	Fiscal Restraints	MD3	If there are increasing cuts to community care programs (postpartum nurse visits, homecare visits), then many women (including the most vulnerable) will not access care and support through social services.	Stakeholder map	
67	Medicalization	MD3	If providers tend to "medicalize" issues that might fall more comfortably in the realm of 'social' or 'spiritual' issues for migrant women, then providers may disregard their wishes and mis-characterize their patient's needs and response to their recommendations.	Stakeholder map	
68	Access to care, information	MD3	If recent immigrant women do not know where to access, face stigma around accessing or cannot afford contraception, then they may be more likely to have an unwanted pregnancy and may delay or avoid seeking care.	Stakeholder map	
69	Stress, coping	MD3	If families are under financial stress and facing multiple pressures without family or community support, then family members may be more likely to enact poor coping strategies.	Stakeholder map	
70	Low Social support	Information MD3	If recent immigrant women feel that they "don't have a village, don't have a community, don't have a friend, don't have a neighbour", then they may lack information and support to access services.	Stakeholder map	
71	Power differences	Patient-provider relationship MD3	If providers do not actively work to lessen the power imbalance between themselves and their patients by listening, "taking the time to care as prevention" or "get into the pain" with their patients, then they may not address patient's underlying needs.	Stakeholder map	
72	Communication Bias	MD3	If providers make assumptions about women's desire to be pregnant, then they may not discuss options around abortion with recent immigrant women.	Stakeholder map	
73	Fragmentation	MD3	If providers are not working within a system with effective inter-professional collaboration infrastructure and if they are willing/interested in doing so, then it may be difficult for them to navigate the system and they may feel more disconnected with patients and colleagues, contributing to feelings of frustration, lack of motivation and isolation as a provider.	Stakeholder map	
74	Fragmentation	MD3	If health services decisions are made without adequate input and leadership from community care organizations, then services may not address community needs and/or priorities.	Stakeholder map	
75	Fiscal Restraints	Patient-provider relationship MD3	If institutional mandates focus primarily on efficiency (for example by limiting the time of clinic visits), then providers will not be able to "take the time to care as prevention" or "get into the pain" and they may not address patient's underlying need.	Stakeholder map	
76	Fiscal Restraints	Fragmentation MD3	If adequate consideration of the requirements of community-based practice (forms of remuneration, expectations around home visits) are not incorporated into provider adequately remunerated then providers may end up feeling unsupported, frustrated and unmotivated.	Stakeholder map	
77	Organizational management	MD3	If provider remuneration is based in fee-for service, then providers are paid less when women have a natural delivery and then may contribute to a perverse incentive for unnecessary interventions in labour and delivery, potentially contributing to greater postpartum concerns.	Stakeholder map	
78	Perceived discrimination	MD3	If women and their families perceive that they are being treated unfairly or discriminated against in their everyday life, then they may face chronic levels of stress and anxiety, contributing to poor perinatal outcomes, a feeling of isolation, frustration and hopelessness.	Stakeholder map	
79	Socio-cultural construction of disease	BC	If women do not recognize how they are feeling as issues related to mental health and/or depression, then they may not see a need to seek help, or delay seeking help.	Stakeholder map	
80	Care responsibilities	Compounded vulnerability BC	If recent immigrant women face multiple other care responsibilities, or if they have family members that require high levels of care, then women may prioritize taking care of others before taking steps to care for her own needs.	Stakeholder map	
81	Low Social Support	BC	If recent immigrant women are struggling with symptoms of depression or anxiety as well as multiple other care responsibilities, then they may not prioritize their own care before that of others.	Stakeholder map	
82	Access to care, information	Support BC	If recent immigrant women do not have access to information about services and community supports, as well as community support, then they may feel alone and overwhelmed in pregnancy and early parenthood and be less motivated to seek out help.	Stakeholder map	
83	Perceived discrimination	BC	If women perceive that they are being treated unfairly or discriminated against, then they may feel isolated, less deserving of care and be less motivated to seek out help.	Stakeholder map	
84	Socio-cultural construction of disease	BC	If family and social norms have a strong influence over women's care, then the provider may find themselves with cultural clashes with family members, affecting trust, open communication with patient and patients may be more hesitant to bring up topics that may be socially or culturally stigmatized (eg. abortion, contraception, mental health).	Stakeholder map	
85	Self-determination	BC	If women feel that they do not have a sense of agency and dignity in their perinatal care (prenatal, L&D, postpartum) women may feel unexpected, unheard, and uncomfortable with their provider or that they had no title/control over their delivery experiences and be less willing to engage with and access care postpartum.	Stakeholder map	
86	Patient-provider relationship	Self-determination BC	If women are not familiar or comfortable with their provider, and if they don't feel they have dignity, agency or connectedness throughout their perinatal care, then they may be less willing to engage with and access care postpartum.	Stakeholder map	
87	Patient-provider relationship	BC	If providers do not actively work to lessen the power imbalance between themselves and their patients by listening, "taking the time to care as prevention" or "get into the pain" with their patients, then they may not address patient's underlying needs.	Stakeholder map	
88	Socio-cultural construction of disease	Patient-provider relationship BC	If providers tend to "medicalize" issues that might fall more comfortably in the realm of 'social' or 'spiritual' issues for migrant women, then providers may disregard their wishes and mis-characterize their patient's needs and response to their recommendations.	Stakeholder map	
89	Socio-cultural construction of disease	BC	If providers do not use women's cultural, spiritual and social practices around pregnancy and early motherhood as a complement to clinical care, then they are not working with all of their patient's strengths and resources.	Stakeholder map	
90	Perceived discrimination	Patient-provider relationship BC	If women do not feel welcome" (due to time or communication style), then they may "prefer not to say anything".	Stakeholder map	

Additional File 4.4: Consolidated explanatory accounts

	Theme	Explanatory Accounts	Consolidated Accounts	Sources
1			If recent immigrant women are living in poverty, then they may not be able to afford transportation and/or additional care recommendations (eg. prescriptions, contraception, counselling, etc), they may have insecure or unsafe housing, and may face multiple pressures without family support, eroding their coping capacity and they or their family members may rely on unhealthy coping strategies	Gagnon Carnavale 2013; Stakeholder (MD)
	Navigation	Poverty	1,2,3,4,50, 53, 69	Munro
			If recent immigrant women are living in poverty, then physicians may try to save their patients money by altering their standard of care.	
			If aspects of perinatal and reproductive care are not covered by public insurance (IUD, some vaccinations, counselling) and recent immigrant women are living in poverty, then they will not be able to access these services.	Stakeholder (MD)
2	Isolation	Social Support	5,6,22,23,24, 37, 47, 51, 62,70, 82	Gagnon Carnavale 2014; Lee/Ng; Omahoney 2012; Stakeholder (MD)
		weathering		
	Organization of care (efficiencies...)	Individualization of care	34, 46, 60,75, 12, 13,66	Gagnon Carnavale 2014; Omahoney 2012; Stakeholder (MD)
3				
	Organization of care-patient navigation	Accessability-language	14,15,16,30, 31, 35	Gagnon Carnavale 2014, Omahoney 2012
4				
	Conception	Medicalization/individualizing blame	7, 11, 17, 18, 20,21, 44, 45, 67, 88	Gagnon Carnavale 2014; Higginbottom-sudanese;Stakeholder (MD); Stakeholder (BC)
5				
			If family and social norms have a strong influence over women's care, then providers may find themselves in cultural clashes with family members, affecting trust and open communication, while patients may be more hesitant to bring up topics that may be socially or culturally stigmatized (eg. abortion, contraception, mental health).	
			If recent immigrant women do not know where to access, face stigma around accessing or cannot afford contraception, if then they may be more likely to have an unwanted pregnancy and may delay or avoid seeking care; if providers make assumptions about women's desire to be pregnant, then they may not discuss options around abortion with recent immigrant women.	Stakeholder(MD), Stakeholder (BC)
			68, 72, 84	
	Access to			
6	Information		19,25, 32, 36; 52, 79	Gagnon Carnavale 2014; Lee/Ng; Omahoney 2012; Stakeholder (MD); Stakeholder (BC)
			If the provider pool were more diverse, and if high quality interpreters were more accessible, then patients and providers would be able to better communicate around concerns, care plans and challenges.	Stakeholder (MD)
			63	
	Health	Agency	8, 33, 86, 90	Gagnon Carnavale 2014; Omahoney 2012; Stakeholder(BC)
7				
	Complex Care/whole person		42,56	Stakeholder (MD)
			If providers do not consider that recent immigrant women may have had traumatic experiences associated with their migration experiences and adjust their care accordingly, then they may not address patient's underlying needs and/or gain their patient's trust	
	Culture as			
9	strength		43, 57, 89	
		Trust in Provider/Syst em	9,10, 26, 38,78, 83, 85	Gagnon Carnavale 2014; Stakeholder (MD); Stakeholder(BC)
10	Othered			
			If providers, support staff and others do not actively work against implicit bias, then they may inadvertently make care decisions based on stereotypes or false beliefs about a patient's social, religious, ethnic, economic group or class and be less responsive to the needs of recent immigrant women.	Vanthuyne; Stakeholder (MD)
11	Othering		39, 48, 65, 71	
			If providers do not actively work to lessen the power imbalance between themselves and their patients by listening, addressing patient hesitancy around seeking care, "taking the time to care as prevention" or "get into the pain" with their patients, then they may not address patient's underlying needs and/or gain their patient's trust.	Omahoney 2012; Stakeholder (MD); Stakeholder(BC)
12	Taking time to care	Trust	27,28,29, 49, 55, 87	
	Knowledge-Health and			
13	Navigation		58	Stakeholder (MD)
			If providers do not have strong and open communication as part of integrated care teams, as well as specific roles between different health and community service organization, then it may be difficult for them to navigate the system and they may feel more disconnected with patients and colleagues, contributing to feelings of frustration, lack of motivation and isolation as a provider, pushing providers to "work outside of their licence" and patient follow-up may fall through cracks between different organizations/care team	Stakeholder (MD)
14	Stretching professions		40, 41, 54,61, 62, 73	
			59, 74, 76	Stakeholder (MD)
			If provider remuneration is based in fee-for service, then this may contribute to a perverse incentive for unnecessary interventions in labour and delivery, potentially contributing to greater postpartum concerns.	Stakeholder (MD)
			77	
15			80, 81	Stakeholder(BC)
			If recent immigrant women face multiple other care responsibilities (such as a high needs infant or family member), or if women are struggling with symptoms of depression or anxiety themselves, then they may prioritize taking care of others before taking steps to care for her own needs.	

Additional File 4.5: Narrative of findings relevant to perinatal health

Results from Step 3 (Developing Explanatory Accounts)

Physicians identified additional structural and organizational aspects of care that contributed to a mismatch between patient needs and available services, particularly when women may have more complex care needs due to past experiences of trauma. Examples included specific policies around patient volumes, the lack of effective multi-disciplinary care models and poor inter-professional collaboration in the care of recent immigrant women.

Birth companions suggested that women's sense of having less power or little room to voice their perspectives was shaped by healthcare provider workload, individual provider characteristics as well as social and cultural norms in provider and patient communities. This power differential sometimes contributed to women feeling disrespected or unheard during delivery and may affect willingness to access care postpartum. Stigma around mental health and the perceived value of mental health services played an important role in recognizing care needs and shaping access, particularly around concerns about postpartum depression. Birth companions also expressed that many clients lack information about community resources, or they are uncertain about which health and social services provide care with a culturally respectful and trauma-informed approach.

Results from Step 4 (Developing Explanatory Accounts)

Numbered explanatory accounts are referenced throughout the text, while sources for each explanatory account are provided in the Additional Files 3&4.

The effects of social isolation and chronic economic insecurity converged throughout women's perinatal care experiences. Poverty and a lack of community or strong social ties limited women's overall stability through a lack of access to secure housing and increased vulnerability directly influenced women's access to postpartum care, limiting access to transportation or critical postpartum services not covered by public insurance, such as contraception or mental health counselling. (EA1) (Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013; Gagnon et al., 2010; Munro, Jarvis, Kong, DSouza, & Graves, 2014) to stressful or negative environments, with negative implications for overall health. (EA1) (Gagnon et al., 2013; Geronimus, Hicken, Keene, & Bound, 2006) Poverty also

Women's decisions to seek medical care was shaped by perceived risk (*EA4, EA12*), comfort with providers (*EA6, EA8, EA9*), together with past clinical experiences (*EA8*), social norms around care and health (*EA5*) as well as by broader experiences of marginalization or discrimination throughout women's lives. (*EA3, EA8, EA12*) (Crenshaw, 1991; Dixon-Woods et al., 2006; Gore, 2016; Phelan, Lucas, Ridgeway, & Taylor, 2014; Sen, Reddy, & Iyer, 2018) Signs and symptoms may be down-graded due to expected time, financial and family care costs associated with seeking medical care (*EA1, EA3*). (Dixon-Woods et al., 2006) This may be exacerbated by social isolation commonly reported among recent immigrant women, often leaving women without a regular primary care provider or other community supports that may motivate them to seek out care (*EA3*).

Success in negotiating care depends on past and present patient-provider relationships, shaped by both personal and institutional factors. Articulating health needs across language barriers, cultural differences and given past experiences of poor treatment can be an important challenge (*EA4, EA5, EA10, EA11, EA12*). (Dixon-Woods et al., 2006; Gagnon et al., 2010; Higginbottom, 2013; O'Mahony & Donnelly, 2010) Provider judgments about women's candidacy for care also influence access, shaped by provider experience (*EA6, EA7, EA9*), and individual commitment to culturally respectful, trauma-informed care that supports women's own self-determination (*EA7, EA9*). (Dixon-Woods et al., 2006; Greaves et al., 2002; Price & Hawkins, 2007; van Ryn, 2015) However, when policies and resource allocations do not match community needs (*EA14*), providers may lack the support of strong inter-professional collaborations, pushing them to "work outside their license", with patient follow-up falling through cracks between different organizations or care teams. (*EA13*) (Benoit, Stengel, Phillips, Zadoroznyj, & Berry, 2012; Freedman & Kruk, 2014; Shaw et al., 2016; Spitzer, 2004) This can leave providers frustrated and feeling powerless while also leaving women feeling isolated and without adequate support in the postpartum period. Women may find themselves labeled as "non-compliant" when they cannot access care in a system that does not adequately consider their needs. (*EA4, EA7, EA8, EA12, EA15*) (Crenshaw, 1991; Higginbottom, Hadziabdic, Yohani, & Paton, 2014; O'Mahony & Donnelly, 2010)

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Appendix 3: Additional files for Chapter 5: Evidence-based priorities of under-served pregnant and parenting adolescents: Addressing inequities through a participatory approach to contextualizing evidence syntheses

Additional File 5.1: Youth-friendly consent forms

Additional File 5.2: Pregnancy risks and outcomes in adolescent and adult pregnancies in the Champlain Local Health Integration Network and across Ontario, 2012-2017

Mapping Our Understanding of Maternal Health



What is this project about?

It is about better understanding the reasons for challenges faced by young pregnant and/or parenting people to improve health and social services before and after pregnancy.

Why am I invited?

We are inviting you to participate in this project because we want to hear what is important to you as a young parent. We also want to ask what your ideas are for solutions to common issues faced by young pregnant and parenting people.

Who is running this project?

This project is run by Anna Dion, a PhD student at McGill University, and has been developed under the supervision of Dr. Neil Andersson, and in partnership with staff of XXXX. This research is supported by a scholarship from the Pierre Elliott Trudeau Foundation.

What do I have to do?

We are asking you to participate in 4 meetings. Each meeting will last about 2 hours and will take place between May and November 2018.

At the first meeting (on Wednesday May 30th from 1:00-3:00pm)

We will share some information about health issues that are common in people who are young and pregnant and/or parenting. In a group with other young women, we will ask you to tell us which ones are most important to you and why.

At the second meeting (in June and July):

In a meeting with the researcher (Anna Dion), we will ask you to tell us the reasons why you think a specific health problem is common in people who are young and pregnant. We will ask you a series of questions about your experience as a person who is young, pregnant and/or parenting and ask you to make a map of your ideas with magnets, markers and a magnetic white board (which we will give to you). We will also ask what reasons you think are most important. You will be able to choose whether you participate in this meeting with others or by yourself.

At the third and fourth meetings (in September and October):

In a group with 6-8 other women, we will share some possible reasons to explain why a specific health issue might be common in people who are young and pregnant or parenting. We will ask what you think about these explanations and how they relate to your own experience. We will also ask for your ideas about how to improve services before and after pregnancy for young people. We will also share some suggestions from others groups of people and ask what you think of these suggestions.

What will happen to the information?

This information will be shared with organizations involved in supporting young pregnant and parenting people in XXXX and across Canada. Some of the information will be written in reports, articles and presented at conferences. None of your personal or identifying information will be shared through any of these.

Will it be private?

Yes. You do not need to give your name or you can make one up to use while you are participating in this project. Once the project is finished, there will be no way to connect you with the information you share through this project.

While we ask that everyone participating in the group discussions respects the privacy of others, it is possible that they may not.

Do I have to participate?

No. You can choose not to participate. No one will be mad or upset with you if you don't. You will still be able to come to all of the same programs at XXXXX. You can also decide not to participate at any point in this project. If you decide to stop participating, you can also ask that your map of ideas not be included in this study.

Will I get anything if I participate?

Yes. You will receive a gift card for Walmart for \$25.00 after each of the 2-hour meetings, for a total of 4 gift cards over the course of the study. If you decide not to participate in all of the meetings, you will receive gift cards for the meetings you attend.

Childcare will also be provided by the regular childcare staff at XXXXX during all meetings. We will also give a Presto Card with pre-paid trips on it to cover your costs of getting to and from the meeting by bus. There will also be light snacks and drinks available during all meetings.

Are there any risks to participating?

It is possible that you may feel uncomfortable discussing during some of the meetings if it causes you to remember unpleasant or painful experiences. You are free to not participate in any discussion. You are also free to leave at any time. We will have a place in our meeting rooms for you to have some personal space and XXXXX staff will be available during all of our activities if you would like to speak with anyone about your feelings.

Who can I ask if I have questions about the Mapping Our Understanding project?

You are welcome to ask questions before, during, or after your participation in this research. Please contact: XXXX

Mapping Our Understanding of Maternal Health

Meeting 1: Identifying Focus Areas: May 30th 2018

1:00-3:30pm



I understand that:	Please check:
A researcher, Anna Dion, with up to two peer facilitators, will come to XXX and run a group discussion with me and other young people. We will spend roughly 2.5 hours together.	
They will share some information about health issues that are common in people who are young and pregnant and/or parenting and we will talk about what issues are most important to us.	
I don't have to answer questions that I don't like or don't want to answer. I also don't have to participate in group discussions if I don't want to.	
I can choose to stop participating in the meeting or the whole project at any time without giving any reasons.	
If anything we talk about makes me feel upset, I can take a break from the discussion or leave the meeting. I will be given the names of people who I can talk to about what is making me upset.	
What I say during project meetings and interviews is special and belongs to me. The researcher or peer facilitators won't tell anyone else that I participated in this project. They will ask everyone in the group to agree not to talk about what is said during project meetings unless all of us say that it is okay.	
What I say during this meeting might be used in a report or presentation, but the researcher will make sure that nobody will be able to tell who I am or what I said.	
The only time the researcher would have to tell someone about anything I said is if they were worried: • that I or my child(ren) might be badly hurt by someone • that I might hurt myself • that I might hurt someone else. The researcher will talk to me about this and I will have a say in deciding what happens next.	
I will be given a copy of this form to take home with me.	
I have been able to ask questions about this project and meeting. I am satisfied with the answers to my questions. I understand that it is okay for me to ask questions at any time if I don't understand anything.	

Participant Signature

Date

Researcher's Signature:

I have explained this study and answered questions to the best of my ability. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Researcher Signature

Date

Mapping Our Understanding of Maternal Health

Meeting 2: Mapping Evidence:

Date July 25, 2018

1:00-3:00

Program Room C



I understand that:	Please check:
A researcher, Anna Dion, will come to XXX and interview me about topic my experience of feeling judged throughout maternity care	
They will ask me why this topic is important to people who are young and pregnant or parenting. They will ask me a series of questions about my experience and will ask me to make a map of my ideas with magnets, markers and a magnetic white board. They will also ask me to identify the reasons I think are most important. I will be able to choose whether you participate in this meeting with others or by myself.	
I don't have to answer questions that I don't like or don't want to answer. I also don't have to participate in the interview if I don't want to.	
I can choose to stop participating in the meeting or the whole project at any time without giving any reasons.	
If anything we talk about makes me feel upset, I can take a break from the discussion or leave the interview. I will be given the names of people who I can talk to about what is making me upset.	
What I say during project meetings and interviews is special and belongs to me. The researcher or peer facilitators won't tell anyone else that I participated in this project.	
What I say during this interview, and the map that I create, might be used in a report or presentation, but the researcher will make sure that nobody will be able to tell who I am or what I said.	
The only time the researcher would have to tell someone about anything I said is if they were worried: • that I or my child(ren) might be hurt by someone • that I might hurt myself • that I might hurt someone else. The researcher will talk to me about this and I will have a say in deciding what happens next.	
I will be given a copy of this form to take home with me.	
I have been able to ask questions about this project and interview. I am satisfied with the answers to my questions. I understand that it is okay for me to ask questions at any time if I don't understand anything.	

Participant Signature

Date

Researcher's Signature:

I have explained this study and answered questions to the best of my ability. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Researcher Signature

Date

Additional File 5.2: Pregnancy risks and outcomes in adolescent and adult pregnancies in the Champlain Local Health Integration Network and across Ontario, 2012-2017

	2012-2017			
	Champlain LHIN		Ontario	
	RR	95% CI	RR	95% CI
Self-report drug and substance use in pregnancy	6.34	5.63-7.15	5.63	5.41-5.84
Self-report alcohol exposure in pregnancy	1.38	1.18-1.59	2.33	2.22-2.44
Reporting mental health anxiety*	1.76	1.62-1.9	1.77	1.72-1.81
Reporting mental health depression*	2.05	1.88-2.24	2.16	2.11-2.22
Reporting other mental health conditions* (bipolar disorder, schizophrenia, and others)	3.05	2.65-3.52	2.88	2.75-3.00
Disclose abuse during pregnancy	3.18	2.75-3.68	2.76	2.64-2.90
Did not attend prenatal care in 1 st trimester**	1.11	1.10-1.12	1.10	1.094-1.098
Sexually transmitted infection during pregnancy*** (chlamydia, gonorrhea, syphilis, HSV, HIV, HPV)	1.98	1.59-2.46	2.77	2.62-2.92
Preterm Delivery (<37wks)	1.11	0.99-1.24	1.07	1.03-1.10
Labour and birth complications (Atypical or abnormal fetal surveillance)	0.99	0.93-1.06	1.00	0.982-1.024
Obstetrical Complications (IUGR/SGA, preterm delivery, UTI)	1.51	1.35-1.68	1.44	1.39-1.49

*Concerns during this pregnancy including those pre-existing, diagnosed during pregnancy or active during pregnancy. Both diagnosed or self reported;

**Before 13 weeks gestation

***Infection identified during pregnancy

Appendix 4: Additional files for Chapter 6: How adolescent mothers interpret and prioritize evidence about perinatal child protection involvement: participatory contextualization of published evidence

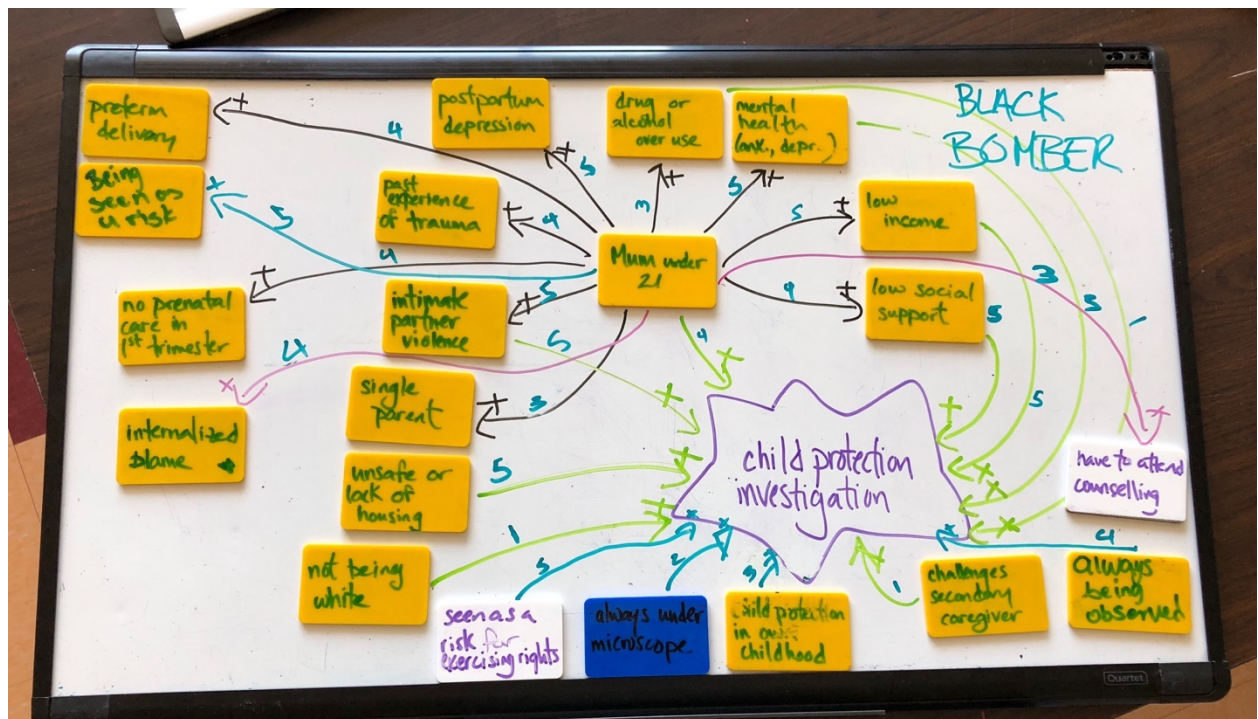
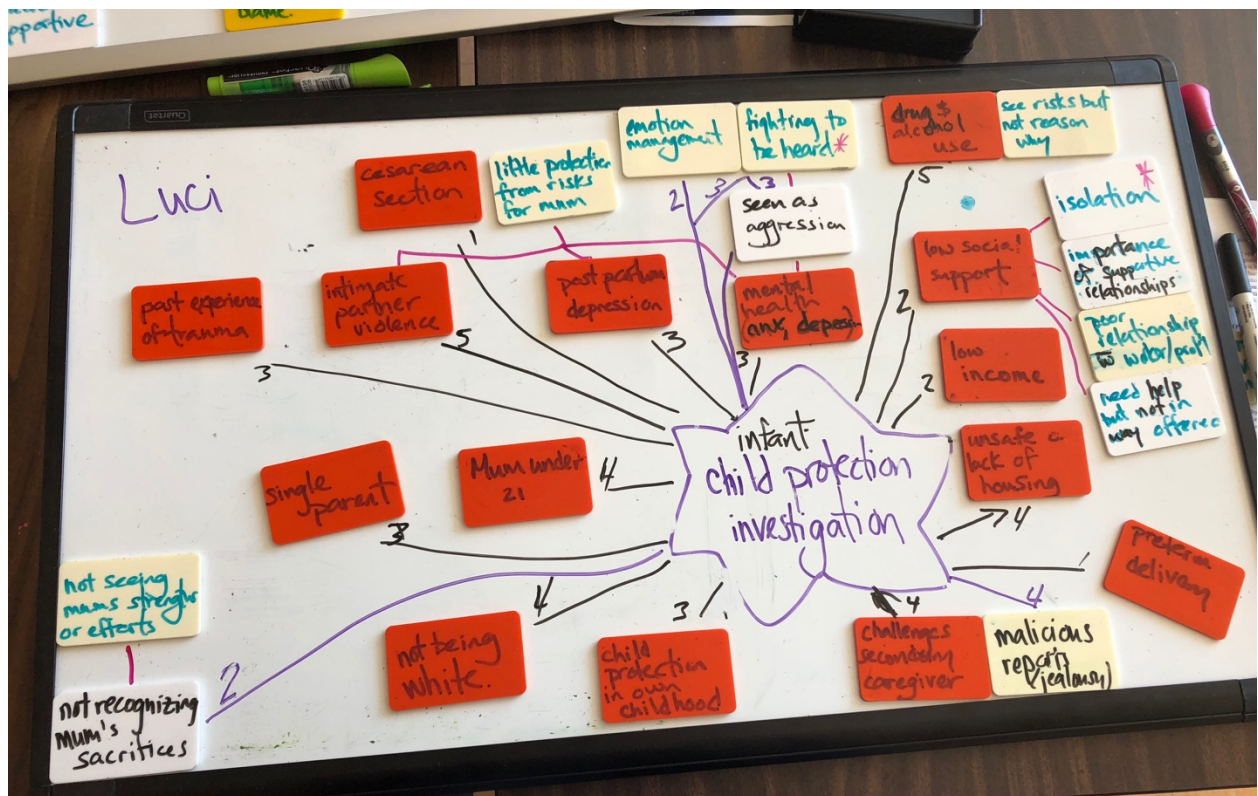
Additional File 6.1: Examples of fuzzy cognitive maps of the literature adapted by adolescent mother describing factors that contribute to infant protection risks among adolescents

Additional File 6.2: Description of Bayesian updating

Additional File 6.3: original explanatory accounts (best viewed at 500% magnification)

Additional File 6.4: Consolidated explanatory accounts

Additional File 6.1: Examples of fuzzy cognitive maps of the literature adapted by adolescent mother describing factors that contribute to infant protection risks among adolescents



Additional File 6.2: Description of Bayesian updating

A Bayesian model begins with a likelihood function over a set of parameters, a conventional measure of plausibility assigned to each parameter. In Weight of Evidence, these are the individual effect estimates and their measures of uncertainty (e.g., confidence interval) identified from the literature. In conventional Bayesian analysis, expert opinion, or other sources of data (e.g., observational studies) contribute to estimating a measure of certainty for each parameter. In Weight of Evidence, these are the stakeholder-assigned weights from the mapping process. Stakeholder-assigned weights for each factor combine to create a central measure and a distribution, representing the variability in stakeholder weights for that factor. These are represented as a normal distribution as it has an easily interpretable measure of central tendency and uncertainty (or variance). This forms the prior distribution, which when multiplied by the likelihood function, updates the parameters identified from the literature. The strength of Bayesian analysis lies in its ability to learn from the data in question by combining it with other forms of relevant knowledge, while explicitly accounting for the uncertainty in all types of knowledge. (Kruschke, 2015) The resulting posterior distribution represents updating on a conceptual, rather than probabilistic basis and contributes to generating explanatory accounts in the next step.

Posterior distributions (or moments) are calculated following Bayes' Rule, where weights from stakeholder and published evidence are represented as distributions. We described what is *known* by a stakeholder group by calculating an average weight and standard deviation to represent the variation in weights across a stakeholder group for each relationship, θ , identified in stakeholder maps. These were described as normal *prior distributions*, $f(\theta)$, where $f(\theta) \sim (\mu_s, \sigma_{st}^2)$.

Similarly, we described what evidence was available about that same relationship, θ , in peer-reviewed literature as the normalized odds ratio (eg. represented on a scale of 0-1) together with its standard deviation (also on a scale of 0-1). This was used to characterize the normal likelihood function, $f(x|\theta) \sim f(x|\mu_{lit}, \sigma_{lit}^2)$. (1) Bayesian analysis then combines what is known about a relationship, using the *prior*, $(f(\theta))$, with observed data about that relationship,

using the likelihood function, $(f(x|\theta))$, by calculating a posterior distribution, $f(\theta|x)$, using Bayes' Rule (2):

$$\text{posterior distribution} = \frac{\text{likelihood of the data} \times \text{prior distribution}}{\text{marginal likelihood of the data}}$$

$$\text{or } f(\theta|x) = \frac{f(x|\theta) \times f(\theta)}{f(x)}$$

References

1. Joseph L. Introduction to Biostatistics: Describing and Drawing Inferences from Data. In: Rosenberg L, Joseph L, Barkun A, editors. Surgical Arithmetic. 1st ed. Landes Bioscience; 2000. pp. 14–62.
2. Kruschke JK. Chapter 5: Bayes' Rule. In: Doing Bayesian Data Analysis. 2nd ed. Waltham, MA: Elsevier Inc; 2015. pp. 99–120.

Additional File 6.3: original explanatory accounts (best viewed at 500% magnification)

[illegible]

Account Number	Source of Explanatory Account	Explanatory Account	Whose Explanatory Account Is It	Notes/Quotes
150	Unicorn Peach	If women chose to continue to use drugs, then they may use in a way that minimizes risks to their children, and this may also continue to be perceived as an unacceptable level of child protection risk	Stakeholder (woman)	Even when my son was in my custody, I would never do drugs when I was with him- I would smoke weed when he wasn't with me, but I still felt that this was seen as unacceptable.
151	Unicorn Peach	If women are only seen for their risks and deficits, then many of their strengths, efforts and accomplishments may go unnoticed, uncelebrated and unused.	Stakeholder (woman)	We don't need to be hovered over, we aren't terrible or scary people or that we have no idea what we are doing. Some of us are in bad situations, or make some poor choices along the way (which for me has left me with a house right now), but it doesn't mean we don't know anything or how to do anything.
152	Unicorn Peach	If women feel that they are being judged without help (due to age, expression of emotion, seen as incapable, or as deficient for mental health concerns), then they may feel that they are seen only as a deficit or risk	Stakeholder (woman)	from map
153	Unicorn Peach	If women feel that their past (including their childhood) is used against them, then they may feel that they are unfairly judged, misunderstood and seen only for their risks.	Stakeholder (woman)	from judgment map
154	Unicorn	If there is community and social norms that stigmatize young mothers, then women may lose their social support network and may feel more isolated.	Stakeholder (woman)	I lost a lot of friends- 6or 5 stuck around... it is when you find out who are your true friends.
155	Unicorn	If women believe that showing emotions may be used against them in child protection investigations, then they will do everything they can to hold back any emotions including not speaking up when they have been poorly treated.	Stakeholder (woman)	from map
156	Unicorn	If women feel isolated and without support, then they may feel that they can only rely on themselves, using this as motivation to take action.	Stakeholder (woman)	In a way, thus pushed me to find my own help. Feeling like I only have myself to rely on
157	Orange Dancer	If women have a physical or cognitive disability, then they may feel that they are judged as less capable by professionals and other.	Stakeholder (woman)	I have a mild form of autism, so that brought additional judgment. Telling me that I shouldn't be having kids because the two of you will grow up and neither of you will know what to do with it
158	Orange Dancer	If professionals are not properly educated on how disability may (or may not) affect pregnancy, labour and parenting, then they may hold incorrect assumptions about the capacity of women with disabilities to be successful parents.	Stakeholder (woman)	
159	Orange Dancer	If women face restrictions on their daily activities as part of a child protection investigations, then they may feel that their freedom is limited.	Stakeholder (woman)	
160	Orange Dancer	If women feel that their skill and competence as a mother is questioned, then they may feel that they are being asked to demonstrate their competence through specific acceptable mothering tasks (changing baby, responding appropriately to needs).	Stakeholder (woman)	
161	Orange Dancer	If women are perceived to have acted inappropriately in the past (eg. no prenatal care, drug use), then they may be assumed to be incapable or a risk to their child.	Stakeholder (woman)	
162	Orange Dancer	If women are not able to find stable and secure housing, then they are perceived as putting their child at risk.	Stakeholder (woman)	
163	Orange Dancer	If women feel that they are being judged without help (due to age, expression of emotion, seen as incapable, or as deficient for mental health concerns), then they may feel that they are seen only as a deficit or risk	Stakeholder (woman)	
164	Orange Dancer	If women are seen as having possible risk factors around child protection, then they may feel that they are being constantly watched, blamed and needing to seek others' approval in parenting.	Stakeholder (woman)	
165	Orange Dancer	If women and child protection workers do not have a supportive relationship, then women may feel that they will be more likely to be investigated.	Stakeholder (woman)	
166	Orange Dancer	If women are living in chronic poverty, then they may not be able to provide food and shelter for themselves and their families.	Stakeholder (woman)	
167	Luci	If women are considered young to be pregnant and/or mothering, then they may feel that they are being unfairly judged or seen as incompetent by hospital staff.	Stakeholder (woman)	I had my son @ 17 and feel that age played a role in how I was treated at the hospital.
168	Luci	If nurses and other health professionals take the time to listen and support young women, then women feel supported and safe.	Stakeholder (woman)	
169	Luci	If women feel that they have to repeatedly fight to be heard and to be believed, then they may lose faith in professionals' ability to provide care and address their needs.	Stakeholder (woman)	I feel I often have to fight to make myself heard over my pediatrician; have to not back down
170	Luci	If women feel that their community or family supports are a risk to themselves or their children, then they may purposefully isolate themselves and take calculated risks to protect their children (eg. multiple moves to find new home).	Stakeholder (woman)	When my son was 8 months, I moved out of my mum's house because she was violent and abusive towards me, at times when I had my son in my arms. I had no choice, I had to get out of there.
171	Luci	If women want to access community supports, then they may have to provide multiple community endorsements to demonstrate their need and "worthiness" of support.	Stakeholder (woman)	Had to get multiple letters of support to get housing, including asking letters from police officers; isolation is seen as a bad thing, even though sometimes it is the best thing...when your support network isn't good for you.
172	Luci	If women do not feel comfortable or safe in community-based support initiatives, then they may find themselves isolated from supportive programs.	Stakeholder (woman)	I got a second call for a house in a baby-mama project in Blenheim Hospital (Jane's notes... maybe Emily Murphy housing). There was a community of baby-mamas there, which was good for some people, but I didn't want to be part of that community.
173	Luci	If professionals do not take the time to listen or consider women's previous experience, then they may recommend actions that women recognize as unhelpful, contradicting to mistreat between women and professionals.	Stakeholder (woman)	Then she began to be really opinionated about me needing to get back together with my son's dad. Eventually, I told her that I didn't want to go back to being beaten every day and she backed off.
174	Luci	If women feel that they are not believed by child protection workers, then they may feel that workers refused to listen or do not see their perspective a trustworthy.	Stakeholder (woman)	...feeling of judgment around having CAS called on her (for physical abuse), and feeling as though the CAS worker refused to listen. Examined her kid.
175	Luci	If women want to defend themselves against child protection claims, then they may have to provide multiple community endorsements to demonstrate their need and "worthiness" of support.	Stakeholder (woman)	Had to organize referral and letters from 7 people to dispute claims of abuse.
176	Luci	If women feel that their community or family supports are a risk to themselves or their children, then they may take calculated risks to protect their children (eg. multiple moves to find new home) and may face what they feel are retaliatory effects.	Stakeholder (woman)	Felt her mother reported her to CAS maliciously.
177	Luci	If women believe that showing emotions may be used against them in child protection investigations, then any emotional responses to may be interpreted as aggression, and may be identified as an additional protection risk.	Stakeholder (woman)	Emotion management takes up a lot of time and energy... that in itself isn't seen as cause for investigation, but sometimes it is seen as aggression- in which they will see as a need for investigation.
178	Luci	If women believe that showing emotions may be used against them in child protection investigations, then they will do the work to stay calm throughout interactions with child protection workers.	Stakeholder (woman)	
179	Luci	If risk assessment does not consider the needs and experiences of the mother/family, then many of the efforts and strengths of the mother are invisible and disregarded.	Stakeholder (woman)	Not seeing mum's sacrifices- also linked to emotion management
180	Luci	Some risks seen as legitimate (IPV, drug and alcohol).	Stakeholder (woman)	
181	Luci	If women recognize that they may need help and additional support, then they type of support and extent of the investigation should not depend so much on the type of worker that you get.	Stakeholder (woman)	Sometimes help is needed, but the type of experience and extent of investigation shouldn't depend on the luck of the worker.
182	Luci	If women have a complaint against a child protection worker and there is no external accountability to receive that complaint, then women may feel that workers have no accountability.	Stakeholder (woman)	No accountability of CAS workers- even if you complain, it is the CAS investigating themselves- that doesn't seem right.
183	Luci	If women feel judged by people that are important to them, then they may feel the consequences of this judgment more deeply.	Stakeholder (woman)	"It is judgment from the people that have meant something to me that stand out"
184	Isary Rider	If women have a partner that is seen as a risk (for whatever reason), then this perceived risk may also be placed on the women for their relationship with that partner.		
185	Isary Rider	If women believe that showing emotions may be used against them in child protection investigations, then they will try to keep their anger and other feelings hidden.		
186	Isary Rider	If women feel that they are seen as a potential risk for child protection, then they may feel that they need to over-perform good motherhood and that they must always be "on".	Stakeholder (woman)	Pressure to go beyond being a good mother and always be the best.
187	Isary Rider	If women feel that they are seen as a potential risk for child protection, then they may feel that they are never trusted or trustworthy.	Stakeholder (woman)	Linked to being invisibly/neglected- being stressed and not getting a break. Never feeling like I am trusted/trustedworth
188	Isary Rider	If women make themselves vulnerable and share their needs, then they may feel that there are subsequently "thrown back in their face" and seen as a protection risk.	Stakeholder (woman)	Offering for help and then having it thrown back in your face.
189	Isary Rider	If women chose to continue to use drug/any substances (tobacco), then they may use in a way that minimizes risks to their children, and this may also continue to be perceived as an unacceptable level of child protection risk.	Stakeholder (woman)	Also get lots of stares when I am smoking. I always take precautions and have his cover closed, blow smoke away from him and not even with him if I can. Not being irresponsible about it.
190	Black Bomber	If women are required to follow programs and/or rules that they do not feel are of benefit to them, then they may push back against them and may be seen as "uncooperative" or combative and their lack of interest may be seen as a protection risk.	Stakeholder (woman)	Pushed back against the rules because she didn't feel they were helpful or what she needed
191	Black Bomber	If there is no flexibility to account for individual women's needs, then women may be required to follow programs and/or rules that they do not feel are of benefit to them.	Stakeholder (woman)	
192	Black Bomber	If there is community and social norms that stigmatize young mothers, then women may lose their social support network and may feel more isolated.	Stakeholder (woman)	
193	Black Bomber	If women have relationship with people they trust and that believe in them, then they may be more likely to feel that they can get through difficult moments.	Stakeholder (woman)	What made a big difference for me was having someone speak to me (for me it was my mum and grandmother), telling me that I am a good person, that I can do this. They made me believe in myself.
194	Black Bomber	If women believe that showing emotions may be used against them in child protection investigations, then any emotional responses to may be interpreted as aggression, and may be identified as an additional protection risk.		
195	Silver Pony	If women chose to continue to use drug/any substances (tobacco), then they may use in a way that minimizes risks to their children, and this may also continue to be perceived as an unacceptable level of child protection risk.	Stakeholder (woman)	If women chose to continue to use drug/any substances (tobacco), then they may use in a way that minimizes risks to their children, and this may also continue to be perceived as an unacceptable level of child protection risk.
196	Silver Pony	If women are perceived to have acted inappropriately in the past (eg. no prenatal care, drug use), then they feel that they are not believed when they tell professionals that they have changed and may be assumed to be incapable or a risk to their child.	Stakeholder (woman)	
197	Silver Pony	If women are perceived to have acted inappropriately in the past (eg. no prenatal care, drug use), then healthcare professionals may assume that they still present the same risk.	Stakeholder (woman)	CAS came and didn't believe me either ("I know that you are still using"); getting information from her MD, who she hadn't seen in 4 months, and she had been clean for 5 months.
198	Silver Pony	If professionals suggest that women will not be able to parent, are incapable, or should look at other options, then women may doubt their abilities or feel unsupported in their decisions and that they may not get the help they need.	Stakeholder (woman)	Mostly just told me I was too young, wouldn't be able to handle this; people kept telling her that adoption was always an option (this was repeatedly told to her)
199	Silver Pony	If health care providers do not take the time to understand women's wishes and support her in the choices she makes, then women may feel that they are being discouraged or judged by providers and professionals.	Stakeholder (woman)	Mostly just told me I was too young, wouldn't be able to handle this; people kept telling her that adoption was always an option (this was repeatedly told to her)
200	Silver Pony	If health care providers and other professionals voice their negative opinions about a woman's choices, then they may be seen as unsupportive and act to shut down open communication with their clients.	Stakeholder (woman)	Mostly just told me I was too young, wouldn't be able to handle this; people kept telling her that adoption was always an option (this was repeatedly told to her)
201	Silver Pony	If women have a partner that is seen as a risk (for whatever reason), then this perceived risk may also be placed on the women for their relationship with that partner.	Stakeholder (woman)	It took me a while to see that my ex was physically abusive... wouldn't hit me but would hold me up against the wall so I couldn't move and yell in my face.
202	Silver Pony	If CAS is not open with all family members about risk investigations, then family members may be pitted against one another.	Stakeholder (woman)	
203	Silver Pony	If CAS does not share information about risk investigations, then women may not understand why certain decisions are made and feel like they are being treated unfairly.	Stakeholder (woman)	Would ask CAS why they were allowing daughter to stay with her ex when it was clear she was not being well taken care of (said that there is a process they have to go through whenever I seemed that there wasn't a process when they took her daughter away the first time).
204	Silver Pony	If women do not know their rights and where to access additional support, then they may feel helpless against the decisions and power of CAS.	Stakeholder (woman)	
205	Silver Pony	If women are seen as a risk during pregnancy, labour and delivery (for age, previous CPS, drug use) then they may be constantly observed, checked-up on, making them feel perpetually watched and unable to relax.	Stakeholder (woman)	"I sneeze and it is judged I go to the bathroom and wonder if it is okay"
206	Silver Pony	If all of the focus is on protecting the baby from risk, then women may feel that their needs are secondary or invisible.	Stakeholder (woman)	I felt like I was a walking bed, like I was only carrying the important one. "For my own needs- felt that I needed more s
207	Silver Pony	If women are seen as a risk during pregnancy, labour and delivery (for age, previous CPS, drug use) then they may feel that they cannot openly express their needs (esp around mental health) out of fear of identifying a reason that she would be unable to care for her child and she will not get the care she needs.	Stakeholder (woman)	"also had to balance not saying too much (couldn't say what I really felt- eg. admitting feeling suicidal would be seen as a risk to my child, would be reason to justify her removal/removal of rights)"
208	Silver Pony	If referrals for women's needs (focused here around mental health) took a long time to be met compared to care for her infant, then women may interpret this as having her needs being secondary to her child.	Stakeholder (woman)	Even postpartum, felt that it took excessively long to get referral to perinatal mental health
209	Silver Pony	If infants are removed from their parents/mother's care without sufficient explanation of the risks and next steps, then women feel frustrated, confused, powerless.	Stakeholder (woman)	
210	Silver Pony	If women are not given clear and full information about the child investigation process, including open and honest communication about legally binding documentation, then they may feel that they were tricked by child protection workers and lose trust in them being fair chances.	Stakeholder (woman)	AS worker tried to get her to sign over custody to her mother, saying that she was signing to have visitation rights. Encouraged her not to read full document.
211	Silver Pony	If women do not know their rights and what is and isn't considered an risk, then they may perceive that they are being judged for insignificant things.	Stakeholder (woman)	
212	Silver Pony	If women are perceived to have acted inappropriately in the past (eg. no prenatal care, drug use), then they may feel that they continue to experience stigma from past behavior.	Stakeholder (woman)	Often feels judged for inconsequential things (these days) like small details about the liners of milk bottles.
213	Silver Pony			I am 6 months sober- but I can't seem to shake them off

Additional File 6.4: Consolidated explanatory accounts

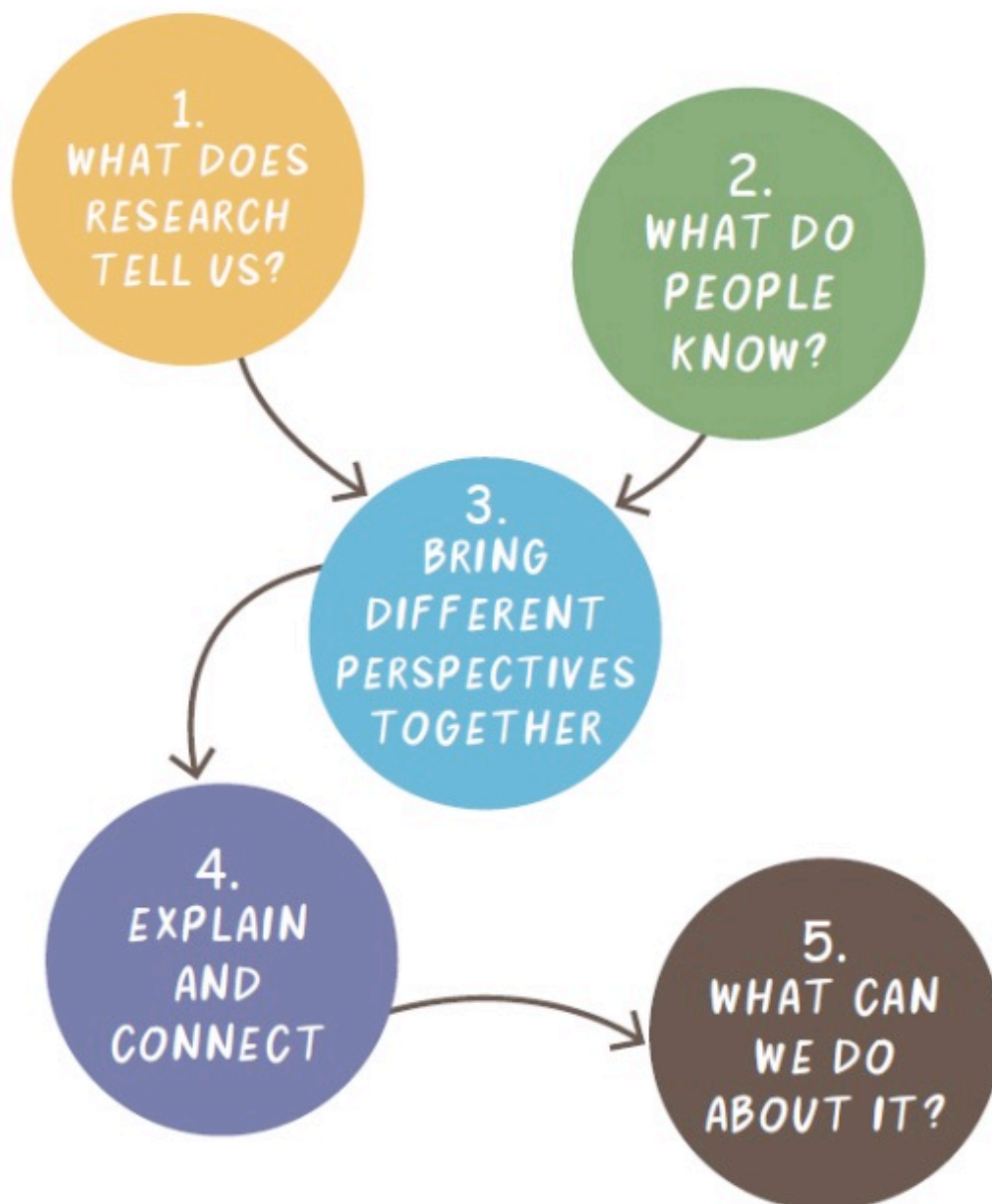
Framework Theme	Reference Explanatory Accounts	Consolidated Explanatory Account	Source
A: DIFFICULT CIRCUMSTANCES AND TOUGH CHOICES	128, 142, 184, 201	If women have a partner or secondary caregiver that is seen as a risk (for whatever reason), then women may also be perceived as contributing to a child protection issue by association .	Stakeholder(w)
	157, 158	If women have a physical or cognitive disability and professionals are not properly educated on how disability may (or may not) affect pregnancy, labour and parenting, then professionals may hold incorrect assumptions and women may feel that they are judged as less capable by professionals and other.	Stakeholder(w)
	150, 189, 195	If women chose to continue to use substances (tobacco, marijuana, street drugs), then they may use in a way that minimizes risks to their children, though this may also continue to be perceived as an unacceptable level of child protection risk .	Stakeholder(w), Kenny 2015
	143, 144	If women are involved with CAS as child, then professionals may assume there is a child protection risk , while women themselves may be highly motivated to be better parents.	Stakeholder(w), Brown 2006
	161	If women are not able to find stable and secure housing, then they are perceived as putting their child at risk, regardless of the challenges across the larger system.	Stakeholder(w), Gill 2017
B: DISCONNECTION FROM SOCIAL SUPPORT	135, 154, 156, 192	If women feel they have lost their social support network because of social stigma, then they may feel they have no one to rely on, be unsure of where to seek help and feel isolated.	Stakeholder(w), Kenny 2015
	17	If women only receive support when they have an open file with child protection services, then they may be concerned about losing critical support when their protection file is closed.	Brown 2006
	94, 113, 118, 171, 172	If women and families do not have access to community support and services (without excessive administrative barriers) prior to a child protection investigation, then risks that could have been prevented may result in a child protection investigation.	Brown 2006; McKegney 2002; Gill 2017 stakeholder(w)
	136	If women receive trauma-informed support in early parenthood, then they may be able to identify and understand how past trauma may affect their parenting and prevent any negative consequences.	Stakeholder(w); Gill 2017
	11, 12, 13, 131, 167, 177	If women do not fit with dominant norms around motherhood, then women may be seen to be incompetent, dangerous or perceived to have unusual behaviour and may be over or under-identified and stigmatized for child protection risks.	Berrouard 2017; Sykes, 2011; Krane 2000; Stakeholder (w)
D: SUPPORTIVE RELATIONSHIPS	132, 165, 168	Women invest heavily in developing good relationships with their workers and are particularly appreciative of professionals that take the time to listen, advocate for and share skills with them.	Stakeholder(w); Hughes, 2016; Dumbrell 2010
	193	If women have relationships with people they trust and that believe in them, then they may be more likely to feel supported and that they can get through difficult moments.	Stakeholder(w); Gill 2017
E: BARRIERS FACED BY PROFESSIONALS	1, 2, 16, 20, 28, 32, 33, 50, 64, 65, 76, 82, 87, 88, 89, 90, 91, 127, 173	If child protection workers do not have enough time to understand their clients underlying challenges, lived experiences or have different understandings of the source of risk from parents, then workers may misinterpret the source of risk and families may not be offered services that address their true needs and be less motivated to participate in mandated risk reduction work (or feel that it is meaningless).	Brown 2006; Dumbrell 2010; Hughes 2016; Berrouard 2017; McKegney 2002; Stakeholders (w)
	23, 34, 36, 49, 93, 111, 112, 127, 47, 77, 139, 143	If professionals tend to individualize issues that might fall more comfortably in the realm of 'social' or structural issues, then, then they may mis-characterize family's needs and responses as a risk rather than coping, and parents may be blamed for factors outside of their control, may be more likely to internalize their guilt and shame and feel less able to influence the outcome of the investigation.	McKegney 2003; Berrouard 2017; Brown 2006; Terplan 2015 Stakeholder(w)
	46, 129, 153, 194, 199, 107, 109, 110, 133	If professionals do not take the time to listen to and empathize with mums and account for past and present lived experience of women experiencing a child protection investigation, then they may misinterpret normal expressions of frustration and anger as aggression or presenting a protection risk and women may feel unsupported or that they cannot express their needs.	Berrouard 2017; Stakeholder (w)
	26, 100	If child protection workers do not recognize their own values and implicit bias, and their role as the brokers of power imbalance between the CPS system and families involved, then they may not recognize how this influences their perceptions of risk and interactions with parents.	McKegney 2002
	14, 15	If inter-agency collaboration does not provide a space for constructive criticism or for employees to feel that their concerns will be adequately addressed by their superiors, then child protection workers may be hesitant to identify areas of improvement in the work of other professionals	Berrouard 2017
	6, 7, 21, 22, 27, 117, 206	If meeting parents' needs are considered as separate to "best interests of the child", then child protection workers may have to choose between protection from risks and support families (they may not be able to provide parent meaningful and relevant supports.)	McKegney 2002, Stakeholder(w)
	18, 19, 24, 25, 29, 30, 31, 69, 73, 152, 190, 191	If risk assessments and accountability are based on preset programs and/or rules that may not address women's of families needs, then professionals may have little flexibility for client-centered support and women may push back against them and be seen as "uncooperative" or combative and their lack of interest.	Brown 2006; Sykes 2011 Stakeholder(w)
	47, 202, 203, 208, 210, 211	If women are not given clear and full information about the child investigation process, including reasons for the investigation and open and honest communication about legally binding documents, then they may feel that they were tricked by child protection workers and lose trust in the process.	McKegney 2002; Sykes 2011 Stakeholders(w)
	18, 19, 24, 25, 29, 30, 31, 69, 151, 179	If risk assessment does not account for the time, thought and effort required of mothers/parents to engage and keep open and accurate lines of communication and comply with child protection requirements, then women may be only seen for their risks and deficits, and their many strengths , efforts and accomplishments may go unnoticed, uncelebrated and unused.	Brown 2006; Krane 2000 Stakeholder(w)
	35, 37, 46, 59, 95, 97, 105, 107, 182, 204	If parents do not feel they understand the legal issues surrounding child protection and their rights, receive contradictory information, are told to "give in" or believe they do not have the power to influence the outcome of the investigation, then they may feel powerless and without recourse against decisions made by CAS	McKegney 2002; Dumbrell 2010; Dumbrell 2006; Stakeholder(w)
G: NOT KNOWING RIGHTS	98, 99, 103, 115, 141	If parents feel like they do not have emotional, financial or structural support in navigating a child protection investigation, then they may experience a sense of powerlessness and be less likely to be able to advocate for themselves and the needs of their families	Dumbrell 2010; McKegney 2002; Stakeholder(w)
	53, 58, 70, 72, 101	Once mothers know their rights and figure out the skills needed to effectively navigate a child protection investigation, then they may use a range of strategies to use child protection policy to advocate for their families and feel that they are able better equipped to "play the game"	Brown 2006; McKegney 2002; Sykes 2011
	39, 43, 45, 68, 96, 102, 104, 122, 125, 134, 169, 174	If women feel that decisions have been made without, or spite of, their input, or that they continually need to fight to be heard or believed then women may feel betrayed by professionals, feel that they do not have a voice and that their needs are misunderstood, or that they have unrealistic expectations placed upon them, and they may feel powerless and lose trust in the intention of the CPS/professionals to support their needs and may be less likely to seek out support.	McKegney 2002; Brown 2006; Dumbrell 2006; Krane 2000; Stakeholder (w)
	39, 40, 44, 51, 52, 54, 55, 56, 57, 129, 155, 178, 185	If expressing strong emotions during child protection investigations is seen as a sign of instability, then women will do everything they can to control their emotions for fear of appearing aggressive or angry. If not offered any support, then they may learn to bury their emotions (often with long term consequences.)	Brown 2006; McKegney 2002; Sykes 2011; Stakeholder(w)
	41, 138, 188, 207	If women are seen as a risk during pregnancy, labour and delivery (for age, previous CPS, drug use) then they may feel that they cannot openly express their needs (esp around mental health) for fear of having it thrown back in their face.	McKegney 2002; Stakeholder (w)
I: BLAME	181	If women recognize that they may need help and additional support and feel that they are not getting the support they need, then they rarely feel that they can safely voice their concerns and/or have a choice in professional support .	Stakeholder(w); Dumbrell 2010; Brown 2006
	175	If women feel that a child protection investigation is unfounded, then they may feel that their perspectives are not valued and that the burden of proof lies disproportionately with them (that they need to prove their innocence)	Stakeholder(w); McKegney, 2002; Sykes 2011
	116, 170	If women feel that their community or family supports are a risk to themselves or their children, then they may purposefully isolate themselves and take calculated risks to protect their children (eg. multiple moves to find new home)	McKegney 2003; Stakeholder(w)
	114	If women are not able to participate in support and skills development programs without their children, then women whose children are not in their care are further disadvantaged in the actions they can take to comply with risk reductions plans.	McKegney 2002
J: JUDGED AND LABELLED	3, 38, 42, 67, 75, 92, 166	If women feel that they are unable to achieve the requirements placed on them by child protection investigations or access support for their own needs (for economic or other reasons) despite going to great lengths, then they may be labelled as "non-compliant" or "unreliable" and may feel powerless , and perceive CAS decision-makers as unsupportive.	Brown 2006; McKegney 2002; Dumbrell 2006, Berrouard 2017; Stakeholder(W)
	85, 106, 123, 124, 130, 137, 140, 145, 146, 147, 148, 160, 161, 163, 164, 186, 187, 197, 205, 212	If women are flagged for child protection risks, then they may feel that their role as a parent is permanently discounted and untrustworthy , that they are always observed and only seen for their present problems , be perceived as incapable and be discouraged from performing basic care tasks for their infant	Berrouard 2017, McKegney 2002, Stakeholder (w)
	198, 200	If professionals voice their negative opinions about a woman's choices or suggest that women will not be able to parent, are incapable, or should look at other options, then this may shut down open communication with their clients and women may doubt their abilities, feel unsupported and may not get the help they need.	Stakeholder(w)

Appendix 5A: Guideline for the Weight of Evidence approach

This is an implementation guide for mid-level researchers and health policy analysts to understand how and why to adapt the Weight of Evidence approach. I am the primary author of this guide, which builds on the intellectual contributions of Dr. Emilie Robert, Iván Sarmiento, Dr. Lawrence Joseph and Dr. Neil Andersson.

A GUIDELINE for

The Weight of Evidence



CIET-PARTICIPATORY RESEARCH @MCGILL GROUP

A guide for the Weight of Evidence 2019

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The Weight of Evidence

The Weight of Evidence is a research method that pushes conventional boundaries of who (or what) constitutes health service expertise through the formal inclusion of experiential knowledge from patients and/or communities, care providers and resource decision-makers, together on even footing with epidemiological studies.^{1,2}

The Weight of Evidence unfolds in five steps:

1. WHAT DOES RESEARCH TELL US?

A conventional mixed methods synthesis of the research literature summarizes what is known about an outcome of interest, representing it as a concept map;

2. WHAT DO PEOPLE KNOW ABOUT IT?

Independently, stakeholders generate cognitive maps that identify and weight factors they believe influence the outcome;

3. BRING DIFFERENT PERSPECTIVES TOGETHER

Bayesian updating of literature incorporates stakeholder perspectives;

4. EXPLAIN AND CONNECT

Collaborate with stakeholders to suggest possible explanations of how social, economic and organizational contexts contribute to outcomes prioritized in cognitive maps; and

5. DEFINING ACTION AND WAYS FORWARD

Stakeholders develop recommendations accordingly.

This guideline document introduces the main tools and concepts guiding the Weight of Evidence method, pointing to additional resources where they might be helpful. This document also outlines questions and choices we have come across in our own use of Weight of Evidence in hopes that it might serve others in deciding how and why the Weight of Evidence might be useful in their own work.

A detailed description of the method, including a description of a pilot application of the Weight of Evidence, can be found in Dion et al. (2019).³

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Why do we need Weight of Evidence?

People-centered health services require that stakeholder voices, especially those less heard, are part of decision-making.⁴ Decision-makers at all levels need robust and locally-relevant tools that take account of both biomedical and cultural understandings of health to support wider participation in planning, implementation and evaluation.⁵

Systematic reviews and meta-analysis have long been considered the highest value synthesis of evidence in medical and public health sciences.⁶ Evidence synthesis without meaningful stakeholder engagement, however, can overlook contextual factors that stakeholders consider relevant.⁷ Patients, their families and caregivers, as well as frontline health and social service providers may also have actionable insights into the influence of social and organizational contexts in health interventions, rarely accessible in conventional evidence syntheses.⁷ Despite widespread recognition that patient and stakeholder participation can improve the relevance of primary care research, improve clinical practice, and reduce healthcare costs, stakeholder involvement in evidence synthesis remains poorly operationalized.^{7,8,9,10,11}

With increasing interest in stakeholder involvement comes a growing recognition that knowledge is not the product of scientific expertise alone, but a complex product of co-creation.^{7,12} Recent advances in mixed methods reviews demonstrate the value of combining qualitative and quantitative findings, often derived from differing perspectives, in evidence syntheses.^{7,12,13,14} This can be complex when translating and synthesizing evidence from differing perspectives and epistemologies, requiring a diversity of concepts, theories and methods that may be at odds with one another.¹⁵ Knowledge management approaches such as critical interpretive synthesis, realist reviews and narrative reviews, offer rich interpretations sometimes across different paradigms.^{16,17,18,19} Few knowledge synthesis approaches, however, explicitly address questions about what counts as “good evidence”, who decides this and how?¹⁵

Wrestling with questions of what counts as valid knowledge requires that we examine evidence in context and that we engage multiple perspectives on complex social problems.¹⁵ Two epistemological or philosophical approaches are key to how the Weight of Evidence method addresses this issue. Each of them is outlined below.

Realist Philosophy

Realist approaches recognize there is a real world with which we interact, though may never truly know, and that particular perspectives ground our understanding and theories about the world. Under realism, both quantitative and qualitative evidence contribute to understanding how processes and mechanisms contribute to an observed outcome.²⁰ Realism leverages an understanding of how context influences outcomes and the processes that contribute to outcomes as an important tool for building causal explanations.^{7,20}

Stakeholders can provide contextual understanding to enrich realist evidence syntheses. Greater stakeholder involvement may lead to more comprehensive and valid syntheses and overall understanding.^{7,21} Yet few realist synthesis approaches integrate patient or community groups throughout the analytical process, and engagement processes are usually poorly defined and are therefore hard to reproduce.^{7,22}

Diverse Ways of Knowing

The first concept we draw on is a respect for and recognition of other ways of knowing from those produced solely by academic institutions or specific research paradigms. This is of particular importance in matters of health inequities, as those affected by an issue bring relevant expertise on their needs, access to care and ability to maintain their health and well-being. However, this expertise is often excluded from decision-making processes. **Error!**

Bookmark not defined.

Recognizing that someone with different lived experience may understand and solve a problem differently can be useful information. This is not to suggest that one type of knowledge has a hierarchy over others, but rather that each perspective sheds light on a different aspect of the same issue.²³ A critical benefit of the Weight of Evidence approach is that it offers a way to bring these different forms of knowledge together in support of a more complete understanding of an issue. By taking a calculus of how and where perspectives overlap (or don't), Weight of Evidence proved an excellent way to engage meaningfully with divergent perspectives, helping to redefine how a problem is understood and its potential solutions.

Standpoint Theory

Another important concept employed in Weight of Evidence is informed by standpoint theory, as described separately by Hill Collins and Harding.^{23,24} We draw of standpoint theory's three general claims:

- 1) That knowledge is socially situated, and therefore shaped by class, race, culture, gender, and ability, among other norms;
- 2) That marginalized and disadvantaged groups have critical perspectives to offer on “the way things are” because they navigate mainstream systems and social norms while also having experiences and perspectives that more privileged groups do not experience and therefore, cannot represent; and
- 3) Research that takes power dynamics into account, needs to centre the lived experience and voices of marginalized or other groups excluded from conventional decision-making settings.

Weight of Evidence requires that we specify when and how we value different forms of knowledge throughout our analysis. This requires a rigorous and transparent approach to the co-production of knowledge by making these often implicit decisions explicit. This opens up analysis and decision-making processes to greater scrutiny and discussion, facilitating collaborative conceptualization of priority issues and causal understanding.²⁵

A Participatory Approach to the Co-Production of Knowledge

We developed Weight of Evidence as a response to calls for more people-centered health systems. The Weight of Evidence is a robust and transparent approach to the co-production of knowledge that makes space for genuine patient or stakeholder authorship. Citizens, particularly those carrying the greatest burden of health inequities, need to have a stronger voice in the planning and implementation of their health care and the systems meant to support it.

The Weight of Evidence holds great potential as a tool for participatory research. However, it is not a specific tool that makes a project or research initiative participatory, but rather an approach to partnerships concerned with research governance, ownership of research products, and the interests behind research objectives and methods.²⁶

Making Research Participatory

For a research project to be participatory, it is not enough to take community or marginalized perspectives into account. For a project to be participatory, researchers must also examine power in the context of the entire research process.²⁶ Linda Tuhiwai Smith offers several questions to guide our thinking about governance of knowledge and the research process ²⁷:

Who owns information/research?

Whose interests does it serve?

Who will benefit from it?

Who will carry it out?

Who will write it up?

How will it be shared, by whom?

Who designed its questions and framed the scope?

Throughout this guideline document, we offer some questions and additional resources that research teams may find useful in determining the extent and type of participatory research most relevant to their setting. We have highlighted key opportunities to engage stakeholders in the co-production of knowledge and the direction, design or sense-making activities throughout Weight of Evidence. It will be up to each individual research team to decide whether these, or other variations, fit within their work. While there are many resources to help researchers think about participatory approaches, we have listed below some that we have found useful:

Winkler, M. and N. Wallerstein, (Ed), 2008. Community-Based Participatory Research for Health, 2nd edition, Jossey-Bass, San Francisco, CA

Tuhiwai Smith, L. 2012. Decolonizing Methodologies: Research and Indigenous Peoples. 2nd edition. ZED Books

Tuck, E., 2009. "Re-visioning Action: Participatory Action Research and Indigenous Theories of Change" Urban Review, 41:47-65

Access Alliance Multicultural Health and Community Services (2011). Community-Based Research Toolkit: Resource for Doing Research with Community for Social Change. Toronto: Access Alliance Multicultural Health and Community Services

HIV CBR Ethics Fact Sheet Series www.HIVethicsCBR.com

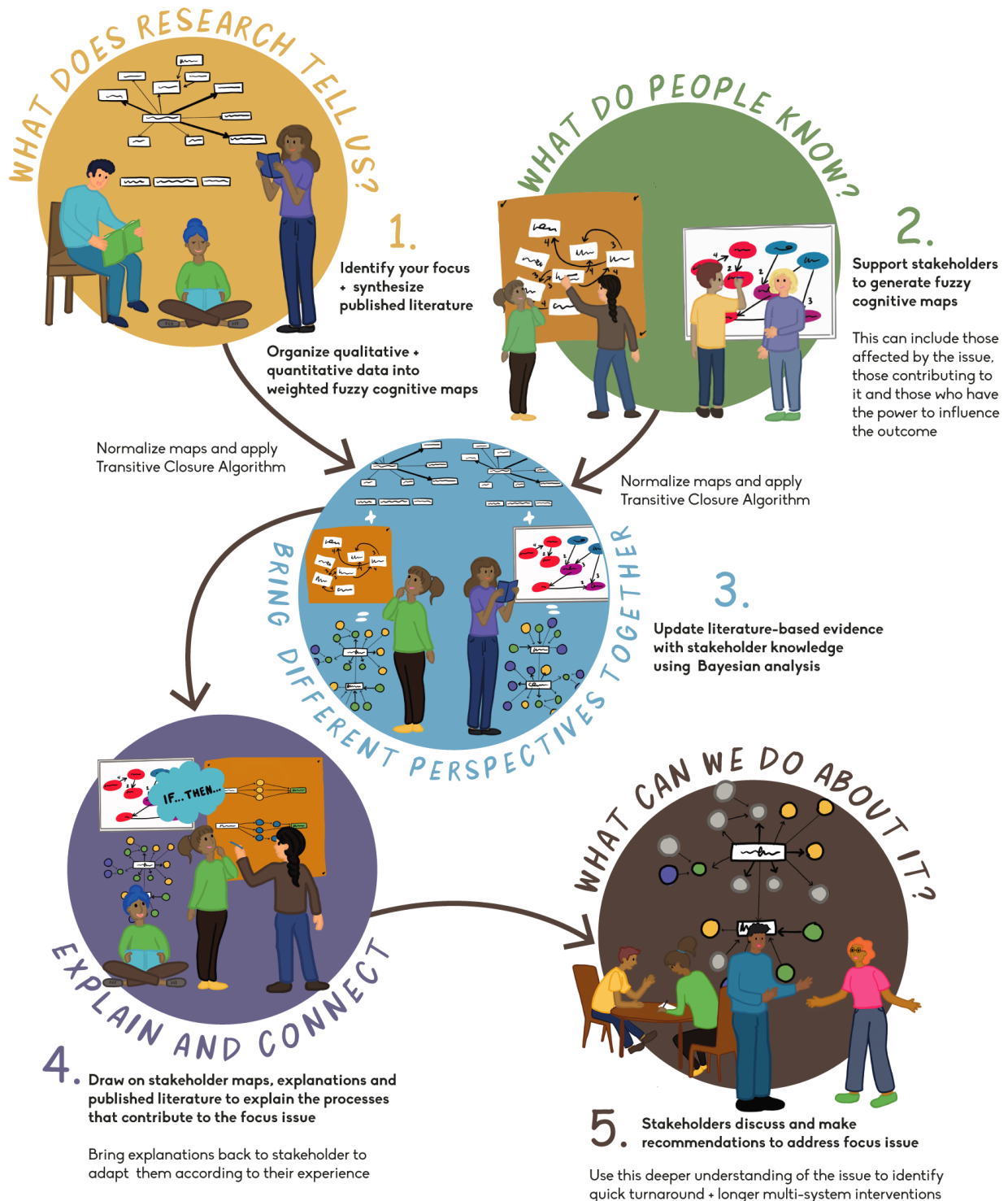
A Note About Language

We refer to people who participate in the Weight of Evidence method and contribute to a greater understanding of the issue at hand as stakeholders.

We refer to people who are actively engaged in deciding the direction, design or analysis activities as co-researchers or collaborators. These people often participate as stakeholders within the research process, but also have a hand in the direction and governance of the overall research project.

The Weight of Evidence Method

WEIGHT of EVIDENCE



What does research tell us?

Identify your focus and synthesize published literature

This step begins by clarifying the focus, or research question, of your initiative and identifying an indicative outcome. This is an outcome that is representative of the experience or phenomena that you are interested in exploring. This outcome should be well-defined, as this helps people provide specific and concrete input about factors contributing to it. An indicative outcome can be identified by researchers, policy or program managers, communities or different groups working together.

We then synthesize available literature on this outcome by determining type of literature review that is most suited to the research question and objectives. Literature can be synthesized from quantitative, qualitative and mixed methods research. While it is preferable to incorporate evidence from the most comprehensive review possible, there are many topics where systematic reviews are not available. Research librarians are often very helpful in designing literature reviews to gather all available evidence. Depending on the type of review, teams may need additional expertise to summarize statistics across studies, synthesize qualitative findings or understand how to conduct mixed methods reviews.



Quantitative data can be summarized to a common effect estimate. Wherever possible, we used odds ratios, and pooled data using standard approaches to meta-analysis when multiple effect estimates describe the same relationship between factors. When other statistics were presented such as chi-square or mean differences, we converted them to the standardized mean difference (d), and then converted d to an odds ratio using readily available and widely accepted formulas.²⁸ Qualitative studies can be summarized by any conventional means coherent with the research question. With the literature review complete, we present the evidence as a fuzzy cognitive map, where nodes in the map represent independent variables from quantitative studies, and the strength of the arcs connecting nodes describe effect estimates; "unattached" nodes represent themes identified in qualitative studies.²⁹ We convert all effect estimates to the same measure (eg. odds ratio).

What do people know about it?

Support stakeholders to generate cognitive maps

Step

2

This step begins by identifying stakeholders - people (or groups of people) that have an interest or a stake in the indicative outcome. This can include those affected by the issue, those contributing to it (knowingly or unknowingly) and those who have the power or are in a position to influence the outcome. This is often a question of expertise balanced with access, resource and equity considerations. Stakeholders can be identified by researchers, co-researchers or through a collaborative process between multiple groups.

We then guide stakeholders through the fuzzy cognitive mapping (FCM) of their own understanding of the factors contributing to the indicative outcome.^{29,30,31} Stakeholders generate ideas independently, and can be prompted to identify any relevant social and structural influences based on factors identified in the literature.

It is worth investing the time to make sure the guiding question to start the mapping session is clear. You may also want to frame the question specifically around strengths or challenges (it may become over-populated if both are included). In this case, you could make two maps (one for strengths and one for weaknesses).



Each stakeholder can make their own maps, or they can be made as a group, but it is important not to combine different stakeholder groups. Differences in power and lived experience may lead to some participants not having their ideas heard or included in the map.

To draw the maps, stakeholders describe and list the factors they believe influence the outcome. We then present the literature-derived cognitive map (created in the previous step) and ask stakeholders to adapt it, incorporating their own ideas, removing factors they considered irrelevant and creating more factors if necessary. After no new factors emerge, the participants group the factors that are similar or synergistic. Stakeholders then draw

arrows to indicate the relationships between the factors. Once all the arrows are drawn, stakeholders assign a weight (from 1 to 5) and direction (+ve or -ve) of effect to each relationship in their map.

In our experience, making and weighting FCMs takes roughly 2 hours. FCMs can be made on poster boards with post-it notes, blackboard, whiteboard with magnets, or electronically (**MentalModeler** or yEd).

Each stakeholder group should have their own facilitated map-making session. Documenting (note-taking or audio-recording) can be very useful to record stakeholder rationalizations as they make their maps, which are helpful in formalizing the maps and sense-making activities in Step 4.

Step 2. Strategies to Ensure Rigorous Evidence within the Weight of Evidence method

Strategies to support implementation:

- Key steps to produce a useful fuzzy cognitive map.³¹

Strategies to support internal validity:

- Conceptual Clarity: Ensure conceptual clarity across stakeholders and with literature. Having stakeholders make their own maps (eg. write categories and organize them) while explaining reasoning supports depth of understanding;
- Weighting consistency: Ensure that participants have a shared understanding of the meaning of a given weight
- Documentation: Thorough recording (note taking or audio recording) supports later analysis
- Member checking: Share maps and transcripts back to those who made them; ensure all relationships and priorities are appropriately labeled; incorporate any changes into revised maps

Process options

STEP 2. SUPPORT STAKEHOLDER TO GENERATE COGNITIVE MAPS
THIS STEP GUIDES STAKEHOLDERS THROUGH THE DEVELOPMENT OF THEIR OWN COGNITIVE MAP, DESCRIBING, AND WEIGHTING, FACTORS THEY BELIEVE INFLUENCE THE OUTCOME.

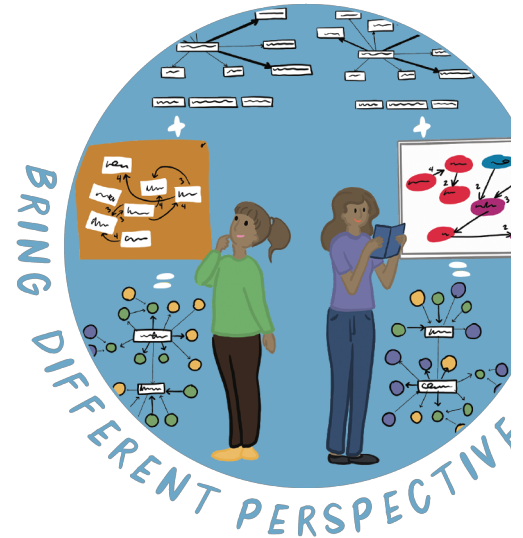
ACTION/ACTIVITY	Advantages	Disadvantages	Examples or References
1. IDENTIFYING STAKEHOLDERS			
RESEARCHER IDENTIFIED	May save time and resources	May not identify most comprehensive or most important stakeholder groups	In the WofE pilot, researchers identified family physicians and volunteer birth companions who had worked with recent immigrant women.
PARTICIPATORY STAKEHOLDER IDENTIFICATION METHODS	More locally-relevant stakeholders involved	Takes more time; Careful attention to process (eg, inclusion or disagreements within group)	In WofE project in partnership with young mothers, they identified health and social services providers, and child protection workers See <u>Community-Based Research Toolkit</u> or <u>SAS2 Participatory Action Research Toolkit</u>
2. DEVELOP FUZZY COGNITIVE MAPS			
GROUP-MADE FCMS	Conceptual clarity built through group discussion; Gathers group perspectives at once	May not capture views of less vocal participants or those who have experiences different from the group	<u>Fuzzy Cognitive Maps as Representations of Mental Models and Group Beliefs</u> <u>Fuzzy cognitive mapping: an old tool with new uses in nursing research</u>
INDIVIDUAL FCMS	In-depth interview documented through FCM; more appropriate for sensitive topics or when participation implies disclosure (eg. HIV status)	Takes more time; challenging for conceptual clarity across multiple individual maps	<u>Ecological models based on people's knowledge: a multi-step fuzzy cognitive mapping approach</u>
SHARING PUBLISHED LITERATURE AFTER	Provides participants with all available evidence to adapt	Consider sharing evidence after stakeholders generated own	

Bring different perspectives together

Combine literature-based evidence with stakeholder knowledge

This step combines one type of knowledge (eg. from the literature) with another (eg. from a stakeholder group). Both maps need to be on the same scale so that they can “speak” to one another. We call this normalizing and use a scale of 0 to 1 to facilitate later analysis. (Please see example in Annex for normalizing formulas).

We then use a mathematical algorithm (transitive closure) to identify all of the implied connections between concepts as a result of them being part of the same indirect pathway in a cognitive map.³² Transitive closure adjusts weights to account for these implied connections and identifies the efficient paths through the maps.^{33,34} Accounting for interdependence between changes the maps from a collection of independent factors to a network of factors that contribute to the outcome. Transitive closure also identifies walks, or the most efficient important pathways, between factors in each map. This step requires access to a transitive closure algorithm (links provided below) or executing software. While this step is absolutely necessary to the Weight of Evidence method, without it, weights will not be adjusted for interdependence and you will not have access to the most efficient pathways through the maps to contribute to your analysis.



To ground published literature in stakeholder perspectives, we use Bayesian statistics to update what is known through research about the outcome with prior, or existing, knowledge from stakeholders.^{35,36} This step lets you see how the evidence is contextualized and prioritized by particular groups of stakeholders – how much that evidence matters in this context according to that stakeholder or group. Bayesian analysis is a well-established logical and transparent way to incorporate expert knowledge with empirical quantitative data, conventionally done by eliciting uncertainty around a parameter's value. Bayesian methods are often used to include evidence and other forms of knowledge external to conventional meta-analyses as they provide a coherent framework to account of evidence from a variety of sources about a specific problem.

Using stakeholder weights specified through fuzzy cognitive mapping provides a systematic and transparent process to develop measures of relative credibility or importance of factors according to different stakeholder perspectives. Using the priors to update and inform conventional epidemiological models offers a powerful way to expand the boundaries of current conceptualizations of an issue and incorporate issues formerly seen as outside of the system of influence.^{2,37,38}

Using stakeholder-generated priors from fuzzy cognitive maps, the mathematics of Bayesian analysis makes explicit any differences and similarities in weighting within as well as between stakeholders and published evidence in a logical and reproducible way.³⁹ This has been an important tool in identifying and understanding differences in understanding of an issue, creating opportunities to identify how and when these differences arise and with what consequences.^{20,40}

We can compare how different stakeholder groups understand an overall issue using graphic representations and pattern matching tables. We can also compare distributions of weights for specific relationships, visually representing the credibility assigned to the evidence by different stakeholder groups, instead of plotting only a single “best” line or average value.³⁹

Recognizing that what counts as knowledge and expertise often depends on the context. Weight of Evidence allows us to assign different weights to different individual or group perspectives. Differentially valuing the perspectives of experts is common practice in Bayesian updating when eliciting expert opinion, where weighting is applied to account for the quality or relevance of different expertise, often through a researcher-defined weight assigning credibility or importance of the knowledge source to the issue at hand.^{41,42}

Drawing from an example from our pilot study on perinatal care of recent refugee women in Canada, when determining the indications for an emergency Cesarean section, an obstetrician's perspective may be most valuable. However, when describing how discrimination affects access to perinatal care, the perspective of those discriminated against may be the most valuable. Weight of Evidence requires that we be explicit about whose knowledge and what evidence is prioritized, while also inviting a more complex understanding of knowledge and expertise in context.

This step requires familiarity with Bayesian statistics and/or access to software (such as R, WinBUGS, python) that can implement Bayesian procedures. If this step is not done, you will still have maps representing the different knowledge sets but will not be able to see how they interact with one another.

Step 3. Strategies to Ensure Rigorous Evidence within the Weight of Evidence method

Implementation Resources:

- See Additional File 1- Bayesian Updating

Strategies to support internal validity:

- Ensure conceptual clarity when updating (ie. that you are updating weights referring to the same concept across the literature and stakeholder perspectives)
- Assess whether participant grouping is appropriate. For example, broad or multi-modal distributions (eg. with more than one peak) in stakeholder weights suggest important differences within the stakeholder group. These differences may need exploring through further group discussion, or different forms of analysis (eg. using non-normal distributions as the assumed underlying probability distribution.)

PROCESS OPTIONS

STEP 3. COMBINE LITERATURE-BASED EVIDENCE WITH STAKEHOLDER KNOWLEDGE
THIS STEP UPDATES ONE TYPE OF KNOWLEDGE ABOUT THE INDICATIVE OUTCOME (EG. FROM THE LITERATURE) WITH ANOTHER (EG. FROM A STAKEHOLDER GROUP).

ACTION/ACTIVITY	Advantages	Disadvantages	Examples or References
1. ACCOUNTING FOR INTERDEPENDENCE BETWEEN FACTORS			
USING FUZZYTIC ALGORITHM USED WHEN CONCEPTS INCLUDED IN MAPS ARE NOT FIXED.WALK WEIGHT IS DETERMINED BY LOWEST WEIGHT IN PATH	Can often run with very dense maps.		<u>Computing transitive closure on bipolar weighted digraph</u> <u>User Manual for FuzzyTC</u>
USING PROBTIC ALGORITHM USED WHEN NUMBER OF CONCEPTS IN MAPS ARE FIXED. WALK WEIGHT DETERMINED BY PRODUCT OF INVOLVED ARCS		May have long run times (or may not compute output at all) when using very dense maps	
2. COMBINING (OR UPDATING) LITERATURE WITH STAKEHOLDER PERSPECTIVES			
CIETMAP SOFTWARE FCM TOOL	Has a user-friendly interface	Need basic understanding of Bayesian statistics	See Additional File 1 : Bayesian Updating from Methods article (currently under review)
OTHER SOFTWARE (R or Python)	Need knowledge of advanced Bayesian statistics to write own code or use ours		

Explain and Connect

Describe explanatory processes leading to priority outcomes

Step

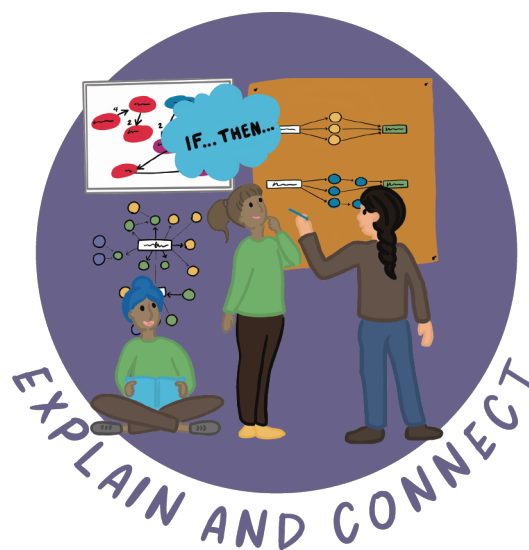
4

In this step, we draw on stakeholder explanations (through their maps and the accompanying narratives) and published research to make sense of, or explain, how factors contribute to the outcome. Consistent with a realist understanding of causal processes, explanatory accounts are informed by results from Step 3, including:

- The relationships and priority factors identified across different stakeholder groups;
- Most efficient pathways between two or more factors (identified through transitive closure); and
- Comparison of how each knowledge source weights specific factors and their influence on the indicative outcome.

We also draw upon notes or recordings from mapping interviews where stakeholders often verbally rationalized their selection and weighting of relationships while making the maps. We examine literature specific to the indicative outcome as well as literature related to possible explanations contributed by stakeholders during map-making.

Drawing on realist approaches to generating explanatory accounts and following the process outlined by Pearson and colleagues²² we generate “If.....then....” statements describing the processes that led to an outcome. By iteratively consolidating explanatory accounts and grouping them by common mechanisms or themes, we develop an overall framework to explain factors and relationships that contribute to our outcome.



We then ask co-researchers and stakeholders to adjust these possible explanations to coincide with their experience. This acts as a check for the researchers' explanatory accounts and can be done by multiple different stakeholder groups. This is especially important when working with marginalized communities, a setting where theories and

explanations generated outside the community may reinforce erroneous stereotypes.⁴³ Bringing diverse perspectives together can balance often implicit assumptions within clinical practice, health services and policies with patient experience and understanding.⁷ If this step is not done, you will not know if the explanations generated by researchers reflect stakeholders' understanding and experience.

We have found realist very useful to make sense of multiple perspectives around the same issue while drawing on quantitative, qualitative and stakeholder-provided evidence. A realist approach guides the development of explicitly stated explanatory processes and the scaffolding of explanatory descriptions to come up with a consolidated framework to explain our outcome. A realist approach, however, is certainly not the only paradigm that can be used to analyze and make sense of the differing perspectives gathered by Weight of Evidence.

Step 4. Strategies to Ensure Rigorous Evidence within the Weight of Evidence method

Triangulation of Data: Use of multiple sources of data (evidence synthesis, stakeholder perspectives, map structures) to generate explanatory processes

Explore plausible alternative explanations through generation of explanatory processes (supports external validity by comparing with available literature)

Co-construction of explanatory processes: Stakeholders review, adapt and adjust explanatory processes to ensure explanatory processes reflect their perspectives, understanding and priorities.

PROCESS OPTIONS

STEP 4. DESCRIBE EXPLANATORY PROCESSES LEADING TO PRIORITY OUTCOMES
THIS STEP GENERATES EXPLANATORY ACCOUNTS OF HOW FACTORS IDENTIFIED IN THE FUZZY COGNITIVE MAPS MAY LEAD TO PRIORITY OUTCOMES TO INFORM THE FORMULATION / ELABORATION OF RECOMMENDATIONS".

ACTION/ACTIVITY	Advantages	Disadvantages	Comments or References
1. DEVELOPING EXPLANATORY ACCOUNTS			
ESTABLISH PROCESS FOR CONSOLIDATING EXPLANATORY ACCOUNTS	"If... then..." statements are easy to communicate	Requires expertise in realist analyses	Using realist review to inform intervention development: <u>methodological illustration and conceptual platform for collaborative care in offender mental health</u>
2. STAKEHOLDERS GROUND EXPLANATIONS BASED ON THEIR OWN EXPERIENCE			
REQUIRES CONSOLIDATING AND TRANSLATING EXPLANATORY ACCOUNTS INTO ACCESSIBLE LANGUAGE/OTHER FORMATS	Supports co-learning and recognition of stakeholder knowledge More robust explanations	Requires additional time Often increases the number of explanatory accounts	<u>Theorizing back: An approach to participatory policy analysis</u> Can be done first by researchers, then shared with co-researchers, or done together, and then adapted by stakeholders

Defining action and ways forward

Stakeholders discuss and make recommendations to address indicative outcome

This step asks stakeholders to discuss and make recommendations to better address the indicative outcome based on their deepened understanding of the individual, organizational, social, political, economic and others types of influences facilitated by the Weight of Evidence process. We have found the consolidated framework created in Step 4 a useful tool as a possible “map of action”, where each stakeholder group can recommend strategies that they can carry out themselves, as well as those that would be most effective in addressing the issue in both the short and long term.



There are several tools that support collaborative decision-making. Some of the ones we have found most useful are [deliberative dialogues](#) and participatory decision-making tools (see [the SAS2 Toolkit](#))

If your stakeholder groups include decision-makers who have participated in the previous steps, then some of them may already know the findings from the Weight of Evidence process. We also recognize that time and resource constraints might limit some stakeholder involvement. Key outputs from the Weight of Evidence (such as the maps of the evidence updated by stakeholder perspectives, the consolidated explanatory framework from Step 4 and a list of prioritized areas for action) offer a distilled understanding of stakeholder perspectives on the issue. Depending on the context of the project and the types of recommendations made by different stakeholder groups, you may want to think about using a variety of knowledge-translation strategies.

Resources to
Support Effective and
Impactful Knowledge
Translation Strategies

[The KT Toolkit](#)

[Knowledge Translation Resource Page](#)

[Equity-focused knowledge translation toolkit](#)

[Engaging Citizens for Decision-making](#)

[SUPPORT Tools for evidence-informed health](#)

[Policymaking \(STP\)](#)

Annex 1: Bayesian Updating

We have found Bayesian updating to be helpful with respect to bringing different types of knowledge together, all the while preserving differences and providing a mathematical accountability of the role of different perspective in decision-making. The most straightforward way to update perspective is what is termed naïve updating in meta-analysis methods, whereby each perspective is considered to carry equal weight, regardless of the quality and/or known and unknown differences in how appropriate a particular knowledge source may be to address the issue at hand.[1]

We calculated posterior distributions (or moments) following Bayes' Rule, where weights from stakeholder and published evidence are represented as distributions. We described what is known by a stakeholder group by calculating an average weight and standard deviation to represent the variation in weights across a stakeholder group for each relationship, θ , identified in stakeholder maps. These were described as normal prior distributions, $f(\theta)$, where $f(\theta) \sim (\mu_s, \sigma_{st}^2)$.

Similarly, we described what evidence was available about that same relationship, θ , in peer-reviewed literature as the normalized odds ratio (eg. represented on a scale of 0-1) together with its standard deviation (also on a scale of 0-1). This was used to characterize the normal likelihood function, $f(x|\theta) \sim f(x|\mu_{lit}, \sigma_{lit}^2)$. [2] Bayesian analysis then combines what is known about a relationship, using the prior, $(f(\theta))$, with observed data about that relationship, using the likelihood function, $(f(x|\theta))$, by calculating a posterior distribution, $f(\theta|x)$, using Bayes' Rule[3]:

$$\text{posterior distribution} = \frac{\text{likelihood of the data } \times \text{ prior distribution}}{\text{marginal likelihood of the data}}$$

$$\text{or } f(\theta|x) = \frac{f(x|\theta) \times f(\theta)}{f(x)} \quad (\text{Eq1})$$

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APPENDIX 5B: Evaluation of resources to support Weight of Evidence

This is a protocol developed to evaluate the presentation and resources to support the use of the Weight of Evidence approach. I am the second author of this protocol and worked with Dr. Émilie Robert under the guidance of an Advisory Committee made of Dr. Serge Djossa Adoun, Dr. Zack Morrison, Dr. Valéry Ridde and Dr. Kate Zinszer to develop this protocol.

Weight of Evidence: evaluation criteria and steps

Emilie Robert and Anna Dion

This protocol describes a process for the refining of Weight of Evidence (WoE), an innovative approach to knowledge synthesis that leverages several well-established tools from participatory research, systems science and Bayesian analysis, under a critical realist philosophy. A description of Weight of Evidence has been published and can be viewed at the following link: <https://link.springer.com/article/10.1007%2Fs00038-018-1180-9>

Targeted users of WofE are academic and clinical researchers, research institutes in hospitals, as well as public health or community health practitioners or knowledge brokers in health agencies, whether in the health field international, national, provincial or regional level. Informed by a participatory approach, WoE calls on the collective contributions of these diverse users, as well as the active involvement of health service users.

In the context of this protocol, the aim is to evaluate three dimensions:

- the validity of the description of the WoE approach;
- the comprehensiveness of information and resources described within the WofE Guideline document to produce valid knowledge;
- the quality of the presentation of WoE guideline document..

For each dimension, the document proposes evaluation criteria and an evaluation process, as well as a process for selecting experts to contribute to the evaluation. A panel of scientific experts will evaluate the first two dimensions jointly. Potential users will evaluate the third dimension.

An Advisory Committee has been formed to validate this protocol. It is composed of the following four experts:

- Serge Djossa Adoun (McGill University)
- Zack Marshall (McGill University)
- Valéry Ridde (Institut de recherche pour le Développement)
- Kate Zinszer (Université de Montréal)

1. Validity of the *Weight of Evidence* approach (Component 1)

1.1. Evaluation criteria

From Creswell and Plano-Clark (2011), we identified and retained six dimensions to determine the validity of a mixed synthesis approach. For each dimension, we propose a series of questions to guide the reflection on the dimension.

Dimension 1: Plausible and explicit justification of the reasoning behind the choice of a mixed synthesis

Do the authors highlight the social relevance and the scientific relevance of opting for a mixed synthesis approach?

Do they explain the limitations of other types of approaches used to achieve similar goals?

Is the reasoning of the authors plausible given the current state of knowledge?

Dimension 2: Explicit Philosophical / Paradigmatic Anchorage

Do the authors specify the paradigm in which the mixed synthesis approach is proposed?

Do they explain the ins and outs of this paradigmatic anchoring?

Do they explain the links between this paradigmatic anchoring and the proposed approach?

Dimension 3: Conceptualization of the stages of synthesis and their mutual contribution

Do the authors describe the different stages of the mixed synthesis approach?

Do they explain how each step contributes to the following?

Do they explain the relevance of each step for the process? Do they explain how each step contributes to the overall reflection?

Dimension 4: Clarity and validity / rigor of collection, analysis and inference procédures

Do the authors specify the criteria of quality or rigor specific to each stage of the mixed synthesis approach?

If so, do they refer the reader to the relevant literature to establish the rigor of the collection, analysis and inference procedures for each step?

Dimension 5: Presence of explicit knowledge integration steps

Do the authors foresee stages of integration of the different types of knowledge produced during the process?

Do they explain how the knowledge generated at each stage is mobilized in the following steps?

Dimension 6: Mobilization / Use of terminology specific to mixed methods

Do the authors use the terminology specific to mixed methods to justify the choice of a mixed synthesis approach, describe their paradigmatic anchoring, and specify the stages of data integration?

1.2. Evaluation steps

A panel composed of at least ten experts will have to, via an online questionnaire (eg Monkey Survey) or in .pdf format and using the Weight of Evidence Guideline document:

- Evaluate the six dimensions of the description of WofE in the guideline document, on a scale of 1 to 4 (and not the questions associated with each dimension);
- Specify the positive points (the added value) of the approach;
- Propose solutions to answer any identified gaps.

The proposed scale is as follows:

- 1 = missing dimension
- 2 = implicit dimension (to be made explicit)
- 3 = explicit but insufficient or questionable dimension
- 4 = explicit and convincing dimension

According to the Delphi method, the panel will have to pronounce on these dimensions three times. Following each step, modifications will be proposed to the Guideline document, in order to take into account the opinions of the experts. The process will be tested by the Advisory Committee and the CIET / PRAM Group at McGill University.

The goal is to arrive at:

- a consensus of at least 80% on the notation of 3 and more, on each of the dimensions;
- a consensus of at least 50% on the notation of 4, on each of the dimensions.

If these consensus levels are achieved in the first or second round, the third step will not be organized. Conversely, in the event that the expected consensus levels are not achieved, the final decision lies with the Advisory Committee, who will decide on the final modifications to the Guideline document.

1.3. Identification of experts

To answer Delphi questions in an informed way, the ten experts will have to fulfill the following criteria:

- Be a researcher affiliated with a university
- Have solid knowledge in research epistemologies
- Have expertise in the use of mixed methods and the conceptualization of mixed methods research
- Have expertise in knowledge synthesis, preferably mixed methods syntheses

In addition to the above criteria, the panel of experts should bring together at least two experts in each of the following areas:

- Systematic review
- Participatory research / co-construction of knowledge
- Realist approach
- Bayesian analysis

- Knowledge translation

The Advisory Committee will be responsible for proposing at least two names for each of the necessary expertise. The selection will use a snowball approach, whereby if people are unavailable, we will ask them to recommend other possible experts

2. The comprehensiveness of information and resources proposed by the Guideline document for WoE to produce valid knowledge (Component 2)

2.1. Evaluation criteria

The ability of each WofE step to produce valid knowledge must be measured according to the criteria specific to the discipline in which it is embedded. The Guideline document offers information and resources at every stage to guide potential users to produce rigorous evidence. This step aims to validate the completeness of the information and resources mentioned by Guideline document.

People with expertise in the relevant field will examine each of the the five steps of WofE. The objective of their evaluation is twofold:

- 1) to validate the proposed explanation of the method for the stage for which they are responsible,
- 2) to validate the resources proposed to carry out this step and ensure the quality of the knowledge produced as part of this step.

2.2. Evaluation steps

The two experts from the previous panel will be asked to evaluate the WofE step that corresponds to their expertise, via an online questionnaire (eg Monkey Survey) or in .pdf format. For example, the two experts with expertise in research from realist perspective will be responsible for assessing the steps in the WofE that most explicitly employ realist concepts and methods, with the understanding that this element may also have implications for other steps in the Weight of Evidence approach.

With respect to the validation of the proposed explanation of the method, the experts should give a score of 1 to 4 (1 = not at all and 4 = quite) to the following statements:

- The description of this step is sufficient to ensure the understanding of the challenges and benefits of the step, as well as precautions and methodological issues, by a non-expert user.
- The concepts defined as part of this step are intelligible to a non-expert user.
- The description of the quality criteria is intelligible to a non-expert user.
- The explanations proposed for this step are sufficient to guide a non-expert user.
- Open question: In your opinion, what additional information would be needed? Is any of the information superfluous?

Regarding the relevance of the strategies and resources proposed to ensure the quality of the knowledge produced, the following questions will be asked to the experts:

- Are the strategies and resources proposed to carry out this step and ensure the quality of the knowledge produced relevant? YES NO
- If no, which ones are not relevant and why?
- Should other resources be mentioned? YES NO
- If so why?

According to the Delphi method, experts will have to decide on these dimensions three times. Following each step, modifications will be proposed to the Guideline document, in order to take into account the opinions of the experts. The process will be pilot tested by the Advisory Committee and the CIET / PRAM Group at McGill University.

The goal is to get:

- a consensus of at least 80% on the notation of 3 and more, on each of the dimensions;
- a consensus of at least 50% on the notation of 4, on each of the dimensions.

If these consensus levels are achieved in the first or second round, the third step will not be organized. Conversely, in the event that the expected consensus levels are not achieved, the final decision lies with the Advisory Committee, who will decide on any approved changes.

3. The quality of the presentation of the *Weight of Evidence* (Component 3)

3.1. Evaluation criteria

The quality dimensions of a guide describing a scientific approach, such as the Guideline document for WoE, can be grouped into three categories:

Dimension 1: General presentation of the guide

Do we know who the guide is for?

Are the objectives of Weight of Evidence explicit?

Is the organization of the guide relevant?

Is the information well presented?

Are you a potential user of WoE?

If not why ?

What are your recommendations for improving the general presentation of the guide?

Dimension 2: Clarity of the method and relevance of the elements described

Is the explanation of Weight of Evidence's relevance convincing?

For each part of the guide:

Is the information available explicit / understandable?

Is the information available sufficient?

Are the table categories explicit?

Could you specify what are the least explicit sections?

What are your recommendations to improve the clarity of the method and / or the relevance of the elements described?

Dimension 3: Language level

Is the level of language adapted to a non-expert public of the methods proposed, but specialist of the stakes of public health / community health?

3.2. Evaluation steps

A panel of potential users of Weight of Evidence will have to:

- evaluate the dimensions of the quality of the document, on a scale of 1 to 4 (1: not at all and 4: quite) or answer open questions;
- suggest ways to improve the document.

The evaluation will take place in two stages. The first will be through a workshop at an international conference (eg Cochrane Symposium and/or the Campbell What Works Global Summit, both in October 2019). The workshop will walk participants through an application of the Weight of Evidence method, including the use of the Guideline document, and then workshop participants will be asked to evaluate the content and presentation of the Guideline document.

The second stage of the evaluation of the Guideline document will be through a short questionnaire (with similar questions to those asked at the workshop) to potential users of WofE. Although a variety of actors may be required to collaborate in the use of WoE, it is expected that researchers will drive the approach from academia, clinical researchers or research institutes, research hospitals, or public health or community health practitioners or knowledge brokers within health agencies, whether at the international, national, provincial or regional levels. The panel should therefore include at least ten potential users, representing the following categories:

- a researcher from an academic environment
- a researcher (e) of establishment
- a researcher from a clinical setting (practitioner-researcher)
- a public health / community health practitioner or broker in a public health department in Quebec
- Public Health / Community Health Practitioner / Broker at Health Canada
- a public health / community health practitioner or broker in a regional health agency in France
- a public health / community health practitioner or broker in an international agency (eg UNICEF, WHO, etc.)

The Advisory Committee will be responsible for proposing at least two names for each category of potential users. The selection will be by snowball, people contacted us recommending other people in case of unavailability.

Appendix 6: Fuzzy cognitive mapping and soft models of indigenous knowledge on maternal health in Guerrero, Mexico

I am a co-author on this publication as I contributed to both the methodology applied in this study and to the analysis of the findings. This manuscript is published in BMC Medical Research Methods and the abstract is included in the appendix.

Ivan Sarmiento, Sergio Paredes-Solís David Loutfi , Anna Dion , Anne Cockcroft and Neil Andersson BMC Medical Research Methodologies 20:125(2020)

RESEARCH ARTICLE

Open Access

Fuzzy cognitive mapping and soft models of indigenous knowledge on maternal health in Guerrero, Mexico



Ivan Sarmiento^{1*} , Sergio Paredes-Solís² , David Loutfi¹ , Anna Dion¹ , Anne Cockcroft¹ and Neil Andersson^{1,2}

Abstract

Background: Effective health care requires services that are responsive to local needs and contexts. Achieving this in indigenous settings implies communication between traditional and conventional medicine perspectives. Adequate interaction is especially relevant for maternal health because cultural practices have a notable role during pregnancy, childbirth and the postpartum period. Our work with indigenous communities in the Mexican state of Guerrero used fuzzy cognitive mapping to identify actionable factors for maternal health from the perspective of traditional midwives.

Methods: We worked with twenty-nine indigenous women and men whose communities recognized them as traditional midwives. A group session for each ethnicity explored risks and protective factors for maternal health among the *Me'phaa* and *Nancue ñomndaa* midwives. Participants mapped factors associated with maternal health and weighted the influence of each factor on others. Transitive closure summarized the overall influence of each node with all other factors in the map. Using categories set in discussions with the midwives, the authors condensed the relationships with thematic analysis. The composite map combined categories in the *Me'phaa* and the *Nancue ñomndaa* maps.

Results: Traditional midwives in this setting attend to pregnant women's physical, mental, and spiritual conditions and the corresponding conditions of their offspring and family. The maps described a complex web of cultural interpretations of disease – “frío” (cold or coldness of the womb), “espanto” (fright), and “coraje” (anger) – abandonment of traditional practices of self-care, women's mental health, and gender violence as influential risk factors. Protective factors included increased male involvement in maternal health (having a caring, working, and loving husband), receiving support from traditional healers, following protective rituals, and better nutrition.

Conclusions: The maps offer a visual language to present and to discuss indigenous knowledge and to incorporate participant voices into research and decision making. Factors with higher perceived influence in the eyes of the indigenous groups could be a starting point for additional research. Contrasting these maps with other stakeholder views can inform theories of change and support co-design of culturally appropriate interventions.

Keywords: Safe birth, Intercultural dialogue, Indigenous health, Fuzzy cognitive mapping

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Background

Childbirth involves a range of cultural practices and meanings [1] that contribute to women's perinatal experience and their health outcomes [2]. Many indigenous communities in Latin America have poor access to conventional health services and face harsh living conditions [3]. As we try to understand the dramatic health disparities between indigenous and non-indigenous communities [4], it is difficult to disentangle the effects of poor access to conventional health services from effects of communities losing their own cultures and traditions. There is a need for methods that assess how culture and traditions can impact health outcomes [5].

Effective perinatal care requires services that are responsive to local needs and contexts [6]. Since the 1980s, the concept of cultural safety has gained recognition as a key ingredient in the delivery of quality care, particularly among indigenous communities. Culturally safe practice recognizes that power imbalances shape intercultural interactions and have historical effects on health disparities by influencing the lives and opportunities of marginalized groups [7]. The central idea of cultural safety is to provide health care without diminishing or disrespecting the cultural identity of patients and their communities.

Indigenous communities in Mexico's Guerrero state lost much of their ancestral traditions as they embraced new elements from Western culture. In transitions like this, in theory people have access to both conventional and traditional health care. In practice, they face complex health choices [8] as the transition from traditional to conventional health care is incomplete in many places, leaving important gaps [9]. Because they usually live in remote parts, many indigenous communities have access only to the very periphery of conventional health services. Distance, inappropriate allocation of state resources, and weak local governments are part of the problem on the supply side [10]. The perceived lack of respect for their traditional knowledge systems leads to an aversion to conventional health services among many indigenous people [11]. This hinders access to conventional medical facilities [12]. In the indigenous communities in the southern mountainous areas of Guerrero in Mexico, traditional midwives are either the only source of perinatal care or the one that women prefer [12, 13].

Traditional midwives are the cornerstone of health care developed over generations by indigenous communities [14]. These systems are culturally specific and have strong links with the environmental conditions grounding each group [15]. Anthropologists have described some elements of traditional health care, mostly using ethnography and interviews [1]. Almost invariably, however, the scientific literature describes these systems from the perspectives of outsiders and using cultural

reference points that do not necessarily coincide with those of the indigenous community themselves [16].

Our objective was to systematize the knowledge of traditional midwives about risks and protective factors for maternal health among indigenous communities in southern Mexico, to improve the interface between traditional practitioners and the local health services [17]. The work in this manuscript is part of a bigger project to promote safe birth in cultural safety among indigenous communities in the south of Guerrero State. The overall project includes a cluster randomized controlled trial comparing maternal health outcomes in indigenous communities with and without a co-designed intervention to support the role of traditional midwives [17]. The intervention asserts the principles of cultural safety [18] and intercultural dialogue [19]. The mapping process described in this manuscript will contribute to elicit prior stakeholder knowledge to inform Bayesian analysis of the trial.

Methods

In recent years, fuzzy cognitive mapping [20] has allowed inclusion of the knowledge of stakeholders into models to describe their understanding of determinants of poor health [21] and, in an additional step, juxtapose this knowledge with conventional biomedicine evidence [22]. These maps describe different knowledge systems and can thus contribute to establishing common reference points to advance shared views of specific health issues [23]. "Fuzzy" refers to the stakeholder assigned weights to grade influences of different factors on each other and on a specific outcome [24]. The maps represent soft models of the way people reason, depicting their knowledge structures [20].

In fuzzy cognitive mapping, each factor is drawn as a node, and each relationship is represented as an edge (arrow) linking nodes. The arrows represent assumptions about causal relationships that can be based on data or on unwritten knowledge [20]. Authors of the maps attribute different values to weight the strength of each arrow. Weights can have positive signs to indicate that, as one node increases, the linked node also increases (excitatory relationship), or negative signs for inhibitory relationships (as one node increases, the linked node decreases). The causal weights express knowledge-holder opinions, their explanatory models and theory of change, rather than a predictive statistical model. By contrasting different stakeholder groups, fuzzy cognitive maps can highlight similarities and differences of alternative explanatory models and theories of change [25].

Participants

The *Nancue ñomndaa* and *Me'phaa* people have experienced cultural loss associated with the growing Western

influence in their area. Nonetheless, both indigenous groups still maintain their identities. This is reflected in the use of traditional languages and, especially in the case of the *Nancue ñomndaa*, clothing. The main economic activities of both indigenous groups are subsistence agriculture, raising cattle, and migrant labor. During the last two decades, these communities have experienced out-migration mainly of male adults and youth looking for jobs in other states, Canada and the United States, to send money back to their families in Guerrero. The minimum wage in the region is about USD40 monthly, but for indigenous populations is around USD34 [13].

Traditional midwives accompany indigenous women throughout pregnancy, provide support through labour and advise on care of the newborn [1, 26, 27]. We recruited 29 indigenous traditional midwives, 18 from the *Me'phaa* indigenous group (Tlapaneco) in the municipality of Acatepec and 11 from the *Nancue ñomndaa* (Amuzgo) indigenous group in the municipality of Xochistlahuaca. A household survey in 2015 interviewed each indigenous woman who had delivered their children in the last two years [17]. The answers allowed us to identify active traditional midwives with *de facto* recognition in their communities, based on the number of births they attended, the health outcomes of their patients, and the traditional knowledge they hold. The traditional midwives invited to the mapping sessions also took part in the intervention of the cluster randomized controlled trial. We invited each midwife in person, as expected in indigenous customs, some weeks before the meeting. All accepted the invitation. The group in Acatepec included two male traditional midwives.

Drawing the maps

Two community members fluent in both Spanish and the indigenous language who were trained as intercultural brokers [17], two field coordinators from the *Centro de Investigación de Enfermedades Tropicales* (CIET) at the *Universidad Autónoma de Guerrero*, and the lead author facilitated the mapping sessions. After the participants gave their oral informed consent to participate, the lead author gave a further detailed explanation of the mapping steps, using lay language. Participants constructed their maps in one three-hour group session in each indigenous community. The intercultural brokers translated into Spanish the ideas voiced by the traditional midwives. Two additional local translators identified any distortion of the meaning introduced in translation.

Once participants confirmed they understood the mapping process, we invited them to map their answers to the question: To your knowledge, what are the factors related to maternal health in your communities? Each

group completed two maps: one of factors that promote safe motherhood (protective factors) and another for factors that impede safe motherhood (risks). Through group discussion, participants first listed the factors they considered to be related to maternal health in their communities. The facilitator wrote each factor on a card and stuck the cards on a wall. Some factors described concepts defined by the participants' traditional culture. In these cases, the facilitator asked for additional information to clarify the meaning. When no additional factors were forthcoming, the facilitator then asked the participants to identify the causal relationships between factors. The facilitator drew the arrows linking factors and confirmed at each time with the participants that the arrow represented the causal relation they wanted to convey, asking for more details as necessary to understand why they identified that relationship.

After defining all the relationships, participants then ranked the strength of each relationship, using a scale from one to five (with five being the strongest influence, one being the weakest influence). The facilitator explained that the strongest influence (5) was a relationship where the factor in question would almost always cause the linked outcome, while the weakest influence (1) was a relationship where the factor would seldom cause the linked outcome. The midwives decided the weight of each link by consensus. When one irreconcilable difference of opinion about the influence of hospitals occurred, we incorporated this in a sensitivity analysis. An experienced researcher fluent in indigenous language took notes of the explanations and discussion during the session, without recording any personal identifying data about participants. At the end of the session, facilitators took pictures to record the final maps. We used multiple translators to increase the likelihood of capturing the meaning correctly.

Analysis of the maps

We digitized the maps using the free software yEd [28] and generated a list of nodes and adjacency matrices for the numerical analysis of the relationships. An adjacency matrix presents the structure of the map as a square table with n number of rows and n number of columns, where n equals the total number of nodes. The value of each cell is the weight of the relationship between two nodes (directed from the row to the column). For the matrices of the original maps, we scaled the weights 1 to 5 by dividing all with a constant 5.

For each original map, we calculated the fuzzy transitive closure [29] between nodes, to measure the influence each node had on others in the map. Transitive closure takes account of each pair of linked concepts in the context of all the possible connections in the map. A "walk" is any succession of edges (arrows) that allows

transit from one node to another. The value of the fuzzy transitive closure between two nodes A and B is the maximum weight of any of the walks from A to B, and the weight of each walk is the minimum weight of any of the edges (arrows) involved in the walk. After transitive closure, the maps had a new architecture that included all the possible connections between nodes, with values from 0 to 1 representing the strength of the influence (with one being the highest influence) and positive or negative signs to represent excitatory and inhibitory relationships respectively. After transitive closure, we combined the maps using a weighted average of the strength of the influences [23]. The weight assigned to each map was the cumulative experience of the midwives who made it, defined by the number of them in each.

We used thematic analysis to condense the concepts (nodes) into fewer categories to facilitate the communication of the content [30, 31]. The lead author developed a first level of aggregation using a pattern matching table to arrange the nodes of each map with similar meanings and their corresponding categories (Table 1). Each factor represented an idea that was discussed and agreed upon, with traditional midwives clarifying the words and specifying their meaning. Identifying categories from factors across maps thus incorporated those deeper meanings described in the notes from the mapping session. A group of researchers with extensive experience with indigenous communities in Guerrero, including two who participated in the mapping sessions, confirmed the categories developed in the first aggregation (SP, NA, AC, Abraham de Jesús García, Nadia Maciel Paulino, and Germán Zuluaga). In a member checking exercise [32] in July 2018, IS presented the maps to the traditional midwives who confirmed their agreement with the results of the analysis.

Using the aggregation categories, we described similarities and differences of maps from each municipality (Table 2). A formal comparison between maps identified: (a) validated connections (both maps share the non-zero connection with the same sign), (b) non-validated connections (it is only mentioned in one map), and (c) conflicting connections (both maps include the edge but with different directions). We summarized the cumulative net influence of each category from the thematic analysis as a proportion of total weight for each factor in two steps. First, we calculated the cumulative weight for each category as the sum of weights of the influences of the factors in the transitive closure maps in the corresponding category. Second, we divided each cumulative weight by the maximum total cumulative weight across all the categories in the synthesis map. As a measure of the overall agreement in the cumulative net influence, we divided the total size of all differences (summation of

the absolute value of the differences) by the number of differences. An average difference closer to one indicates less agreement about the weight of the relationships.

Results

The traditional midwives from Acatepec described unsafe maternity as a set of traditional diseases that can affect women, symptoms associated with those diseases, and events that affect the women and their babies' health and well-being. They included two additional categories to describe the concrete events of maternal and infant deaths. When describing safe maternity, in addition to not having a disease, they emphasized the happiness and confidence of the women. Traditional views characterized a healthy woman as one who can give birth at home. In a similar integrated approach to healthy maternity, midwives in Xochistlahuaca explicitly included as outcomes in this category the health status of the offspring and even the health status of the husband.

Risk factors

In the map from Acatepec, participants described 44 risk factors (nodes) with 87 relationships (edges). Xochistlahuaca traditional midwives included 42 nodes and 87 edges. The thematic analysis grouped the nodes into 17 categories of risk factor. Table 1 presents the factors included in each category. Factors with the same meaning in both municipalities align in the same row. Figure 1 presents the fuzzy cognitive map of categories with the highest cumulative net influence. The full adjacency matrix with all the relationships for this map is available as Additional file 1.

The most influential category of risk for unsafe maternity was "not following self-care practices" as defined in the customs and traditions of these communities. These practices can include dietary restrictions, reduction of heavy work, less exposure of mother's body to cold water, or hygiene practices. Midwives from both communities included this category, although the actual contents of these practices are heterogeneous and could be culture specific. During thematic analysis, the researchers recognized that factors in other categories (such as rituals or nourishment) could also correspond to self-care practices, which would increase their relevance within the system. This category appeared as protective in Xochistlahuaca ("The woman follows self-care practices"), but not explicitly mentioned in the Acatepec protection map. Among the risk categories, the midwives identified gender violence and mental health of women ("The woman has worries, feels disgust or nervous during pregnancy") as highly influential (second and third order importance respectively). They described

Table 1 Matching table of the concepts grouping the risk and protective factors

Risk factors in Acatepec		Risk factors in Xochistlahuaca	
<i>Category: The woman does not have a healthy maternity (nor a healthy delivery)</i>			
The woman suffers "Espanto" (fright)		The woman suffers "Espanto" (fright) (traditional disease)	
The woman suffers "Antojo"/Craving		The woman suffers "Antojo"/Craving (traditional disease)	
The woman suffers "Shaime" (traditional disease)			
The woman suffers "Smoke" (traditional disease, different from smoking)		The woman suffers "Nahual" (traditional disease)	
The woman suffers "The evil eye" (traditional disease)		The woman suffers "Coraje" (anger) (traditional disease)	
		The baby suffers "Nquio" (traditional disease)	
Woman's body and face swelling		Woman's feet swelling, abdominal swelling	
Cold / Coldness of the womb		Cold / Coldness	
Hemorrhage (pregnancy)		Bleeding (pregnancy)	
Headache (pregnancy)			
Decreased appetite			
Chills (fever and cold)			
Cough		Flatulence	
		Seizures	
		Weight loss	
		Vaginal discharge, itching	
		Dizziness, nausea, vomiting (during pregnancy and delivery)	
		Painful labor and delivery	
		Vaginal swelling (delivery)	
Breech presentation (delivery)			
Baby wrapped in umbilical cord (delivery)			
Prolonged labor		Prolonged labor	
Tiredness (delivery)		Fatigue (delivery)	
		Seeing flashing lights (delivery)	
		Faint during delivery	
Headache		Headache (delivery)	
Hemorrhage during delivery		Hemorrhage during delivery	
Retained placenta		Retained placenta	
<i>Category: The woman dies</i>			

Table 1 Matching table of the concepts grouping the risk and protective factors (Continued)

Maternal Death	Maternal Death	
Category: <i>The baby dies</i>		
Infant death	Infant death	
Pregnancy loss		
Category: <i>Abnormal position of baby</i>		
Abnormal position of baby	Abnormal position of baby	
Abortion	Abortion	
Category: <i>The woman suffers violence</i>		
Violence (partner or family, sexual abuse, absent father, extramarital children, treats from the father to make her abort)	Violence (domestic violence related with alcohol consumption) Disagreement or fight	
Category: <i>Unsupportive family environment</i>		
Unsupportive family environment		
Category: <i>The woman does not follow protective rituals</i>		
Not following protective rituals (lighting candles in the mountain or prayers)		
Category: <i>The woman does not follow self-care practices</i>		
Practices such as: cooking too close to the fire, using long thread when sewing.	Practices such as: carrying heavy loads, shower with cold water, eating cold tortillas, eating pork, eating too much chili pepper, or not covering the head after delivery.	
Eating forbidden food (a long list of fruits and animals)		
The woman has multiple sexual partners		
Shower with cold water		
Expose to cold environments		
Heavy work		
	Poor hygiene Ignorance of when to push Wrong position while sleeping Sexual relations too early after delivery Drinking alcohol (getting drunk) and infidelity	
Accidents		Category: <i>Accidents</i>
Poisonous animal bites		
Category: <i>Intended spiritual attacks from others</i>		
Intended spiritual attacks from others		

Table 1 Matching table of the concepts grouping the risk and protective factors (Continued)

Envy	
Category: <i>Physical or spiritual imbalance</i>	
Someone with "heavy" sight looks the women	Physical or spiritual imbalances
Category: <i>Primigravida</i>	
Primigravida	
Category: <i>The woman has poor health condition (before pregnancy)</i>	
Category: <i>The woman is poorly nourished</i>	The woman has "weak blood"
Bad nutrition	Bad nutrition
Category: <i>The woman has worries, feels disgust or nervous during pregnancy</i>	
The woman feels nervous during pregnancy	The woman has fright
The woman has fright caused by thunders, animals, or accidents	
The woman feels embarrassment or sadness	The woman finds something disgusting
Category: <i>Unwanted pregnancy</i>	
Unwanted pregnancy	Unwanted pregnancy
Protective factors enumerated in Acatepec	Protective factors enumerated in Xochistlahuaca
Category: <i>The woman has a safe birth and healthy maternity</i>	
The woman is happy	The woman is happy, beautiful, good worker, not lazy, does not get "coraje" (anger). Also, she has a healthy husband
The woman is strong and brave	
The woman is able to give birth at home	A good labor and delivery: healthy pains, less blood loss, fast healing
The woman does not get sick	Healthy postpartum: healthy baby / the woman is willing to eat after labor
Category: <i>The woman has support of a traditional midwife or healer</i>	
Support of a midwife or traditional healer	The woman receives care from the traditional midwife (and she takes care of the position of the baby)
A midwife counsels the husband	Traditional midwives in the community
Category: <i>Healthcare center or hospital is available</i>	
Healthcare centers available	Hospital available (Hospital básico comunitario)
Category: <i>The woman follows protective rituals</i>	
The woman follows protective rituals (lighting candles or indigenous prayers)	The woman follows protective rituals associated with traditional medicine
Praying in the church (Cristian or Catholic) asking for health	

Table 1 Matching table of the concepts grouping the risk and protective factors (Continued)

Category: <i>The woman follows self-care practices</i>	
Category: <i>The woman does not suffer violence</i>	
The woman does not suffer violence	The woman takes care of herself
Category: <i>The woman lives without worries</i>	
Category: <i>The woman has a caring, working, and loving husband</i>	The woman lives without worries
The woman has a caring and loving husband	The woman is well treated by the husband
Category: <i>The woman has good communication with husband</i>	The woman has a caring and working husband
	The husband talks to the baby in the womb
	Good communication with husband
	The woman discusses (talks) with husband about pregnancy and delivery
Category: <i>The woman has a good health condition (before pregnancy)</i>	
Category: <i>The woman has economic stability</i>	The woman does not get sick
	The woman heals from her diseases
	Economic stability
Category: <i>The woman is well nourished</i>	
The woman eats good (enough) food	The woman eats good (enough) food

Table 2 Pattern marching table of the cumulative net influence of each category on maternal health

Risk factors							Protective factors						
<i>Me'phaa</i> Acatepe		<i>Nancue ñomndaa</i> Xochistlahuaca		Final map			<i>Me'phaa</i> Acatepe		<i>Nancue ñomndaa</i> Xochistlahuaca		Final map		
Factors	CNI	Factors	CNI	Validation	Difference	CNI	Factors	CNI	Factors	CNI	Validation	Difference	CNI
<i>Category: The woman does not have a healthy maternity (nor a healthy delivery)</i>							<i>Category: The woman has a safe birth and healthy maternity</i>						
17	0.29	23	1.00	Val.	0.71	0.76	4	0.00	3	0.30	Val.	0.30	0.18
<i>Category: The woman dies</i>													
1	0.00	1	0.00	Val.	0.00	0.00							
<i>Category: The baby dies</i>													
2	0.00	1	0.00	Val.	0.00	0.00							
<i>Category: The woman suffers violence</i>							<i>Category: The woman does not suffer violence</i>						
1	0.11	2	0.46	Val.	0.35	0.34	1	0.50	0	0.00	Nval.	0.50	0.24
<i>Category: The woman has worries, feels disgust or nervous during pregnancy</i>							<i>Category: The woman lives without worries</i>						
3	0.29	2	0.18	Val.	0.11	0.30	0	0.00	1	0.36	Nval.	0.40	0.22
<i>Category: The woman does not follow protective rituals</i>							<i>Category: The woman follows protective rituals</i>						
1	0.11	0	0.00	Nval.	0.11	0.07	2	1.00	1	0.36	Val.	0.60	0.70
<i>Category: The woman does not follow self-care practices</i>							<i>Category: The woman follows self-care practices</i>						
6	1.00	6	0.71	Val.	0.29	1.00	0	0.00	1	0.36	Nval.	0.40	0.22
<i>Category: The woman has poor health condition (before pregnancy)</i>							<i>Category: The woman has a good health condition (before pregnancy)</i>						
0	0.00	1	0.07	Nval.	0.07	0.04	0	0.00	2	0.73	Nval.	0.70	0.44
<i>Category: The woman is poorly nourished</i>							<i>Category: The woman is well nourished</i>						
1	0.04	1	0.09	Val.	0.05	0.08	1	0.81	1	0.42	Val.	0.41	0.65
<i>Category: Abnormal position of baby</i>													
3	0.11	1	0.02	Val.	0.09	0.08							
<i>Category: Abortion</i>													
1	0.04	1	0.00	Val.	0.04	0.02							
<i>Category: Unsupportive family environment</i>													
1	0.11	0	0.00	Nval.	0.11	0.07							
<i>Category: Accidents</i>													
2	0.04	0	0.00	Nval.	0.04	0.02							
<i>Category: Intended spiritual attacks from others</i>													
2	0.21	0	0.00	Nval.	0.21	0.12							
<i>Category: Physical or spiritual imbalance</i>													
1	0.04	1	0.21	Val.	0.17	0.15							
<i>Category: Primigravida</i>													
1	0.04	0	0.00	Nval.	0.04	0.02							
<i>Category: Unwanted pregnancy</i>													
1	0.04	1	0.00	Val.	0.04	0.02							
							<i>Category: The woman has support of a traditional midwife or healer</i>						
							2	0.94	2	0.79	Val.	0.14	0.93
							<i>Category: Healthcare center or hospital is available</i>						
							1	-0.13	1	0.36	Con.	0.43	0.16
							<i>Category: The woman has a caring, working, and loving husband</i>						
							1	0.81	3	1.00	Val.	0.19	1.00

Table 2 Pattern marching table of the cumulative net influence of each category on maternal health (Continued)

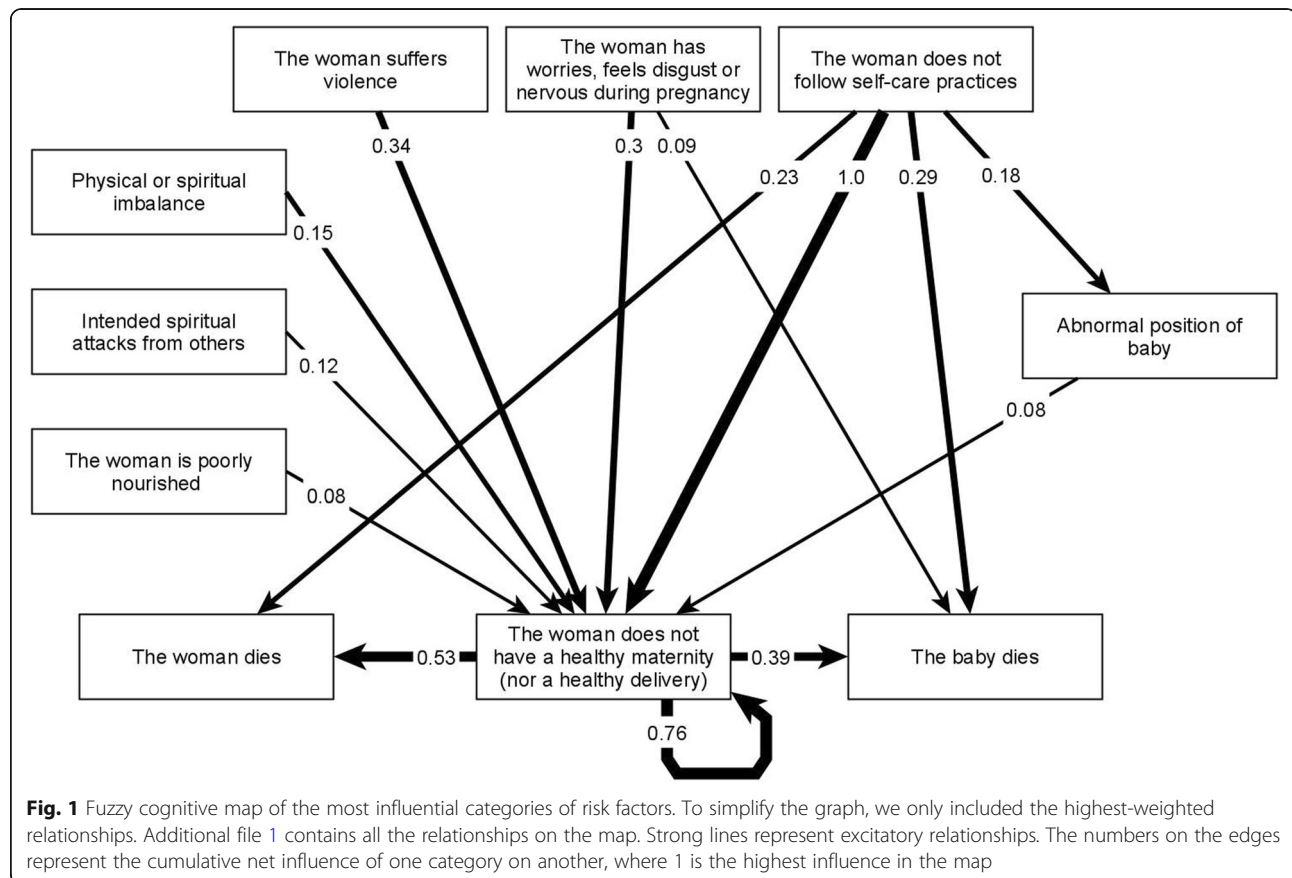
Risk factors							Protective factors						
<i>Me'phaa</i> Acatepe		<i>Nancue ñomndaa</i> Xochistlahuaca		Final map			<i>Me'phaa</i> Acatepe		<i>Nancue ñomndaa</i> Xochistlahuaca		Final map		
Factors	CNI	Factors	CNI	Validation	Difference	CNI	Factors	CNI	Factors	CNI	Validation	Difference	CNI
<i>Category: The woman has good communication with husband</i>													
	0	0.00	2		0.73	Nval.		0.70		0.44			
<i>Category: The woman has economic stability</i>													
	0	0.00	1		0.33	Nval.		0.30		0.20			
44	41			0.14	–		12	18			0.42	–	

factors: number of factors included in the category; Validation: Val validated, Nval non-validated, Con conflictive; CNI cumulative net influence by municipality and final map. Difference: absolute value of the difference between CNI in the two municipalities

an unsupportive family environment as a cause of violence against women.

In the final map, the multi-concept category “the woman does not have a healthy maternity” has a self-pointing edge with a cumulative net influence of 0.76 (Fig. 1). This loop, from the node back to itself, implies that factors within the category influence other factors grouped in the same category. We reviewed the initial maps to identify concepts with greater influence within the category. Three factors showed a strong influence in maternal health outcomes, “cold or coldness of the

womb”, “espanto” (literally translated as fright), and “coraje” (literally translated as anger). They also had a strong influence on maternal and infant death. Both indigenous groups confirmed “coldness of the womb” and “espanto”, but “coraje” was a specific factor for the *Nancue ñomndaa* from Xochistlahuaca (Table 2). Even with translation, the words do not hold an equivalent meaning in English or Spanish. Traditional midwives explained that “coldness of the womb” resulted from exposing the mother’s body to cold elements such as water, fresh air, or certain foods considered of cold



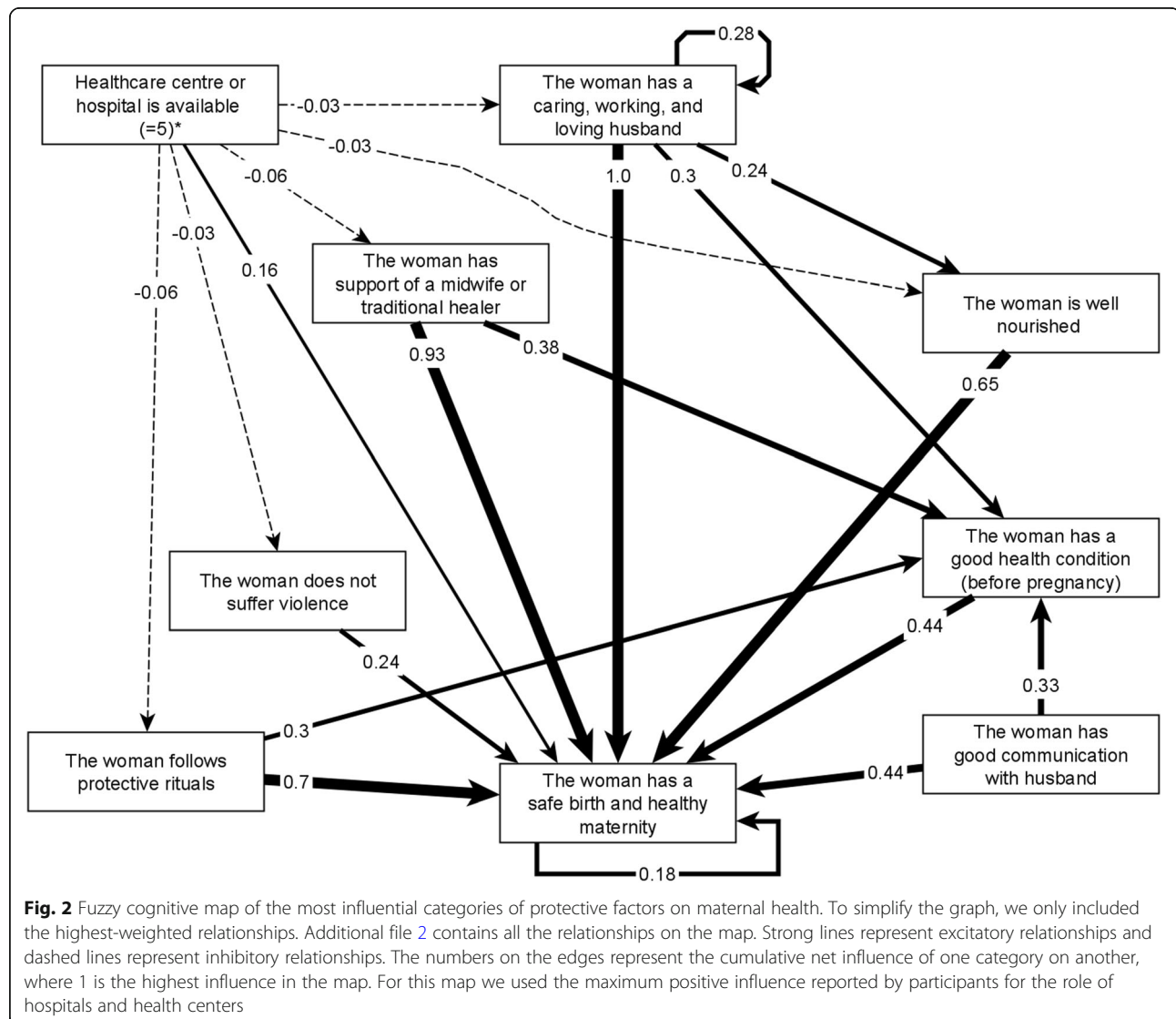
nature. They explained the womb needs to remain warm to allow for the correct development of the baby and to function properly during delivery. The concept of “espanto” (fright) describes a strong emotional impact that alters one’s mental health. Examples include violence, an animal attack, or an accident. They explained that “coraje” (anger) as caused by an imbalance produced by violence, not necessarily directed at the woman, that affects the “aire” (air) or environment of the mother and consequently affects her health.

Protective factors

In Acatepec, traditional midwives reported 12 protective factors (nodes) with 38 relationships while in Xochistlahuaca, traditional midwives included in their map 18 nodes and 31 relationships. The thematic analysis condensed the protective factors into 12 shared categories (Table 1). Figure 2 presents the

map of the strongest protective factors and Additional file 2 has the full adjacency matrix with all the relationships among categories. Protection maps highlighted the importance of male support (described as having a caring, working, and loving husband) and support from traditional midwives in promoting maternal health. Midwives in both municipalities mentioned both these two factors (Table 2). They rated protective rituals and access to adequate food for pregnant women in third and fourth place for influence. The map also showed the influence of protective factors over the intermediate outcome of women’s health condition before pregnancy (Fig. 2, category P10 in Additional file 2).

In line with the risk map, the map of protective factors showed non-exposure to violence as a strong influence. The map showed how other factors were protective through decreasing the levels of violence that women



experience. These factors included counseling by traditional midwives, protective rituals, access to food, economic stability, and having a caring husband. Having a caring husband was validated across both indigenous groups. The map of protectors included other “mirror images” of risk categories for mental health of women, practicing protective rituals and self-care practices, good nutrition and health condition of the women before pregnancy (at the top of Table 2).

One category, “Healthcare center or hospital is available”, had a conflictive validation. Acatepec midwives showed it as a negative influence on safe maternity whereas it was a positive influence in Xochistlahuaca, where it was the only relationship for which participants did not reach consensus (Additional file 2). Individual traditional midwives weighted its protective influence on women’s health between no protective effect at all (0) and a high positive effect (5). Per protocol, we sought reasons for this divergence: one participant wanted to assign a 5 and the others were discussing between 0 and 1. The participant who suggested a weight of 5 was a very experienced traditional midwife who was well-respected by the medical staff at the healthcare center, suggesting that strong inter-professional and cross-cultural relationships can greatly change the role that healthcare centers can play in indigenous communities. Additional file 2 includes an additional row to present the variation of the cumulative influence when assuming a positive effect of five or no-effect in the map from Xochistlahuaca. The negative effect assigned in the map from Acatepec not only affected safe maternity, but also had negative impacts on other categories, particularly those related with the services of traditional practitioners, following traditional rituals, male involvement, violence against women, and access to food (dashed lines in Fig. 2). These effects did not emerge in the Xochistlahuaca map.

Discussion

We used fuzzy cognitive mapping to document traditional indigenous knowledge related to maternal health. FCM is particularly useful in multicultural contexts, as it can be used across language barriers and educational levels [20]. Fuzzy cognitive mapping offered a transparent and systematic way to organize and to summarize indigenous views despite intercultural differences. Traditional midwives described a broad understanding of maternal health that included their well-being and their surroundings. This comprehensive approach to health highlights the need for better indicators, measures, and benchmarks to assess quality of care [33]. We will use the models to support discussion of future actions to promote maternal health with health providers and community members.

The views of indigenous traditional midwives on maternal health in their communities included a complex set of concepts and relationships. Prominent among the risk factors mentioned by the traditional midwives were failure to follow traditional practices of self-care, those associated with cultural concepts of disease (“espanto” (fright), “coraje” (anger), and “coldness of the womb”), and women’s mental health and experience of violence. Among the protective factors, male involvement (having a caring, working, and loving husband), support of traditional healers, protective rituals and adequate nourishment were most influential.

The literature is replete with examples of traditional practices for childbirth and maternal health [34–39]. Traditional practices associated with maternal health are best viewed as complex interventions with many interacting aspects. This makes it difficult to tease out the key element in any change [40]. Despite this lack of understanding, potential benefits or harms of these practices are usually defined authoritatively from a conventional medicine perspective [41]. A cultural gap prevents many of us going beyond initial judgements of implausibility based on Western world-views. This in turn hampers research on the etiology, symptoms, and indigenous health concerns [1]. Methods like FCM can help to document and interpret traditional practices, thus helping to bridge this gap [16, 42]. With these methods in hand, Western epistemological frameworks need not go unchallenged in intercultural settings [43, 44].

The culturally specific conditions listed by the traditional midwives are not limited to pregnancy and childbirth. A study of Mexican populations in the United States associates “espanto” (fright in English also called *susto* in Spanish) with the onset of type 2 diabetes [45]. Other studies present “espanto” as the somatic expression of psychiatric disorders, often as a consequence of domestic violence or other traumatic experiences [46]. And some other authors see these diseases as physical consequences of unfulfilled social expectation, inequities, or harsh environmental conditions [47–49]. The cold-hot dichotomy associated with “coldness of the womb” is a theory of disease etiology found in traditional health systems of indigenous groups in the Americas, Africa, Europe and Asia [40]. The concept is complicated by the relative independence from temperature as understood in conventional medicine [50]. Recent reports suggest an association, however, between this indigenous classification of diseases and physical responses to chemical stimuli of medicinal plants for their treatment [51].

Traditional midwives promote male involvement and increase family and community support for women. Supporting them in this role can use existing cultural dynamics to promote positive change, for example to

decrease domestic violence [52]. Reducing the role of traditional midwives to “birth attendants” ignores the crucial fact that they also work as counselors of women, men, families and communities in general. Even those who advocate replacing traditional midwives with practitioners trained in conventional medicine acknowledge it is worth keeping positive aspects of their role: “the sense of caring, the human approach, and the response to cultural and spiritual needs” [53].

The map of protective factors also highlighted traditional rituals of fertility and proper nourishment of women. The health effects of traditional rituals remains an unexplored field with significant methodological challenges, mainly associated with the multifactorial nature of these interventions [5, 54], as we have explained before for the category of self-care practices. Poor nutrition is an important concern for populations like those in our study, who have a disproportionately lower income, depend on subsistence agriculture, and have been displaced to less productive land. Poor nutritional indicators are common among indigenous communities [55], which often suffer from structural inequities [56]. Cultural continuity and preservation of local resources, both goals of a culturally safe approach, can improve food security among indigenous groups [57].

Strengths and limitations

The advantages of FCM are several. It takes only a short time necessary to summarize a lot of information. The graph language facilitates data collection, analysis, and interpretation across cultural, language and educational barriers, and it is easily adjusted for different knowledge systems [20]. It can take into account complex socio-cultural mechanisms that effect the well-being of women, offspring and communities [33]. It is easy to share knowledge in an accessible form to facilitate discussion with others and can facilitate intercultural dialogue [19] to improve the interface of indigenous communities with conventional medicine.

In research, fuzzy cognitive mapping helps to summarize participant views of causality. The maps can identify theories of change and frame hypotheses for empirical research and decision making. The bigger project with indigenous communities in southern Guerrero used a parallel group randomized controlled trial to test some of the causal relationships in the maps, particularly the influence of traditional midwifery on health outcomes [17]. The maps also opened opportunities for evidence-based conversations to deepen our understanding of the factors involved in safe birth [58].

One risk category defined with the midwives to consolidate the maps turned out to be larger than other categories and it included what seemed like heterogeneous factors. At first glance, for example, “coldness of the womb” seems

very different from “hemorrhage”. But for traditional midwives hemorrhage is the outcome of coldness and it can lead to the death of a woman. Category maps are models of individual concepts generalized to a larger scale, which simplify the contents to facilitate communication. But scale matters, and interpretation of maps has to follow the level of generalization of the model [59]. We cannot assume that relationships between categories apply equally to all the factors within those categories. Doing so would constitute a cross-level fallacy [59, 60]. It is possible to unpack aggregated category maps by going back to the transitive closure maps to identify specific paths through which individual factors influence each other.

Interpretation across languages is a challenge in most intercultural settings, especially when full translation is not practical (as in a group discussion). As researchers, we made several assumptions during the thematic classification of factors and the overall weight assigned to the maps from the two groups to calculate the weighted average. We documented these assumptions so their impact in the analysis can be assessed. Member checking with the authors of the maps encouraged us to believe that researcher assumptions during the analysis did not contradict the meaning of the information the traditional midwives provided. The mapping exercise took place in the context of years of work and trust building with the communities concerned, and it was greatly helped by the involvement of local personnel with skills and experience in intercultural dialogue. Implementing a similar exercise in settings without a history of collaboration would be challenging.

Conclusions

Fuzzy cognitive mapping provided a robust way to summarize and to value the complex knowledge of indigenous midwives. In our example, the maps identified locally relevant cultural concepts related to maternal health in Guerrero State. Better understanding of these could promote collaboration and help to defuse disagreements between conventional health services and indigenous communities; thus, increasing the effectiveness of perinatal care in those disadvantaged communities.

More broadly, fuzzy cognitive mapping is a tool for indigenous and other marginalized communities to communicate their way of seeing things to health authorities and to open discussions about health initiatives. In combination with maps from other sources, such as researchers or published literature, the maps can be used to develop composite theories of change. They can identify key factors for inclusion in questionnaires and to frame health outcomes and weight stakeholder prior beliefs to serve in Bayesian analysis. From clarifying the causal concepts through to formal statistical analysis, fuzzy cognitive mapping helps to build the voices of indigenous participants into modern health research.

Supplementary information

Supplementary information accompanies this paper at <https://doi.org/10.1186/s12874-020-00998-w>.

Additional file 1. Adjacency matrix of the final map showing categories of risk factors for maternal health in the South of Guerrero.

Additional file 2. Adjacency matrix of the final map showing categories of protective factors for maternal health in the South of Guerrero.

Abbreviations

CIET: *Centro de Investigación de Enfermedades Tropicales*; FCM: Fuzzy cognitive mapping

Acknowledgements

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Authors' contributions

IS designed and conducted fieldwork, conducted the analysis and drafted the first manuscript. SP developed the collaborative work with traditional midwives and advised the field procedures. DL and AD provided advice for the methods and interpretation of results. AC and NA supervised the research process and guided the application of FCM. All the authors contributed to the final version of the manuscript.

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Availability of data and materials

The datasets generated during or analyzed during the current study will be available upon request from CIET. Before the information can be shared, the requester will need to present a plan for data analysis. Also, the requester will need to complete the procedure for ethical approval of the secondary analysis in accordance with the procedures defined by the Ethics Board of the *Universidad Autónoma de Guerrero* and the agreements with communities to ensure the protection of the participants.

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Consent for publication

Participants authorized the publication of the results during the mapping sessions. They confirmed this authorization on July 2018 during the member checking sessions to review the results.

Competing interests

The authors declare that they have no competing interests.

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Appendix 7: Combining conceptual frameworks on maternal health in indigenous communities -- Fuzzy cognitive mapping using participant- and operator-independent weighting

I am a co-author on this publication as I contributed to both the methodology applied in this study and to the analysis of the findings. This manuscript is accepted for publication in Field Methods.

Combining conceptual frameworks on maternal health in indigenous communities -- Fuzzy cognitive mapping using participant and operator-independent weighting

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Abstract

A recurring issue in intercultural research is whose knowledge informs conceptualisation and design of projects or interventions. Fuzzy cognitive mapping uses arrows and weights to represent stakeholder knowledge on causal relationships and can generate composite theories to inform research and action. Cognitive mapping is accessible across different cultures, but participant weighting is not always straightforward. We describe a procedure to combine and to condense maps from different stakeholders and an alternative operator-independent weighting procedure adapted from Harris' discourse analysis.

As part of an initiative to contrast conceptual frameworks of intercultural researchers and traditional midwives, eight intercultural researchers each produced a map of factors they saw contributing to maternal health in indigenous communities. We compared the strength of each factor's outgoing arrows and the influence of categories of factors between participant- and operator-independent weighting. The maps from both procedures reflected the perspectives of the eight researchers in a consistent way. Almost identical condensed maps from the two weighting procedures suggests Harris' discourse analysis is relevant in exploratory inquiries using fuzzy cognitive mapping.

Introduction

Grounded knowledge synthesis incorporates information from experience and local realities or cultural contexts (Andersson 2018). Combining stakeholder perspectives with formal literature is often an effective basis for local decision-making and action (Davidoff et al. 2015). A recurring issue in intercultural research is whose knowledge should inform project conceptualisation and design. A related concern is how to contrast or to combine different theories or knowledge, some from standard literature reviews and others from informal knowledge.

Fuzzy cognitive mapping (FCM) has been used to combine different perspectives into composite theories that inform research and action (Andersson and Silver 2019; Giles et al. 2008). Cognitive maps are directed graphs composed of three elements: factors (causes or outcomes), relationships between factors, and weights of relationships. The maps depict causal factors as nodes linked by arrows to describe how changes can happen (Harary, Norman, and Cartwright 1965). The maps are graphic forms sharable across different cultures and literacy levels. They collate complex knowledge as multiple sets of relatively simple components of cause, link and outcome. As long as each component cause and outcome can be identified or translated into the same language or symbols, the language or culture of authors of each individual map does not affect interpretation. A common communication format for different cultural backgrounds facilitates intercultural dialogue and the synthesis of evidence from multiple sources.

FCM recognises uncertainty and accepts that multiple answers exist for the same question (Kosko 1994). Instead of using a binary indicator such as an arrow or no arrow to define certainty of relationships in the map, fuzzy maps allow a range of weights allocated to the relationship (arrow). Since causal knowledge is often uncertain and different from the viewpoints of different stakeholders – for each of whom it might feel certain – FCM allows modelling of “hazy degrees

of causality between hazy causal concepts” (Kosko 1986a:1). The technique provides a visual representation of different knowledges (Andersson and Silver 2019) using well-established analytical tools (Felix et al. 2019). These maps can represent cyclic dynamics (Gray, Zatre, and Gray 2014; Osoba and Kosko 2019) when a factor is both a cause and an effect of another or when a self-pointing arrow indicates reinforcing internal dynamic (Osoba and Kosko 2019).

Intercultural researchers have used fuzzy cognitive mapping to explore indigenous perspectives on maternal health (Sarmiento et al. 2020) and to examine how stakeholder perspective vary from and expand upon published literature in diabetes and maternal health (Dion et al. 2019; Giles et al. 2008). The *Weight of Evidence* method uses FCM to contextualise literature-based evidence according to the knowledge of relevant stakeholders (Dion et al. 2020). Previous FCM analysis with multiple stakeholder groups in Canada (Tratt et al. 2020), Mexico (Sarmiento et al. 2020), Nigeria (Sarmiento, Ansari, et al. 2020), Uganda (Belaïd et al. 2020) and Botswana, combined multiple maps within each stakeholder group. Matching and reduction of concepts juxtapose concepts across maps, before consolidating individual maps into a single collective combined one (Papageorgiou and Kontogianni 2012). Combined maps are easier to communicate as there is less to visualise, but the process of combining maps can be easily influenced by the researchers, raising concerns about whose views are ultimately reflected in the maps (Andersson and Silver 2019).

An additional concern is that weighting the strength of relationships on the maps increases the length of the mapping sessions considerably, which risks reducing participant engagement. This challenge is more significant when multiple participants build the maps. In some concepts of causality, an outcome is the result of all interactions across the whole system. Although the elements can be identified, their working together defies weighting the influence of any one component against another. FCM is relatively simple to do and easy to understand by participants

from different backgrounds (Gray et al. 2012), but weighting of relationships is challenging for stakeholders who do not, as part of their culture, parse elements of causality (Tratt et al. 2020). In these views of causality, establishing a hierarchy of factors that contribute to an outcome may be incompatible with their overall understanding of an issue

Research context and objectives

This project is part of the Safe Birth in Cultural Safety project in Mexico, which aimed to improve maternal health outcomes in indigenous groups without undermining their culture or identity. This approach recognized equal value of indigenous and Western knowledge and aimed to bridge them through an intercultural dialogue in the search for solutions. The project used FCM to contrast and to combine three knowledge sources about factors that affect maternal health in indigenous communities. The first two sources were traditional midwives in the South of Guerrero state (Sarmiento et al. 2020) and a literature review of published and unpublished evidence (Sarmiento, Paredes-Solís, et al. 2020). This paper describes the third source, researchers with experience in indigenous health promotion. We introduce a procedure to combine and condense maps made by different stakeholders. We also describe and test an alternative procedure to calculate the weights of relationships within the maps, as an alternative to obtaining the weights directly from mapping participants, and compare the results obtained from the two weighting approaches.

Methods

We invited eight international researchers with extensive experience in culturally safe health promotion to participate in online sessions to map their understanding of factors affecting maternal health in indigenous communities in 2019. All the researchers had contributed to our work in Mexico (Sarmiento et al. 2018). Supplemental material 1 shows characteristics of the participants.

Drawing maps and initial rationalisation

FCM participants (mappers) can create maps individually or in groups to describe their knowledge of complex systems one relationship at a time. They begin with the factors (nodes), then show how they are related to one another (arrows), and then weight the strength of the relationships.

Individual FCM sessions followed a standardised protocol (Andersson and Silver 2019). We opted for individual sessions to accommodate the busy schedules of researchers and, given the different backgrounds of the researchers, to reflect as much as variation in perspectives as possible. The lead author (IS) provided each researcher with a guide about the process before facilitating individual mapping sessions. After informed consent, IS drew the maps using yEd (yWorks 2017) following the mapper's directions and recorded each session to document discussions behind each decision. The mappers indicated the factors, relationships and weights. They then rationalised their maps by identifying duplicated concepts and unnecessary distinctions between similar factors to reduce their number. Mappers weighted the causal influence of each relationship using a scale from one for the weakest to five for the strongest. To facilitate weighting, the lead author asked two "if-then" questions for each relationship in the map (Stylios, Groumpos, and Georgopoulos 1999). First, if (the origin factor) increases, then would (the resulting factor) increase or decrease? Weights were positive for the former and negative for the latter. Second, if (the origin factor) increases, then would (the resulting factor) rarely change (weight of 1) or very often change (weight of 5)? After each session, each mapper received an electronic version of the individual map to confirm the content.

Combination

We calculated the fuzzy transitive closure (Niesink, Poulin, and Šajna 2013) for each map, and combined the results into a single average map. Transitive closure is an algorithm that identifies all the possible paths between factors and calculates the total influence that one factor might have

on another when all the possible paths between those factors are considered. Fuzzy transitive closure implies that indirect relationships between factors are only as strong as the weakest weight within the paths between them. It is the algorithm of choice when the number of factors and relationships differ across maps (Niesink et al. 2013).

We used a pattern matching table (Supplemental material 2), in which each column reflects one map with factors in the map arranged by rows to line up with the factors of the other maps that share meanings. We used the row label as the standard name for factors mentioned in several maps. Sometimes the map authors described the same factor but as opposites in name and weight. For example, one map included violence with a negative effect on maternal health, while another included “no violence” with a positive effect on maternal health. Before combining the maps, we adjusted these differences. If one factor in a causal chain had to change from a positive to a negative relationship, the sign of the relationship would change. If both factor and outcome changed, the sign of the relationship remained the same.

Once all factors on the maps received a standard name, we calculated the average weight for each relationship. The resulting value was the sum of all the weights for that relationship across the maps divided by the total number of maps in the set (Kosko 1986b). The average is a simple way to combine stakeholder maps with equivalent perspectives and relevance. Weighted averages or Bayesian updating can help to adjust for differences in expertise, relevance or uncertainty around the weights (Dion et al. 2020). Group discussion among mappers can also be a way to define summary values for the relationships in a combined map.

Condensation

Condensation reduces the number of nodes and relationships by grouping them. Condensation helps to avoid semantic differences that might hide similar meanings of concepts and facilitates

combining multiple maps (Papageorgiou and Kontogianni 2012). It is particularly useful when a large number of factors hinders interpretation. A qualitative step identifies categories, and a quantitative step condenses factors and calculates the influence of each category (Gray et al. 2012; Özesmi and Özesmi 2004). We followed principles of coding and categorisation (Saldaña 2016) for the former and principles of directed graphs theory (Harary et al. 1965) for the latter.

Defining categories

Categorisation allows organisation and grouping of factors based on shared characteristics (Saldaña 2016) relevant for the research question that represent some level of patterned response or meaning within the data set (Braun and Clarke 2006). Using inductive analysis, the lead author initially arranged the factors in the maps into categories, aided by the records from the mapping sessions. In a member checking exercise (Birt et al. 2016), each of the eight mappers examined the categories and suggested any necessary adjustments. After two iterations, the participating researchers agreed on a final set of categories. The matching table (Supplemental material 2) shows the final classification.

Condensation of factors and category weights

Harary (1965) initially described condensation in the analysis of unweighted directed graphs as the process of reducing parts of the map (nodes and arrows) into single nodes and arrows. Several authors have described procedures for condensation (Balakrishnan 1995; Iwasaki and Simon 1994; Louati, Aufaure, and Lechevallier 2011; Sterling 2004) based on the weights of nodes, arrows or both. Here, we used only the arrow weights because mapping sessions focused on weighting the relationships between factors, rather than the factors themselves. Condensation of factors followed a qualitative procedure.

We renamed the factors (nodes) in the combined map described above (under subheading Condensation) with the agreed-upon categories. We then listed all the relationships in the map to indicate one cause and one outcome linked by an arrow. Condensation is equivalent to aggregating multiple sub-maps (sub-graphs) each corresponding to a relationship (cause-arrow-outcome). We then added the weights of all the relationships with the same category names (Kosko 1988). The resulting list had the relationships of the map condensed at the category level. In this map, the weights of each arrow indicated the strength of the influence of one category on another, and we normalised these weights into a range between 0 (no relationship) and 1 (the maximum category weight) to facilitate comparability. If an initial and landing factor belonged to the same category, condensation will result in a self-pointing loop indicating reinforcing dynamics within the category. Loops are common results of operations with maps (Osoba and Kosko 2019). Supplemental material 3 has a step by step graphical description of the condensation process.

Following the same procedure, we then generated a condensed map for each of the eight individual maps. The comparison of these eight condensed maps identified: (a) validated connections (all maps share the non-zero connection with the same sign), (b) non-validated connections (the connection is not mentioned in all the maps), and (c) conflicting connections (the connection is positive in some maps and negative in others). As described elsewhere (Sarmiento et al. 2020), we used a similar process with traditional midwives to identify shared and conflicting views to develop intervention strategies grounded in community understanding of maternal health.

Harris' discourse analysis and comparison with participant weights

Zellig Harris proposed the earliest formal discourse analysis in the 1950s to explore meaning based on the frequency of occurrence of discourse elements (Harris 1952). The approach identified the role of morphemes (part of a word, word or several words with an irreducible meaning) exclusively

from their relative frequency in the text without assuming any prior meaning for them. The comparison of frequencies between texts allowed Harris to identify similar structural meanings of morphemes. Harris' analysis thus collated the patterns of relationships between words (internal structure) to understand how interactions between words held meaning. Because it was based on frequency of occurrence, among other criteria (partial order, redundancies and dependencies), it did not depend on the researcher assumptions of meaning. This operator/researcher independence is a major advantage in the intercultural context.

We applied the concept of morpheme frequency across different maps to establish weights of causal relationships between two factors. A factor that caused an outcome across multiple maps would have stronger influence than a factor that causes the same outcome only on one or two maps. In the eight original individual maps of the independent researchers, we ignored the participant weights. We kept only the indication of whether a mapper said a causal relationship and whether it was positive or negative. We used a weight of 1 if the relationship was on the map and 0 if it was not. For the relationships with weight 1, we maintained the sign (positive or negative) as indicated by the mappers. The analysis started by calculating the transitive closure of each map to identify direct and indirect relationships, revealing the internal structure of the map (Niesink et al. 2013). We then calculated the number of times each relationship repeated across all the individual transitive closure maps and established their relative frequency by dividing each occurrence by the highest frequency across the eight maps. Thus, we obtained a value between 0 for the relationships that did not exist and 1 for the relationship that was most frequently mentioned. We then used the same procedure described before to create a condensed map.

To compare participant-weighting and Harris' discourse analysis at the factor level, we calculated outdegree centrality on the combined maps (described above) as the sum of the absolute values of

the weights for each factor's outgoing edges (Papageorgiou and Kontogianni 2012). This measure indicates the total strength of the factor in terms of its outgoing relationships (Gray et al. 2012). Higher outdegree centrality suggests a higher level of influence of one node in the map and signals actionable factors, that could be of interest to promote change. The free software yEd (yWorks 2017) generated this and a graphical output scaling the size and position of the factors in a relative order from the highest to the lowest for each map. To measure the overall agreement of category weights between participant-generated and operator-independent weights, we calculated the average of the absolute value of the difference in weights. A small average difference indicates similarity of the weighting approaches and higher values indicate less agreement.

Results

For the eight researchers, maternal health was a broad concept that included all aspects of woman's wellbeing during pregnancy, childbirth and postpartum periods, including for example the spiritual dimension, the physical condition and positive mental condition. The eight individual maps each identified between 10 to 24 causal factors for maternal health, and between 32 to 99 relationships between those factors – between 1.9 and 4.3 relationships per factor. The eight maps together identified 106 unique factors, which we grouped into 12 categories, linked by 886 relationships identified after transitive closure.

The values of all the relationships in the condensed maps are available as Supplemental material 4. We describe below the three categories with the highest influence on maternal health based on 330 relationships between 67 factors identified after transitive closure. Figure 1 presents a sub-map of the relationship at the category level and the factors involved in the strongest internal dynamics of each category.

Figure 1. Map of the three strongest categories and their internal dynamics

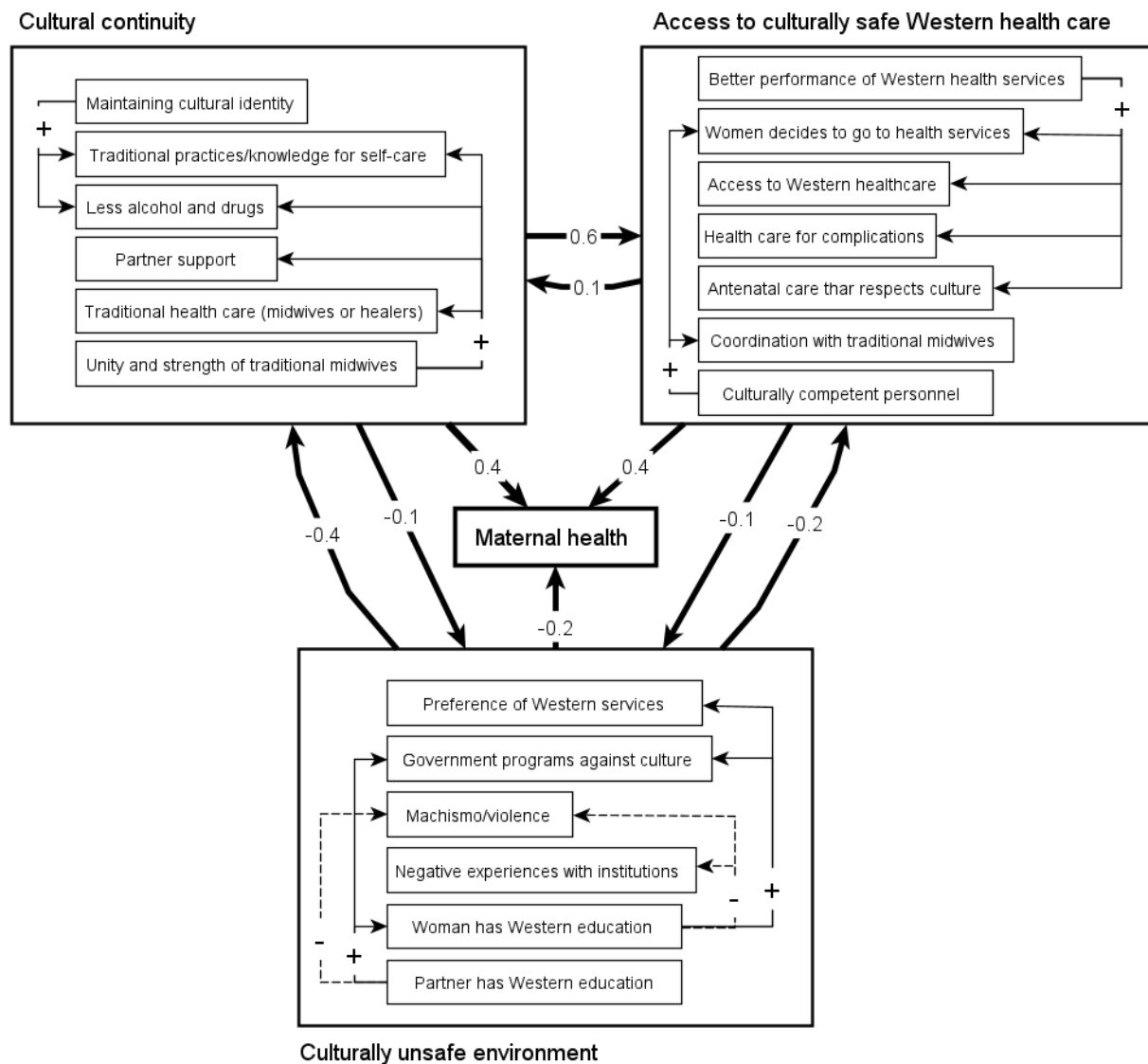


Figure 1 Map of the three strongest categories and their internal dynamics

Legend: Each box corresponds to a category and the thick arrows to category-level relationships. Within the categories some factors had positive and negative interactions, thus indicating internal dynamics.

Cultural continuity included maintaining indigenous identity and support of traditional midwifery as the two most influential factors (higher outdegree). This category also included spiritual

practices, access to traditional midwifery, following traditional self-care practices (diets, purge, menstruation care etc.), and respectful behaviour in the family. A self-pointing loop described the reinforcing dynamics of maintaining identity in higher engagement with self-care practices, including traditional diets, and less use of alcohol and drugs. The reinforcing role of traditional midwifery was reflected through a range of paths, including: more self-care practices, more support from traditional midwives for women during pregnancy and delivery, more positive partner attitudes and less alcohol consumption. This category was validated across all the maps.

Access to culturally safe Western health care included quality and accessibility of health care services, especially for complications, as the most influential factors (higher outdegree centrality). Other factors in this category referred to respectful health care and antenatal care within an intercultural framework, coordination with traditional midwives, and cultural competence of health personnel. A prominent self-pointing loop depended on a better performance of health services that contribute to women's decision to seek care and increasing access to health services; and the impact of culturally competent personnel on increasing coordination with traditional midwives and reducing women's delay in deciding to visit health services.

A culturally unsafe environment had a negative impact on maternal health, decreased access to Western medicine and impaired cultural continuity. This category included institutions and programs that do not value indigenous culture, religious missionaries or Western education that replaced cultural values, structural or personal racism, loss of territories, negative experiences of indigenous people in their interaction with Western institutions, a culture of violence and inadequate communication strategies. The most influential factors according to their outdegree centrality were Western education of the woman and her partner guided by Western values with

ambiguous positive and negative effects. Another category with negative, although weaker, influence on maternal health was *woman's comorbidities*, particularly diabetes.

Comparison of participant and Harris' discourse analysis weights

All but one of the ten factors with the highest outdegree centrality in the participant-weighted consolidated map coincided with the top ten in the Harris' discourse analysis consolidated map (Supplemental material 5 shows the outdegree centrality of each factor). The order of importance as cause across the system varied for these factors (Table 1). When we considered only the influence on maternal health, the strongest factors were *previous poor health conditions of the woman* in the discourse analysis map and *maintaining cultural practices* and *support from a traditional midwife* in the participant weighted map.

Table 1. Factors with higher outdegree centrality

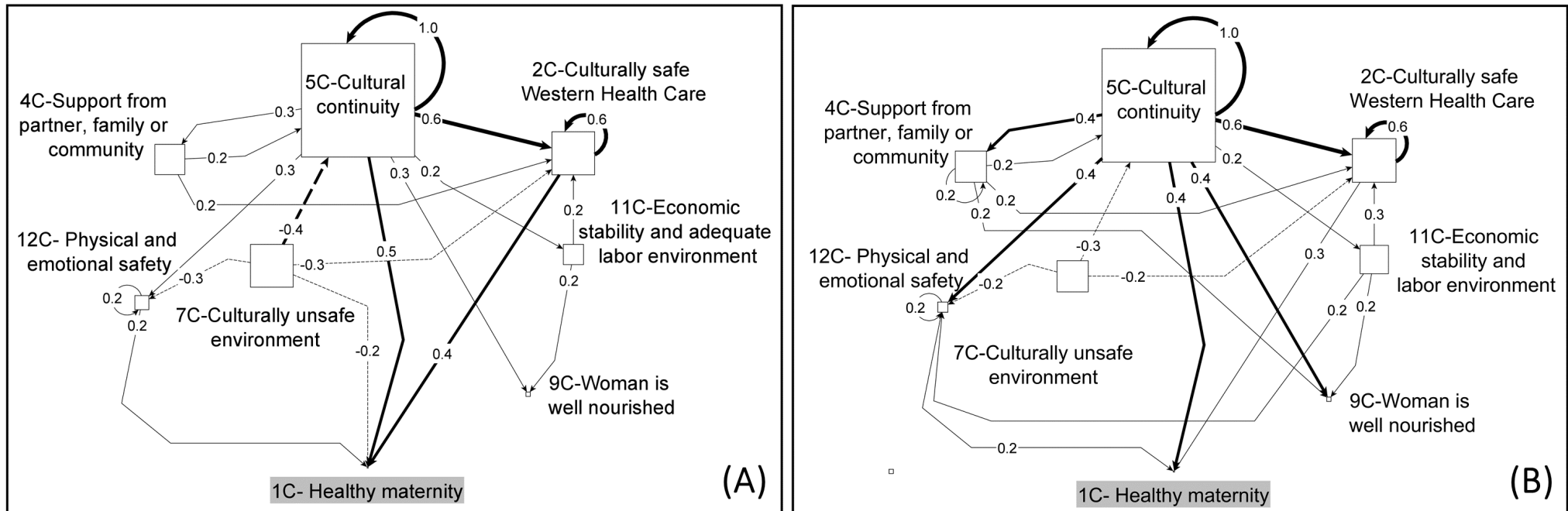
Centrality (and order) in participant-based weights			Centrality (and order) in Harris' discourse analysis	
Support from partner or family	1.00		1.00	Support from partner or family
Woman has caring and working husband	0.99		1.00	Support from the community
Western health services are available	0.90		1.00	Western health services are available
Maintain the cultural identity	0.88		0.97	Woman has Western education
Woman has Western education	0.87		0.90	Traditional practices (food, purge, others)
Woman's economic stability	0.86		0.90	Woman has caring and working husband
Strength and unity of traditional midwives	0.85		0.83	Strength and unity of traditional midwives
Support from the community	0.80		0.79	Woman's economic stability
Traditional practices (food, purge other)	0.76		0.69	Maintain the cultural identity
Western education against culture (community) ^a	0.74		0.62	Traditional midwives in the community

^a These factors did not appear among the most important factors identified by the other weighting procedure.

Figure 2 shows the condensed maps with each node scaled according to its outdegree centrality. The condensed maps showed an almost identical internal structure, whether based on participant- or discourse analysis weighting. Both similarly identified those categories with stronger influence in the system. The average difference of relationships between the two weighting procedures was

0.01, and the largest difference was 0.1, for the effect of *woman's comorbidities* on *maternal health*. *Cultural continuity* had the highest outdegree centrality or the strongest influence on the system for both weighting procedures. Similarly, in the second and third order of importance of both *condensed maps* were *culturally unsafe environment* and *access to culturally safe Western health care*. These two categories also had the most prominent positive influence on *maternal health* (Figure 2).

Figure 2. Map of categories affecting maternal health in indigenous communities



Legend: The figure compares the condensed maps obtained from participant-based (panel A) and discourse analysis weighting (panel B). To simplify the graph, we only included the relationships with the five strongest levels of influence. Appendix B contains all the relationships on the map. Solid lines represent positive relationships and dashed lines negative ones. The numbers on the edges represent the cumulative net influence of one category on another, where 1 is the highest influence in the map.

Discussion

The combined map is a soft model (Strickland 2011) of the views of eight knowledge sources (independent researchers) about influences on maternal health in indigenous communities. The researchers shared several characteristics, including positive attitudes towards participatory approaches and respect for indigenous traditions. The purposive sampling explains the prominence of indigenous cultural continuity and cultural safety as strong positive influences. Recognition of these influences is growing (Curtis et al. 2019), particularly in the Americas, where indigenous groups are vocal about the value of their worldview and knowledge (Dietz 2018; Walsh 2008). At best, however, the soft model generated by these experienced intercultural researchers would only be generalisable to a certain type of intercultural researcher, not all researchers.

Fuzzy cognitive mapping offers a sharable language to collate knowledges from multiple sources. Combining maps offers a partial answer to uncertainty about the “correct” knowledge of causes of a particular outcome (Kosko 1986b). Peirce proposed a pragmatic response to uncertainty of beliefs as “the final opinion”, the one which is fated to be ultimately agreed to by all who investigate it. (The Peirce Edition Project et al. 1998). Although new inquiry may modify what is known about something, the aggregation of knowledge contributed by an indefinite community of inquiry reduces uncertainty (Kosko 1994).

In conventional research, researchers trained in Western scientific methods have conventionally held a monopoly of inquiry. FCM extends the boundaries of what could be included in research synthesis (Dion et al. 2019). This expansion of what is perceived as valid knowledge is particularly relevant for indigenous groups who have developed complex bodies of knowledge, know-how and practices over many generations (International Council for Science 2002), and whose knowledge has been systematically ignored for centuries (Santos 2009). Increased collaboration across

cultural differences opens space for intercultural dialogue (Dietz 2018; Pérez Ruíz and Argueta 2011), a communication process in which different parties contribute their knowledge to identify solutions for a shared concern (Council of Europe 2008).

Participant weighting of influence and Harris' discourse analysis of the frequency of relationships showed very similar outdegree centrality for the ten most important individual factors and almost identical broader categories. Harris' discourse analysis uses binary indicators of the presence or absence of a relationship *across multiple texts* or, in this case, across multiple maps. This analysis cannot work for a single map. Our application of discourse analysis considered each cause-outcome set as we would consider a similar causal concept in an interview/discussion. Our intention was not to eliminate participant weighting of influence, but to adapt FCM to stakeholder settings where participants declined or could not generate the weights.

Limitations and challenges

The causal relationships in the maps is a soft model of participant knowledge and, as such, bound to be partial. One makes the models not so much for prediction as for learning about how different stakeholders see possible paths that would lead to an outcome (Mingers 2006). In this application, FCM allowed us to present perspectives of a small number of participants with similar viewpoints about maternal health. The smaller the number of maps, the less amenable this would be to Harris' discourse analysis and the generalizability of results.

Condensation of factors into categories carries the risk of any summary of complex information from multiple sources (Louati et al. 2011). Categories are an abstraction to deal with different framing of factors across individual perspectives (Felix et al. 2019). In our case, we included map authors in the categorization process, an option that might not always be available.

Analysis at this higher level of abstraction (categories) often addresses structural issues, like behaviours shared by groups or maintained for a long time, often overriding important details within the categories. We should thus not infer factor level conclusions from category level results. A relationship between two categories does not imply that all factors in one category will have the same summary influence on all factors in the outcome category (Harary et al. 1965). Once categories help to clarify the general picture, it may be appropriate to revert to factor-specific measures identified by outdegree centrality as the most influential.

Conclusions

The most influential factors in maternal health identified in the combined maps were consistent with the mappers' experience with indigenous traditions. These eight researchers believe culturally safe approaches and adequate intercultural interactions can make positive contributions to indigenous maternal health. The procedure to combine and condense maps allowed us to present the perspectives of this group in a concise yet meaningful format. Increasing the level of abstraction using categories made the combined map more accessible. The condensed maps explored structural issues and offered suggestions for future research. Exploring internal dynamics of condensed maps indicated relevant factors that could contribute to promote change.

Harris' discourse analysis to generate user-independent weights of influence makes FCM relevant in communities where participant-weighting is not feasible. It could thus increase participation of stakeholders with causal philosophies that do not include parsing causes and their relative importance. This should complement, not replace, a commitment to intercultural dialogue.

Declarations

Conflict of interests

The authors declare that they have no competing interests.

Ethics

The research project received approval of the Ethics Committee of the *Centro de Investigación de Enfermedades Tropicales* of the *Universidad Autónoma de Guerrero*, Mexico, and of the McGill University Faculty of Medicine IRB.

Availability of data and materials

The data that supports the findings of this study are available in the supplementary material of this article.

Supplemental materials

Supplemental material 1. Profile of researchers who contributed their fuzzy cognitive maps

Supplemental material 2. Matching table of factors and categories across all the maps

Supplemental material 3. Step by step description of the condensation process

Supplemental material 4. Adjacency matrices of the category maps

Supplemental material 5. Comparison of factor-level outdegree centrality

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Appendix 8: Making sense of fuzzy cognitive mapping: four analytical approaches

I am a co-author of these teaching notes developed as part of a doctoral-level 3-credit class on Advanced Participatory Methods (FMED 702).

Making sense of fuzzy cognitive mapping: four analytical approaches

Background:

Cognitive mapping is frequently used as a decision support tool to better understand causal contributions to outcomes or decisions[1]. It has wide applications in ecological management, decision-analysis, information technology, economics, organizational behaviour, as well as in medicine[2]. Regardless of the application, many cognitive maps start from a person or group's perspective of what is relevant to a specific question or issue. Drawing on critical social science theories, one person or group's perspective could be completely different to another's view, and each set of views is probably partial, incomplete and changing over time[3]. But when we construct digraphs of our views, the shared language of concepts and space become comparable *and sometimes combinable*[4].

Our use of cognitive mapping is a conceptual shift from quite mechanistic artificial intelligence – and the attendant issues of “programming” – to the view that these maps are *soft models of how people see things*. This conceptual shift also requires that we move beyond depending solely on a regularity or variance-based understandings of causation, to one that also relies on an understanding of the social and structural *processes* that lead to observable outcomes[3].

Defining Fuzzy

Cognitive maps are made up of concepts or nodes (determinants or factors impacting the system or issue) and causal links (connections between nodes) that can be weighted by relative importance. Using fuzzy weights recognizes that different factors have different strengths of influence on a particular outcome. Moving beyond a simplistic dichotomy of a risk factor causing an effect or not, fuzzy weighting invites an understanding of degree of influence of each factor on a specific outcome, and this can be direct (factor to outcome) or indirect (factor through intermediates to the outcome)[3].

From a participatory and narrative perspective, fuzzy cognitive mapping offers a way to express what those concerned about an issue know, think or feel are its contributing causes. If we think about an outcome with multiple contributing causes with different degrees of influence, we can present the narrative or the person's belief structure as a formal system – a “soft model”[5]. The output then represents an often complex and interdependent model with differentiated (and therefore fuzzy) measures of influence of the factors within the model[4]. Figure 1 illustrates a cognitive map generated by a group of traditional midwives to describe protective factors that contribute to maternal health among indigenous communities in Guerrero, Mexico. When the traditional midwives weight the relative importance of each connection between nodes, the cognitive map becomes a fuzzy cognitive map.

We turned to cognitive maps as an accessible and comprehensive way to represent knowledge around an issue. We were particularly interested in reliably representing and incorporating marginalized or otherwise unaccounted for stakeholder knowledge with other perspectives on a similar issue, whether it be knowledge from other stakeholders or from published evidence.

In this text we use the term fuzzy cognitive mapping (FCM) to refer to the *process* while the visual products are called maps – which might be weighted, unweighted, adjusted, combined, and so forth.

Different Perspective on Evidence and Causality

At the cognitive level, people have at least two ways of making sense of the world around them, each providing distinct ways of ordering their experiences and with significant and systematic differences in how understanding and knowledge is gathered, analyzed and assessed for validity[6, 7]. One, the *paradigmatic mode of thinking*, is based on the principles of mathematical logic applied to empirical proofs, underlying much of the Humean, regularity or variance views of causation, focused on identifying systematic relationships between observable and measureable events. Hume argued that observation

and measurement were necessary elements to understand causality in the world around us, and that little could be inferred without direct observation[8]. This assumption underlies much of frequentist statistics, where causation is inferred through a constant conjunction of events, making it difficult to include factors or reasoning that may not be observable or measurable in our conceptualisation of causality[9].

The other mode of thought is a *narrative* one, which is more concerned with whether a claim can be considered to be true based on human intentions, reasoning, meanings, and experiences. This approach informs much of qualitative and theory-building analysis, whereby knowledge and understanding about the world around us is garnered by understanding how reasoning, beliefs and emotions have generative and causal capability[10]. Both modes of thought are complementary but irreducible to one another. We have found FCM offers an in-between language to communicate these perspectives and to bridge different ways of portraying and understanding causality and, ultimately, reality[9].

When created from stakeholder perspectives on what is important, cognitive maps show how stakeholders make sense of their experience around a specific issue. They name many social and structural influences and situate these in relation to key outcomes. Subsequent weighting by stakeholders (see next section) helps inform where to focus additional analysis[9].

When created from probability measures, cognitive maps often mirror directed acyclic graphs (DAGS), a well-known epidemiological tool. The main characteristic of DAGS is the absence of loops from a node back to itself (cycles), either directly or through other nodes. Although fuzzy cognitive maps can have such loops and be cyclic, it is possible to convert cyclic into acyclic graphs[11]. DAGS often inform epidemiological models and their assumptions, justifying which factors need to be included in a model and which others are considered to have negligible, spurious or confounding effects[12, 13]. This is the work of model building, which has conventionally been the purview of scientists and clinicians as

experts, and often requires that factors in the model be assumed to be independent from one another. Fuzzy cognitive maps make no such requirement, and readily accept that many factors are inter-related within one another[4].

Bridging between different perspectives about a shared issue benefits from the systematic representation of knowledge that includes different perspectives. In our work, for example, traditional midwives recognize traditional stories and rituals as valid sources of knowledge to inform their practice. In Western medicine and public health sciences, systematic reviews and meta-analyses that draw primarily upon the systematic and reproducible application of the scientific method, are often seen as the most reliable form of evidence. We have also used FCMs as an important tool to share and discuss epidemiological information with general audiences. Incorporating stakeholder perspectives in creating and/or adjusting causal diagrams can challenge and improve assumptions inherent in many epidemiological studies, contributing to more accurate models built on more transparent assumptions. Grounding evidence in stakeholder perspectives encourages a cross-examination of evidence that can re-orient our understanding of an issue and its potential solutions[14]. Most causal knowledge is inherently uncertain, or at least what is certain in one point of view might be uncertain in another point of view, and support for causal claims might not be the same for all stakeholders. Anchored around different understandings of causality, fuzzy cognitive mapping allows different forms of knowledge to connect across contrasting assumptions, where they meet not in competition, but as complements to one another[9, 15].

Applications of FCM

Fuzzy cognitive maps have multiple uses. They can be used to describe knowledge systems in terms of concepts and causal relationships, which when used across different stakeholder groups can be an important tool in identifying diversity in perspectives where differences are not lost or “averaged out.” Fuzzy cognitive maps can also support the formulation of theories and frameworks to inform the design, implementation and evaluation of programs and interventions. In this case, understanding how different

factors are connected to one another, either directly or indirectly, helps identify strategies or pathways that might contribute to desired scenarios. Other applications include questionnaire design and validation. This usually requires pinpointing relevant variables and their ranges of variability, usually based on expert's knowledge to assure the questions effectively capture the topic under investigation.

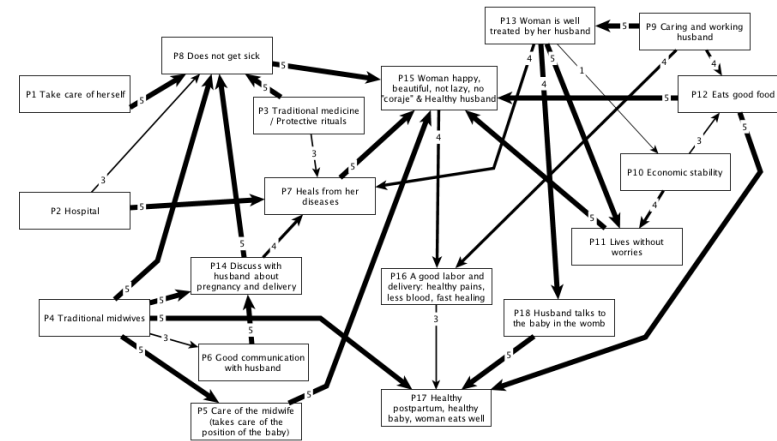
Fuzzy cognitive mapping offers a relatively neutral language to share ideas between stakeholders and, in consequence, to inform dialogue. This often requires the use of visual tools and rigorous ways to put different maps into comparable formats. Finally, having accessible tools for communication and interaction, like FCM, will have additional applicability in supporting meaningful engagement.

There are several protocols for developing fuzzy cognitive maps; we refer readers to key references for a more detailed description[1, 16–18]. We follow the protocol outlined in Andersson and Silver (Table 1), which steps one to six describe the map-making process and steps seven to ten describe the analysis and knowledge translation process[18]. This paper looks at how to leverage the information in fuzzy cognitive maps as an analytical tool and, when appropriate, a bridge between quantitative and qualitative methods and evidence.

A FCM protocol
1. Develop the focus (questions and outcome of interest).
2. Identify participants
3. Group or individuals generate ideas
4. Rationalize the ideas
5. Arrange and draw links
6. Weighting each link between concepts
7. Pattern matching
8. Digitalization
9. Network analysis, map combination and updating
10. Use in deliberative dialogue

Table 1: FCM protocol adapted from Andersson and Silver, 2019.

The same fuzzy cognitive map can be represented in three ways, each useful for different settings. Figure 1 presents the graphical (diagrammatic) representation of the map from the *Nancue ñom ndaa* people and its corresponding edge list and adjacency matrix. An edge list is a list of all the links in the map in the form of a table with three columns: from (starting node), to (ending node), and weight (magnitude and direction of the influence). An adjacency matrix is a squared table in which each row and each column correspond to one node in the map. The value of the cell lying at the intersection of a row (starting node) and column (ending node) corresponds to the weight of the link [17]. Both adjacency matrices and edge lists are used to manipulate the maps numerically (e.g. by combining maps), and the graphical representations provide an accessible representation of the entire knowledge system, often helpful for sharing different knowledge systems across stakeholder groups. We generally use visual representations of the maps when discussing evidence with stakeholder groups, however, it is also possible to use edge lists or adjacency matrices for data collection. Doing this would be possible, for example, when we have a predefined map and want to consult the weights of the edges or identify additional relationships.



b)

From	To	Weight
P9	P13	5
P13	P11	5
P13	P10	1
P10	P12	3
P10	P11	4
P12	P17	5
P12	P15	5
P13	P7	4
P11	P15	5
P1	P8	5
P2	P8	3
P2	P7	5
P3	P8	5
P3	P7	3
P4	P5	5
P4	P17	5
P4	P6	3
P4	P14	5

d)

Figure 1: Four options to represent a fuzzy cognitive map. Map of protective factors for maternal health according to a group of indigenous traditional midwives in Xochistlahuaca (Guerrero, Mexico). a) Original map; b) Digitized diagram; c) Adjacency matrix; d) Edge list.

In this paper, we present four analytical techniques in fuzzy cognitive mapping with applied examples from our work incorporating voices of marginalized groups into decision-making around perinatal health in Mexico and Canada[19, 20]. Our work in Canada explored how the perspectives of family physician and volunteer birth companions in Montreal overlap and update findings from published literature around unmet care needs among recent immigrant women in Canada[21]. Our work in Mexico explored the views of 11 traditional midwives from the *Nancue ñomndaa* and 18 from the *Me'phaa* people in the Southern state of Guerrero (Mexico) describing factors that promote maternal health in their communities. The traditional midwives draw the map in July 2017[20].

While we do not prescribe a specific analytical order; we describe the process and the outputs of each of the analytical approaches so that the reader may decide which approach is most appropriate to their needs. We have found transitive closure a helpful initial step, as it accounts for interdependence between factors within a fuzzy cognitive map. Several analytical approaches can be done without first computing transitive closure (such as thematic analysis and social network analysis). We have tried to identify the necessary previous steps where they apply for any of the analytical methods, though each use will depend on the specific question at hand.

Accounting for Interdependence of Factors: Transitive Closure

Transitive closure offers a way to take account of the context of each weight within a map, adjusted for interdependence between factors. It is a mathematical algorithm that calculates adjusted weights to account for all other relationships in the map and identify walks or underlying relationships between factors[22]. A helpful corollary to this adjustment is a standard multivariate analysis, with the important exception that in fuzzy cognitive maps, we readily accept and expect that the concepts are linked and interdependent, whereas in multivariate analysis we have to make some heroic assumptions about independence of factors[23]. By adjusting the weights for interdependence, transitive closure transforms the collection of factors within this map

into a network, including the identification of indirect relationships between two factors[22]. A path between two factors (A:B) can either be through a direct influence (arc) (A;B), or from a walk (sequence of arcs) starting at A, through one or more additional factors, and ending at B. Transitive closure does not identify *all possible walks* through the map, but points to the underlying architecture within the map that holds it together[24].

There are two approaches to calculate transitive closure: probabilistic and fuzzy which both follow the same principle but use different underlying algorithms[22]. The probabilistic transitive closure is most appropriate when the set of factors across maps is predetermined, as probability is path dependant. For the probabilistic TC, the resulting weight of the walk (A;B) is the product of the weights of each component arc. When the maps come from different stakeholders the length of the walks will depend of the level of detail that participants provide; thus, being somewhat arbitrary. In this case, fuzzy TC would be more appropriate, where the resulting weight of the walk (A;B) corresponds to the minimum weight among all the arcs participating in the walk[24].

We generally calculate the transitive closure of a cognitive map before carrying out any comparisons (thematic or relative weighting) across maps. A full description of the mathematical basis of transitive closure is available elsewhere. We have integrated the algorithm within an analytical software so that upon finalizing the adjacency matrix, one can specify the use of ProbTC (probabilistic transitive closure) or FuzzyTC (fuzzy transitive closure), and the adjusted weights and underlying walks will be returned as an adjacency matrix.

In our work examining family physician and birth companion perspectives on unmet postpartum care needs of recent immigrant women in Canada, we worked with family physicians and birth companions to generate maps of their own understanding of the issue. Transitive closure helped us identify different underlying relationships, or walks, in each of the maps (described in Figure 2), helping us understand how different stakeholder groups conceptualize and link different factors. Using transitive closure to account for how factors

are related to one another and to identify underlying walks is a helpful way to focus on particularly salient aspects in what can sometimes be an unwieldy amount of information in the maps themselves[18].

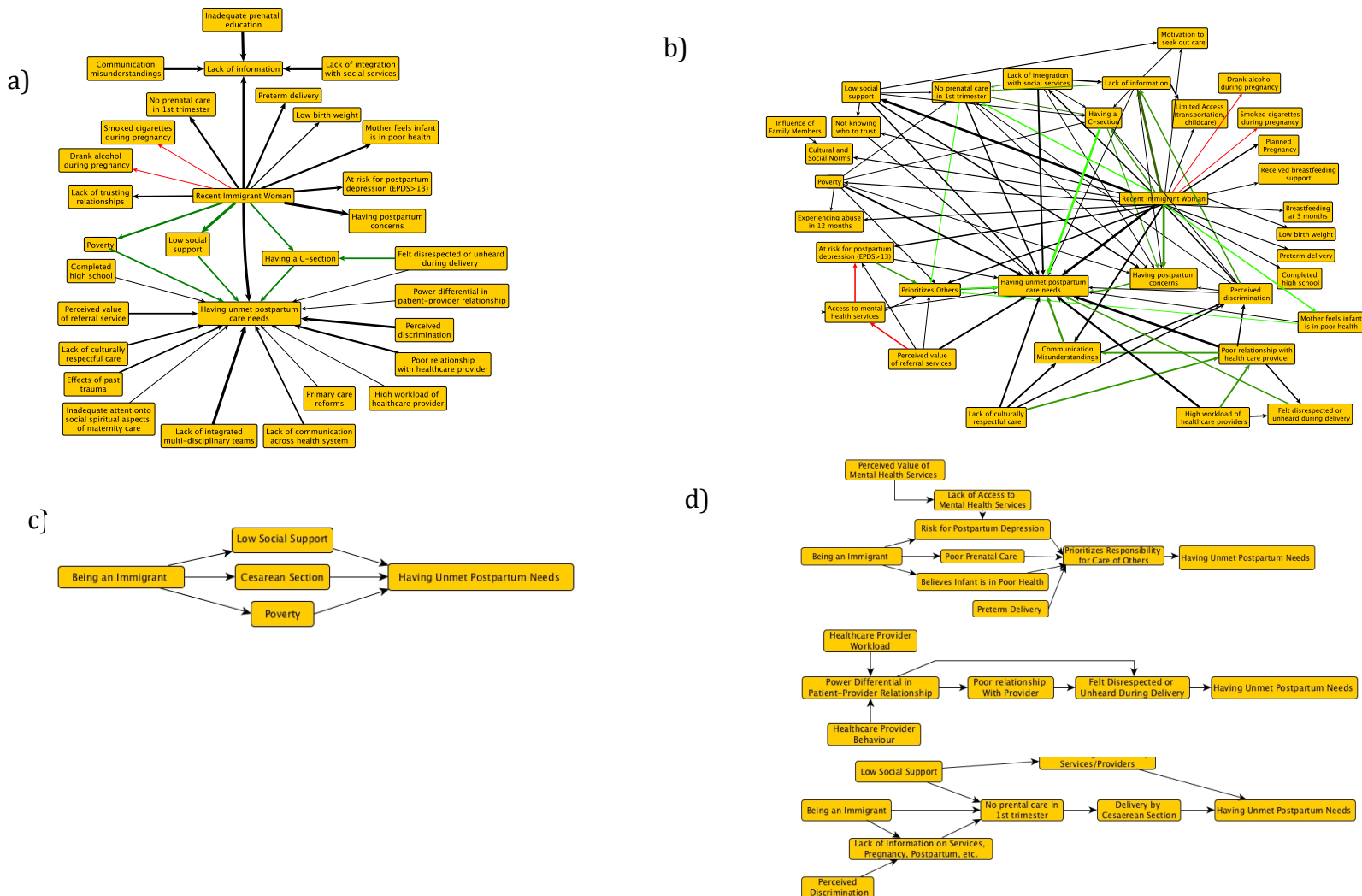


Figure 2: Fuzzy cognitive maps of family physician (a) and birth companion (b) perspectives on causes of unmet postpartum care needs among recent immigrant women in Canada. Lines in black represent reinforcing relationships, in red represent an inverse relationship, and walks identified by transitive closure are shown in green. Walks identified by family physicians are shown in c), and those identified by birth companions in d).

Grounded Themes, Reduction and Conceptual Clarity

When comparing maps from different knowledge sources, a non-trivial step is to match whether the factors or concepts in different maps have similar meanings. One of the emphasis of Andersson's protocol (Table 1) is to involve participants as much as possible in this step. Regardless of how this step is completed, a clear accounting of the decisions and assumptions are essential for transparency, while sensitivity analysis can help establish the impact of such assumptions.

One way to simplify the maps and to arrive at more manageable results is a condensation of factors by themes. This procedure follows the same general principles of thematic analysis[25, 26]. However, the researchers do not need to re-code the content, but they work grounded on the original labels assigned to the nodes by stakeholders during mapping sessions. This step benefits from skilled facilitation and detailed documentation of discussions from the mapping sessions to support the identification of common underlying themes, and is a reminder to consider how map-making discussions will be documented well before the mapping interview takes place.

To guarantee complete authorship of the maps, stakeholders should be involved in the condensation process. However, often logistical and analytical challenges can make this difficult. In 2017, a study in Nigeria used FCM to represent the views of 52 communities on factors contributing to short childbirth spacing. The challenges of engaging all 52 communities in the thematic analysis precluded their involvement. Instead, the researchers carried out a thematic analysis and then confirmed and adapted the results with the facilitators of the mapping sessions. The facilitators adjusted the themes according to their knowledge of the original discussions.

In other cases, analytical challenge might occur when researchers need to use categories for the analysis that although grounded in the data, might not be the main interest of communities.

In our work with traditional midwives in Mexico, researchers suggested the categories of synthesis inductively[27] drawing from the midwives' maps and accompanying discussions. Facilitators of the mapping sessions and a group of experienced researchers in indigenous health further refined these categories, which were subsequently compared with categories identified through a review of the literature on maternal care for indigenous communities. After this phase of the analysis was completed, a member checking session[28] with the traditional midwives confirmed their acceptance of the identified categories.

A tool to support the thematic analysis and reduction across maps is a *matching table*, which consists of an initial column with a standardized or core categories and one additional column for each map. The factors in each map are listed in the corresponding column and matched with the row of the category they belong to. Once all the unique factors in the maps are identified with the matching table it is possible to convert all the maps into a standard and comparable format, for example renaming the nodes in an edge list or adjacency matrix. Table 2 presents the thematic classifications of the nodes from the maps in Mexico, where 12 themes were identified from 20 unique factors. This table is especially useful to keep track of any reductions and adjustments made to different maps throughout the reduction process, including a description of who participated in which decisions. Finally, it is also possible to propose multiple thematic classifications and establish how each view of the themes would modify the results.

Category/theme	Protective factors enumerated in Acatepec	Protective factors enumerated in Xochistlahuaca
<i>The woman has a safe birth and healthy maternity</i>	The woman is happy	The woman is happy, beautiful, good worker, not lazy, does not get "coraje". Also, she has a healthy husband
	The woman is strong and brave	
	The woman is able to give birth at home	A good labor and delivery: healthy pains, less blood loss, fast healing
	The woman does not get sick	Healthy postpartum: healthy baby / the woman is willing to eat after labor
<i>The woman has support of a traditional midwife or healer</i>	Support of a midwife or traditional healer	The woman receives care from the traditional midwife (and she takes care of the position of the baby)
		Traditional midwives in the community

	A midwife counsels the husband	
<i>Healthcare centre or hospital is available</i>	Healthcare centres available	Hospital available (Hospital básico comunitario)
<i>The woman follows protective rituals</i>	The woman follows protective rituals (lighting candles or indigenous prayers)	The woman follows protective rituals associated with traditional medicine
	Praying in the church (Cristian or Catholic) asking for health	
<i>The woman follows self-care practices</i>		The woman takes care of herself
<i>The woman does not suffer violence</i>	The woman does not suffer violence	
<i>The woman lives without worries</i>		The woman lives without worries
<i>The woman has a caring, working, and loving husband</i>		The woman is well treated by the husband
	The woman has a caring and loving husband	The woman has a caring and working husband
		The husband talks to the baby in the womb
<i>The woman has good communication with husband</i>		Good communication with husband
		The woman discusses (talks) with husband about pregnancy and delivery
<i>The woman has a good health condition (before pregnancy)</i>		The woman does not get sick
		The woman heals from her diseases
<i>The woman has economic stability</i>		Economic stability
<i>The woman is well nourished</i>	The woman eats good (enough) food	The woman eats good (enough) food

Table 2: Matching table of the concepts grouping protective factors for maternal health identified by two groups of traditional midwives in Guerero, Mexico

Once the synthesis of factors is completed, the weights of reduced factors must be *aggregated*[17]. During condensation, the nodes belonging to the same category can be considered a subgraph of the map and will become one category node[29]. The edges linking the nodes within the same subgraph will constitute a self-loop for that single category node. This loop gives a sense of the internal dynamic of the category according to the original map. When internal dynamics suggest important influence because it produces higher weights, researchers can go back to analyse the factors in the subgraph. The edges linking different category nodes represent the cumulative net influence that the nodes

within each subgraph have on another subgraph. The net influence is the summation of the weights of the edges over the maximum cumulative weight[23].

We generally adjust map weights using transitive closure before identifying condensing themes. Figure 4 presents the synthesized maps with protective factors for maternal health in Guerrero. The self-edge/loop in healthy maternity reflects that maternal health depends of the influence of pregnancy, delivery and postpartum, all three collapsed in this category.

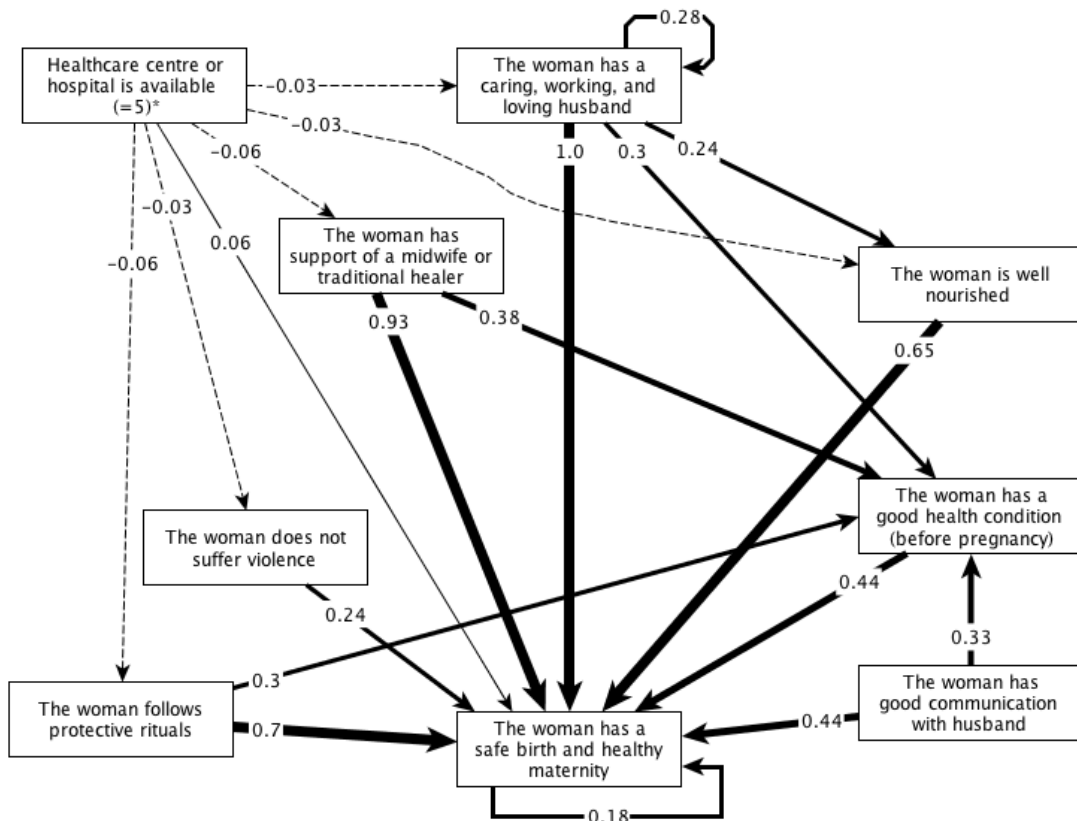


Figure 4: The synthesized map of protective factors for maternal health in Guerrero after the described reduction process.

Pattern Matching Table

Once we have made the maps comparable, a useful tool is a *pattern matching* table which describes for each unique node, how each stakeholder group or knowledge source weighted the node and the walks that connect that node with the outcome of interest. We can also calculate the level of disagreement between maps as the average difference in weights assigned to specific relationships between two maps. Similarity increases with the frequency of similar connections and decreases with the frequency of different or conflicting connections. The absolute difference ($\bar{d}$) between all pairwise factors calculates an average degree of disagreement between two knowledge sources, according to:

$$\bar{d} = \frac{\sum |d|}{N}, \quad (\text{Eq1})$$

where a higher value for $\bar{d}$ represents greater differences between knowledge groups. A pattern matching table with the calculated degrees of disagreement between published evidence, family physicians and birth companion perspectives is provided in Table 3.

Concept	Literature	Family Physicians	Birth Companions
Similarities:	0.23		
Being an Immigrant		0.79	0.99
Poor relationship with provider		0.53	0.9
Having a Caesarean Section	0.17	0.46	0.8
Provider Workload		0.27	0.62
Lack of Respectful Care		0.33	0.5
Perceived value of care		0.4	0.5
Poverty	0.4	0.47	0.5
Low Social Support		0.47	0.48
Patient Has No Voice		0.27	0.32
Perceived Discrimination		0.6	0.22
Fragmentation between health and social services		0.47	0.5
Less Than High School	0.18	0.27	
Differences:			
Lack of multi-disciplinary teams		0.73	
Communication Misunderstandings			0.6
Family Responsibilities			0.4
History of Trauma		0.4	
Experience of Delivery			0.4
Risk for Depression			0.32
Not Knowing Who to Trust			0.32
Lack of Access to Mental Health Services			0.26
Degree of Consensus between Family Physicians and Birth Companions		0.31	
Degree of Consensus between Family Physicians and the Literature	0.37		
Degree of Consensus between Birth Companions and the Literature			0.45

Table 3: Pattern matching table of factors relating to unmet postpartum care needs among recent immigrant women identified within the literature, and by stakeholder groups.

Social Network Analysis: The Importance and Role of Nodes

Social network analysis provides several ways to analyse the structure of maps, as networks of concepts[30, 31]. Many indices have been developed since this concept of Social Network Analysis was introduced in 1930s. These indices describe the role and level of importance for each node with diverse applications[32]. Several freely available software provide calculations to identify these measures (for example, R packages *netrankr*[33], *igraph*[34] and *FCMapper*[35]). We use *yEd*, a free graphing software package that provides three informative measures[36]:

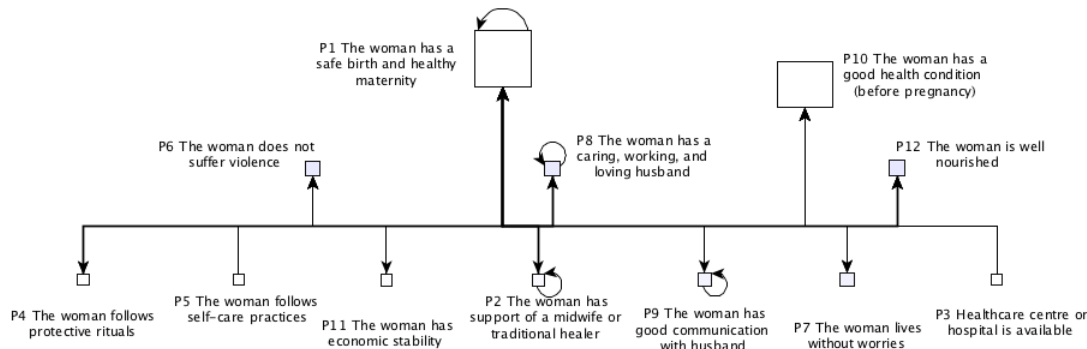
- *Degree centrality* is a simple measurement of the importance of a node defined by the number of the edges linked to it. This measure is called indegree when counting the incoming edges (or predecessor nodes) and outdegree when counting outgoing edges (or successor nodes)¹. Higher values of indegree centrality will identify the nodes that are most commonly depicted as outcomes. In a similar manner, higher values of outdegree centrality will identify the nodes that are most commonly depicted as causes of other factors.
- *Weight centrality* measures the weight associated with indegree, outdegree, or overall degree. This measure is interpreted in a similar way to the degree centrality. However, for two nodes with identical values of degree centrality, the one node connected with strongest edges (those with higher weights) will have a higher overall weight centrality.
- *Betweenness centrality* as a measure how often a node lies on a shortest path between each pair of nodes in the graph. A higher value of this measure will indicate that the node is an important influencer or modifier of the relationship between other nodes.

Because transitive closure adjusts map weights depending on interdependence between factors, it is best to calculate social network analysis measures after applying the transitive closure algorithm. Figure 5 presents the measures of weighted indegree(a), outdegree(b), and betweenness(c) centrality for the map from the *Nacue ñomnda* people in Guerrero. In

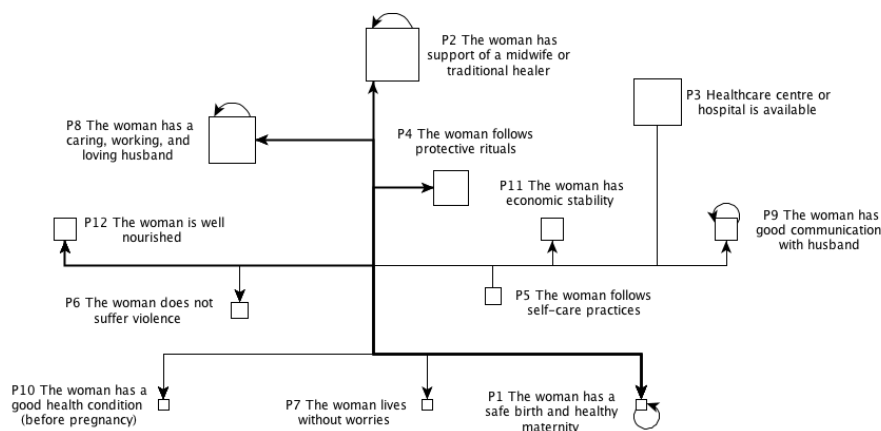
¹ <https://www.sci.unich.it/~francesco/teaching/network/degree.html>

the automatic layout of yEd the size of the nodes is proportional to the value of centrality measures in the map. The bigger nodes have higher values and smaller nodes have lower values. Those factors with higher degree will look bigger.

a) Weighted indegree centrality: receivers of influence



b) Weighted outdegree centrality: factors influencing other factors



c) Weighted betweenness centrality: factors modifying the influence of other factors

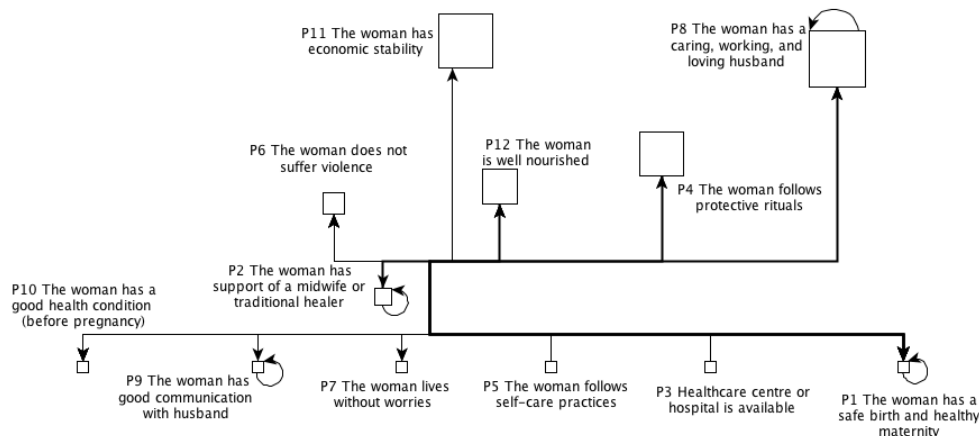


Figure 5: Measures of centrality applied to the maps of protective factors for maternal health from traditional midwives in Guerrero, Mexico. The size of the nodes is proportional to the degree of centrality in each measure. Bigger boxes represent a higher degree.

Fuzzy Cognitive Maps: Contributing to Epidemiology and modern participatory research

Much epidemiological research wrestles with uncertainty, and how and when different types of uncertainty might affect our ability to model reality. Many epidemiological models have implicit assumptions, like independence of variables, that are not known to be correct or are widely recognized to be incorrect. Fuzzy cognitive mapping and the incorporation of a broader range of perspectives has important implications for the design and theory informing epidemiological studies[13]. By incorporating stakeholder perspectives in creating and/or adjusting the causal diagrams and contributing to refining analytical models, stakeholder-informed theories can challenge and improve assumptions inherent in many epidemiological studies[15, 37].

Fuzzy cognitive mapping as a tool in participatory research is versatile as creating a sharable platform for portraying different understandings around a similar issue[1, 19, 38]. It has been particularly useful in engaging stakeholders often excluded from conventional research processes and decision-making, such as traditional midwives in Guerrero or patient groups among highly marginalized populations. Representing tacit or informal knowledge in graphical form, as well as numeric weights capable of interfacing with more established form of statistical understanding, makes an important contribution to engaging with and recognizing different forms of knowledge[39, 40]. Critical to modern participatory research, this is an important step in developing research methods that invite cognitive and epistemic diversity[41].

Working with fuzzy cognitive maps also provides an accessible graphical language to express knowledge across different cultural and epistemological backgrounds. Building a fuzzy cognitive map guides stakeholders in developing and sharing their own theory of change, identifying prioritized factors affecting an issue of interest. Sharing fuzzy cognitive maps of published evidence (for example of a meta-analysis) also provides a way to communicate evidence with groups without prerequisites of advanced training in

epidemiology or statistics, thus solving a major barrier for full and meaningful participation.

ANNEX- Additional Approaches to Analysing FCMs

Causal inference using activation rules (if-then scenarios)

Perhaps the most common approach for the analysis of model implications in FCM is using an iterative procedure to assess the effects of user-specified perturbations on the state of the model[42]. Here we provide a general description of the procedure to offer the reader a comprehensive list of options for FCM analysis. For additional explanations you can see Kosko for the mathematical origin of the procedure[38], Felix for complete review of the evolution of this approach[43], or Peña[44] and Ozesmi & Ozesmi[17] for descriptions of the procedure in an accessible language. Some additional developments using this activation rules are learning algorithms used to recalculate the weights in the maps on the basis of iterative simulations[45].

The simulation process for causal inference starts with a user-specified activation state at the initial time t . Users can also clamp values to define “if-then” scenarios. The activation state is defined as a list of values representing the degree at which the causal effect of a node is present (for example, 0 for no effect and 1 for total effect). This vector is iteratively recalculated using the weights of the relationships in the map until the system stabilize (the new values are almost the same as the previous) or complete a maximum number of iterations. The calculation of the iterative activation states follow an activation rule, basically a function of the summation of the effect that a node receives. These effects are the product of the level of activation of the origin node times the weight of the edge. Felix described the most common activation rules[43] developed since the procedure was first introduced in the late 1980s[46].

Many computational packages for FCM allow the calculation of these simulations, most of them freely available. For example, FCM Expert[47] or FCM[48] and FCMapper[35]

packages in R. Mental Modeler[49]² offers an online interface to create the maps and run if-then scenarios with visual display of the results. We have used Mental Modeler in teaching scenarios and the visual display of different scenarios fosters engagement and contributes to the discussion of results.

There are many additional options available to compare maps[50]. Using indegree centrality measures, Gray[51] suggests a classification of nodes as transmitter, receiver, or ordinary following the idea suggested by Özesmi and Özesmi[17]. Gray also suggests the use of density (proportion of edges in relation with the total possible edges) and centrality (the ration of transmitters factors to receivers' factors) as measures of complexity of the maps. We prefer not to use these measures because maps build in participatory contexts tend to have non-fixed sizes. Therefore, the number of edges in the map often depends on the time available or emphasis of the discussion.

Giles and colleagues offer a classification that accounts for the weights of the relationships in the map and the variability across different maps[52]. They use three measures: a) levels of consensus, b) causal importance of factors, and c) heterogeneity to identify strong determinants, weak determinants, and controversial determinants. A practical option to compare nodes is to calculate the differences of the net influence that each of them have on the outcome of interest after transitive closure. An average of the absolute value of these differences will offer a general idea of the level of agreement among maps. A formal comparison between maps identified: (a) validated connections (both maps share the non-zero connection with the same sign), (b) non-validated connections (it is only mentioned in one map), and (c) conflicting connections (both maps include the edge but with different directions). The differences of the net influence and formal comparison can also apply to the condensed maps to compare the categories.

² <http://www.mentalmodeler.com/>

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Appendix 9: Fuzzy Cognitive Mapping As Tool to Advance Evidence Synthesis

I am the primary author of these teaching notes developed with Ivan Sarmiento and Dr. Neil Andersson as part of a doctoral-level 3-credit class on Advanced Participatory Methods (FMED 702).

Fuzzy Cognitive Mapping As Tool to Advance Evidence Synthesis

Systematic reviews and meta-analysis have long been considered the highest value evidence synthesis in medical and public health sciences. (1) Recent advances in mixed methods reviews demonstrate the value of combining qualitative and quantitative findings, often derived from differing perspectives and epistemologies, in evidence syntheses. (2-5) These include several approaches to combining observational studies into meta-analyses, for example through hierarchical Bayesian analysis, as well as knowledge synthesis approaches such as critical interpretive synthesis, realist reviews and narrative reviews, that offer rich interpretations sometimes across different paradigms. (6-10)

There is an increasing recognition of the importance of patient and stakeholder understanding in informing evidence/health service improvements. Evidence synthesis without meaningful stakeholder engagement can overlook contextual factors that stakeholders consider influential, and therefore, may also be critical to effectively addressing an issue. (2) Patients, their families and caregivers, as well as frontline health and social service providers may also have actionable insights into the influence of social and organizational contexts in health interventions, rarely accessible in conventional syntheses. (2) With increasing interest in stakeholder involvement comes a growing recognition that knowledge is not the product of scientific expertise alone, but a complex product of co-creation between multiple and sometimes conflicting perspectives. (2,3) This can be complex when translating and synthesizing evidence from differing perspectives, requiring a diversity of concepts, theories and methods that maybe at odds with one another. (11)

We turned to fuzzy cognitive mapping as an accessible and comprehensive way to represent knowledge, whether it be from stakeholders or the results of a literature review. We were particularly interested in reliably representing and incorporating evidence across different audiences- both making meta-analyses and other forms of quantitative and qualitative evidence easily accessible to non-epidemiologists/statisticians or qualitatively trained

researchers, while also inviting stakeholders to represent their own knowledge and understanding on that same (or similar) issue in a systematic way.

Our use of cognitive mapping is a conceptual shift from depending solely on a regularity/frequentist or variance-based understandings of causation, to one that also recognizes people's understanding and sense-making process as valuable to understanding (social and structural) *processes* that lead to observable outcomes. (12) We have found fuzzy cognitive mapping as a valuable tool to develop *soft models of how people see things*. (13) We have previously described analytical approaches to citizen/stakeholder-led fuzzy cognitive maps. (14)

In this paper, we describe four approaches to combining, reconciling and comparing different knowledge sources on the same issue, whether with other stakeholder groups or with synthesized published evidence, as a way to expand our understanding of an issue by considering multiple perspectives. Our examples focus on the integration of perspectives of marginalized populations, who are rarely considered as having expertise on health issues or have little to contribute to scientific inquiry. We make an important deviation from convention by considering people who have knowledge and expertise that goes beyond academic or clinical-based expertise, as experts over their own understanding. This is consistent with arguments long-made by leading feminist, Indigenous, disability-rights and working class academics, activists and communities. (15-18) Doing so recognizes lived experience and more diverse worldviews as expertise, and *as the most relevant voices* to speak about particular issues relevant to their well-being. (15,17)

Bayesian Models

Bayesian analysis is a well-established, logical and transparent way to incorporate expert knowledge with empirical quantitative data, conventionally done by eliciting uncertainty around a parameter's value. (19,20) Bayesian methods are often used to include evidence and other forms of knowledge external to conventional meta-analyses as they provide a coherent framework to take account of evidence from a variety of sources about a specific problem.

Bayesian statistics provide a formal statistical way to learn from data (or knowledge) outside of conventional epidemiological models and incorporate or update these models with this data. A Bayesian model begins with a likelihood model, a conventional measure of plausibility assigned to a specific factor. While any epidemiological model could be used, we use a simple effect estimate. In conventional Bayesian analysis, a measure of the certainty or confidence in this model or estimate is elicited, called a *prior*, often based on what is known from experts or from other sources of data (eg. observational studies in meta-analyses). This measure of uncertainty then updates or modifies the original model to create a posterior distribution by multiplying the prior distribution by the likelihood.¹ The credibility of each estimate is recalculated in light of information provided by the prior, where a more confident or precise prior has a stronger influence on the posterior distribution than a vague or uncertain prior. This kind of learning from each new piece of data is called Bayesian updating. (21) The re-calculated, or updated, plausibility or credibility measure then serves as the new initial plausibility measure to be updated again by another new piece of data. In many Bayesian updating calculations, all of the data are presented as a prior distribution (as a representation of all of the data) for the sake of convenience, but it is important to realize that this is an abbreviation of an iterative learning process of incorporating each new piece of data into our model. (21) While any distribution can be used to model the weight of influence of different factors, we have tended to use more common and interpretable distributions, such as the normal or beta distributions. Conventional goodness to fit tests can be used to assess the adequacy of distribution models.

The mathematics or logic of Bayesian analysis does not have to be complicated. What is unique about Bayesian models is that they demand we be explicit about our collective uncertainty about knowledge and our understanding of the world around us, particularly around theoretical entities that are not observed (most often parameters and overall models.) (10,21) The architecture of Bayesian analysis is well recognized and we utilize fairly (mathematically) simple approaches to Bayesian analysis. Developing priors through fuzzy cognitive mapping provides a

¹ This is a simplified description. A full mathematical description of Bayes' rule is provided in the Annex.

systematic and transparent process to develop measures of relative credibility or importance of factors according to different stakeholder perspectives. Using the priors to update and inform conventional epidemiological models offers a powerful way to expand the boundaries of current conceptualizations of an issue and incorporate issues formerly rejected or seen as outside of the system of influence. (22-24)

Eliciting Priors Through Fuzzy Cognitive Mapping

Conventional prior elicitation for Bayesian updating asks experts to specify, based on their expertise and experience, how likely they consider an outcome, or how likely they consider a factor to influence an outcome. Eliciting several expert perspectives on the likelihood of an event offers a measure of uncertainty around that influence, often represented as a *prior* distribution of probabilities. (25) Fuzzy cognitive mapping offers an accessible and systematic tool to address the long-standing concern in Bayesian statistics of generating meaningful and representative priors. While one needs to give special attention to the rigour of the mapping and weighting *processes*, weights generated through fuzzy cognitive mapping invite experts to analyze problems in context (considering all relevant factors), while generating transparent and meaningful measures, or weights, of influence for each factor.

Determining which stakeholder groups need to be involved in elicitation processes is often driven by what expertise is considered relevant. (22) Conventional approaches to identifying experts are often based on academic qualifications, professional standing, and experience. These requirements can sometimes exclude people with useful knowledge, while also giving space and credibility to those who may not be most qualified or experienced to address the issue of interest. (26) Our work aims to broaden the scope of what counts as evidence and expertise, particularly around the inclusion of often marginalized or silenced perspectives. As described elsewhere, fuzzy cognitive mapping provides an equitable platform for sharing and combining the knowledge of those who have been usually silenced. (14,27,28) The use of a relatively simple visual tool helps to communicate complex concepts and relationships with relative simplicity, facilitating communication across different understandings of an issue.

If cognitive maps are soft models of how people see things, combining cognitive maps across different perspectives can provide insights into how perspectives complement and differ from one another, and can act as an important lever to identify potentially shared priorities as well as areas of disagreement or difference. There are several different ways to combine and compare fuzzy cognitive maps, and the *how* of combining makes a difference in how the maps can be analyzed and interpreted.

Here, we outline four different approaches that we have found useful to combine maps, each appropriate for different circumstances. Equations for each combining procedure are provided in Annex 1. All procedures require that we perform operations at a factor level, requiring that we represent fuzzy cognitive maps as adjacency matrices. All of the procedures described below assume that users are working with maps with transitive closure adjusted weights. (29)

A brief note to mention that there is more than one way to arrive at an “average map”. The process below applies when you have multiple maps from multiple groups of the same stakeholder category. This could be from multiple individual mapping session, group mapping sessions where each participant makes their own map, or maps from similar stakeholder groups across several different communities. As described in the analysis paper, another way to achieve an “average map” is to work with a stakeholder group to create shared fuzzy cognitive map, where through the discussion, the group collectively decides on relevant factors and their weights. Depending on the context, stakeholders may prefer to make their own maps (if the topic is particularly sensitive, if experiences may vary widely or if stakeholders share a common experience but are not a position of making shared decisions). Individual maps can be made through one-on-one mapping interviews or in a group as a way to capture individual perspectives (through their own maps) while benefiting from the shared discussion and potentially accessing perspectives that people may not be comfortable to vocalize.

Similarly, there is no set number of maps that should be made to represent a particular stakeholder perspective, and it will ultimately depend on the coherence of ideas across a stakeholder group. A bigger number of maps will usually lead to a more accurate

representation of the actual weight or causal influence from a particular perspective, and a range of 7-9 maps per stakeholder group is generally sufficient. (13,30)

Maps From Equivalent Groups

Averaging

To combine maps, identical factors or themes across the maps must have common names and refer to the same underlying concept. Each map should include all factors whether mentioned by that stakeholder group or not, while the weights according to each stakeholder or knowledge set will vary. If a map does not include a specific factor, its value should be 0. A matching and reduction process across different maps is detailed elsewhere. (14)

When combining maps that represent equivalent perspectives in kind, expertise or relevance, each perspective is considered to hold equal weight. Simple averaging between two (or more) weights or mean point estimates, where each weight value has equal influence, may be appropriate. (Equation 2 in Annex) This would be the approach to combine maps from members of the same stakeholder group, from the same community or, for the purposes of the research question, from a homogeneous group. The result is an averaged point estimate, where the average is the sum of all the weights for that relationship divided by the total number of maps in the set, including those assigned a zero weighting. This provides a helpful single point estimate of the average value across a group, but one that does not capture the variability (or uncertainty) across measures.

Updating Maps

Updating maps from within a stakeholder group generates a measure of the variability (or uncertainty) around a specific factor within that stakeholder group. A credibility interval shows a measure of central tendency (eg. mean) as well as a distribution of stakeholder-assigned weights. (25) Examining variability within stakeholder groups is a helpful tool to assess the level of agreement. These tests can also help to inform stakeholder grouping and analysis, as broad

or multi-modal normal distributions (eg. with more than one peak) in stakeholder weights suggests important differences within the stakeholder group. These differences may need exploring through further group discussion, or different forms of analysis (eg. using non-normal distributions as the assumed underlying probability distribution.)

When working with different groups, comparing weights between knowledge sources is a helpful starting point. Comparing the average weights and their *distributions* provides an interpretable representation of how different knowledge sources describe or characterize the influence of specific factors. In our pilot work in Canada, we compared the perspectives of practicing family physicians and birth companions on the influence of perceived discrimination as a factor contributing to unmet postpartum care needs among recent immigrant women in Canada. The two groups weighted the influence differently. As described in Table 1, these can be represented as point averages or as normal distributions, where the “gap” or difference in perspectives is represented, as well as the coherence within each stakeholder group (represented by the spread of the distribution). These representations help to identify where differences in perspectives exist, inviting a further discussion around both the reasons for and consequences of these differences.

	Mean	95% credible interval
Family Physicians	0.49	0.2-0.79
Birth Companions	0.18	0-0.37

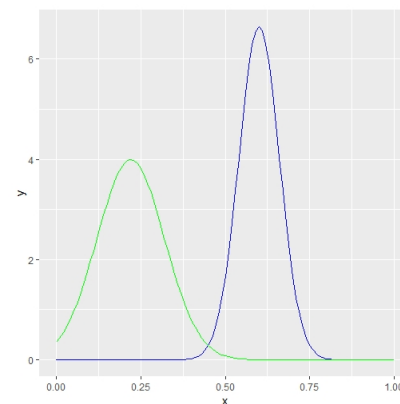


Table 1: Average weight and credible intervals around family physician (in blue) and birth companion (in green) perspectives of the influence of discrimination on unmet postpartum care needs of recent immigrant women in Canada

Combining Maps from Different Perspectives

While averaging maps can be appropriate across maps from a similar source of knowledge, it may also be of interest to combine perspectives across different knowledge sources, such as from different stakeholder groups or between published literature and stakeholder groups. Updating provides a way to formally recognize and incorporate different forms of knowledge about the same issue or factor into a statistical test, providing, for example, a measure of relevance of published evidence according to a particular stakeholder group. This use of fuzzy cognitive maps not only provides a medium to share different forms of knowledge and ways of understanding of an issue, but can also ground one form of knowledge in another, providing a formal way to take account of a range of stakeholder views in assessing the relevance of evidence. Making epidemiological data, or knowledge from other stakeholders, accessible to diverse stakeholder groups helps “level the playing field”, inviting stakeholders to engage with the full scope of evidence often available to other decision-makers and subsequently identify their priorities. This is an important mechanism to prevent the dismissal of community or informal knowledge on the grounds of not having full understanding of an issue, whereby the maps demonstrate the taking into account of others’ perspectives and the identification of priorities in consideration of, and not in isolation, of all available evidence.

We have found Bayesian updating to be helpful with respect to bringing different types of knowledge together, all the while preserving differences and providing a mathematical accountability of the role of different perspective in decision-making. The most straightforward way to update perspective is what is termed *naïve updating* in meta-analysis methods, whereby each perspective is considered to carry equal weight, regardless of the quality and/or known and unknown differences in how appropriate a particular knowledge source may be to address the issue at hand. (10)

In our pilot work in Canada, we asked birth companions and three family physicians providing obstetric care to recent immigrant women to develop a cognitive map of factors contributing to

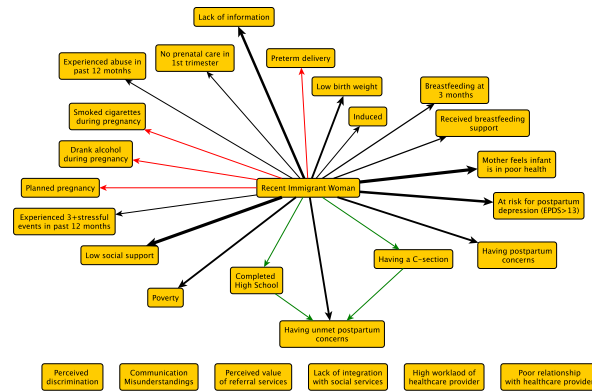
unmet postpartum care needs among recent immigrant women in Canada. We represented family physician and birth companion perspectives separately as normal *distributions*, with an average weight and standard deviation for each factor they identified (as shown in Table 1). We also represented evidence from published literature, using conventional effect estimate and uncertainty measures about the same relationship, as reported in peer-reviewed literature. We used a normalized odds ratio (eg. represented on a scale of 0-1) together with its standard deviation (also on a scale of 0-1) to describe individual effect estimates. Converting both stakeholder weights and literature-based effect estimates to the same scale spanning 0 to 1 translates the weights to relative measures. This also allows us to take advantage of the probability-based architecture of Bayesian analysis by combining what is known about a relationship from an expert stakeholder group (using family physician and birth companion-assigned weights represented as a normal distribution as the *prior*) with observed data about that relationship (from published literature). Figure 1 shows the fuzzy cognitive maps representing perspectives from the literature (Panel A), from family physicians and birth companions (Panel B) and the resulting maps when the literature maps were formally updated by the family physicians and birth companions. These maps provide an overall (or meta) representation of how our understanding of an issue changes with the incorporation of different perspectives.

The results of updating procedures can also be analyzed at a factor level. Table 2 compares weights assigned to *having a Caesarean section* among recent immigrant women according to the literature, family physicians and birth companions. The literature-based weight was calculated from one study with an OR 1.42 (95%CI 1.03-1.96), which was subsequently normalized to a 0-1 scale. (31) *Having a Caesarean section* was also weighted by both family physicians (mean=0.46, $\sigma^2=0.1$) and by birth companions (mean=0.8, $\sigma^2=0.06$). Whereas a simple average weighted each point estimate equally, Bayesian updating (Equation 1, Annex) calculated an updated point estimate and credibility interval, accounting for variability in both the literature-based estimate and across stakeholder groups (Table 2).

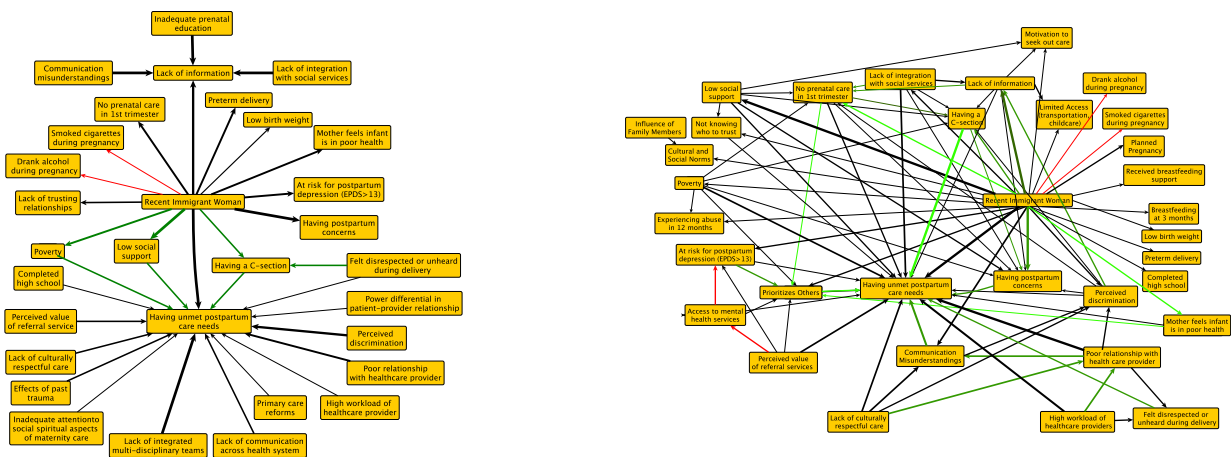
This approach to updating has proven an excellent way to engage meaningfully with divergent

perspectives. Few knowledge synthesis approaches can preserve divergent and often conflicting perspectives, ending up instead homogenizing or losing the richness within difference. (32) By inviting and holding space for multiple ways of understanding the same issue, this approach recognizes and creates opportunities to unpack differences in order to identify how and when these differences arise and with what consequences.

Panel A:



Panel B:



Panel C:

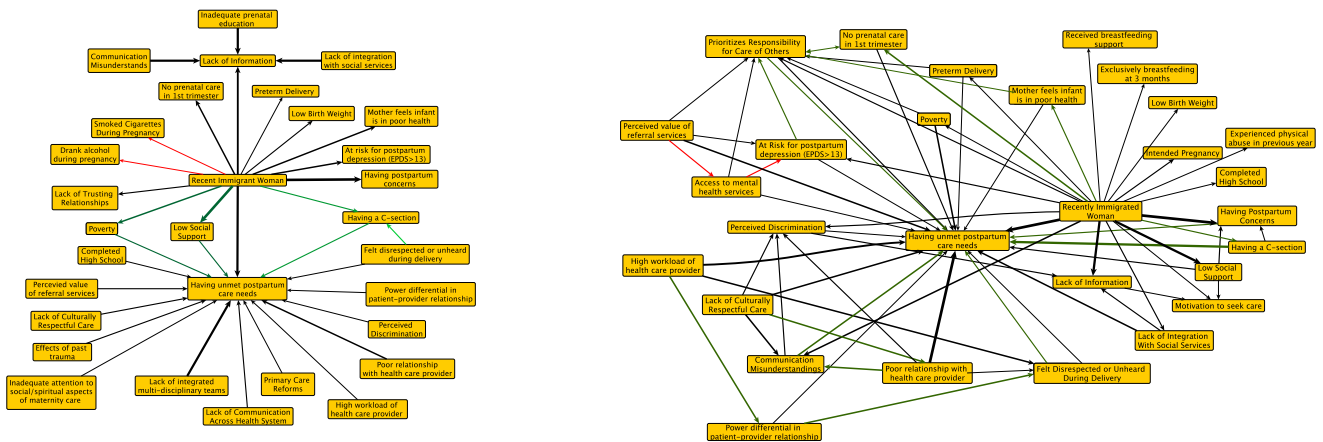


Figure 1: Fuzzy cognitive maps representing perspectives from the literature (Panel A), from family physicians (on the left) and birth companions (on the right; Panel B) on factors contributing to unmet postpartum care needs among recent immigrant women in Canada. Panel C shows the resulting maps when the literature maps were formally updated by the family physicians and birth companions. These maps provide an overall (or meta) representation of how our understanding of an issue changes with the incorporation of different perspectives.

<i>Influence of Having a Cesarean Section on Unmet Postpartum Care Needs Among Recent Immigrant Women</i>			
Source of Estimate or Weight	Odds Ratio or Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)
Literature	1.42	1.03	1.96
Normalized value	0.17	0.01	0.32
Updated by Family Physician Knowledge			
Average weight assigned by Family Physicians: 0.46			
Simple Averaging	0.31		
Bayesian Updating	0.39	0.17	0.61
Updated by Birth Companion Knowledge			
Average weight assigned by Birth Companions: 0.8			
Simple Averaging	0.48		
Bayesian Updating	0.65	0.41	0.89

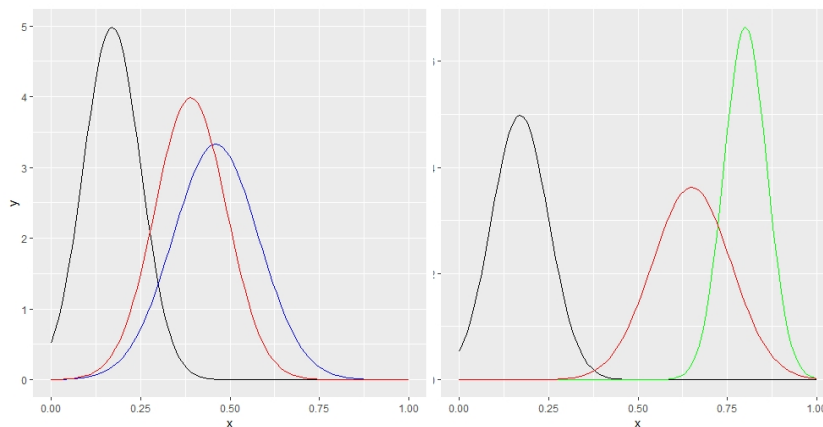


Table 2: Influence of having a Cesarean section on unmet postpartum care needs among recent immigrant women. i) Values from the literature (in black), weighted by family physician (in blue), and when updated (in red). ii) Values from the literature (in black), weighted by birth companions (in green), and when updated (in green).

Contextualizing Perspective When Updating

Differentially valuing the perspectives of experts is common practice in Bayesian updating when eliciting expert opinion. Conventionally, weighting is applied to account for the quality or relevance of different expertise, either through a researcher-defined weight assigning credibility or importance of the knowledge source to the issue at hand (Eq 3a) or by the proportion of data (eg. sample size) that a knowledge source contributes to the model (Eq 3b). (26,33) As the weight of a particular perspective increases, it will play a stronger role in shaping the average (or posterior distribution).

Weighting can be operationalized as a weighted average (as shown in Equations 3a&b in the Annex), or as part of Bayesian updating, which can be carried out at the level of an entire knowledge network (*Network Weighted Updating*) or at a factor level (*Factor Weighted Updating*). In both of these cases, the weighted updating is explicitly included in the updating procedure, making them more easily scrutinized, while sensitivity analysis can demonstrate the changing influence of valuing one perspective over another.

Network Weighted Updating

There may be contexts where our understanding of an issue is changed if one knowledge network has a stronger role in defining the contributing factors shaping that problem. If a perspective has been systematically marginalized, it may be of interest to examine how our understanding may change if perspectives, and therefore the cognitive maps, of marginalized groups “counted” for more than that of other perspectives. For example, in the context of understanding the factors contributing to unmet postpartum care needs among recent migrant women, the perspectives of undocumented families are almost absent from published literature. By up-weighting the cognitive maps from undocumented women, we still incorporate what knowledge is available in the literature, but make explicit that undocumented women have a more informed understanding of challenges they face than how they are often poorly represented in published literature. Operationally, network weighting is made explicit in the updating procedure by applying a weighting factor to the entire knowledge network.

Factor Weighted Updating

There may also be contexts when some stakeholders hold expertise about one aspect of a problem or issue, but may not be sufficiently informed to act as an expert on other aspects of an issue. Drawing from an example from our pilot study on perinatal care of recent immigrant women in Canada, when determining the indications for an emergency Cesarean section, an obstetrician’s perspective may be most valuable. However, when describing how discrimination affects access to postpartum care, the perspective of those discriminated against may be the

most valuable. This approach requires that we be explicit about whose knowledge and what evidence is prioritized and when, a process that is often implicit and unquestioned in most conventional scientific studies. (34) Doing so explicitly through Bayesian updating invites a more complex understanding of knowledge and expertise relevant to a specific context rather than assuming all evidence has the same relevance everywhere.

Operationally, factor weighted updating requires a mirror adjacency matrix for each stakeholder group that includes weights for each relevant factor. This matrix then adjusts (or weights) each factor of each perspective accordingly before carrying out the Bayesian updating procedure. Because each of the factor weights is explicit, they can be more easily scrutinized and sensitivity analysis can demonstrate the influence of valuing one perspective over another for each chosen factor.(21)

Updating using non-normal distributions (in class experiment)

As an experiment in advancing our updating tools, we are exploring updating procedures using non-normal distributions. The example described below is one of a network-weighted updating procedure, where the entire maps are weighted using an estimation of the number of cases that the map represents. We used a beta distribution, often used to describe the probability that one factor occurs or not occurs based on the occurrence of the preceding factor in the network. (35)

Drawing from our work in Mexico with two groups of traditional midwives, we estimated the weight of each map as the minimum number of deliveries each traditional midwife attended in their life by the number of them who participated in the session (in this case 10 births, although most of them have attended many more, by 11 and 18 traditional midwives). In Table 3, we present the original values from the two communities, the simple average, and the results from the updating with the beta distribution.

<i>Influence of “the woman has a loving and caring husband” on “the woman has a safe birth and healthy maternity”</i>			
Source of Estimate or Weight	Weight	Lower 95% CI (or CrI)	Upper 95% CI (or CrI)
Traditional midwives in Acatepec	0.8 (4/5)	NA	NA
Traditional midwives in Xochis	1.0 (5/5)	NA	NA
Average	0.91	NA	NA
Updated value	0.86	0.80	0.92

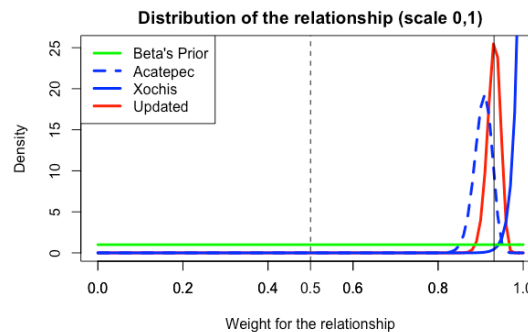


Table 3: Original weight values from both communities, the simple average, and the results from the updating with the beta distribution.

Interpreting Updated Cognitive Maps

Interpreting the findings from fuzzy cognitive mapping fundamentally depends on the questions used to make the maps, and the reasoning and ways that maps were updated or combined together. As soft models of people’s understanding, cognitive maps are often conceptual not probabilistic models. They show how stakeholders make sense of their experience, and can be informed by the literature as well as lived experience. We have drawn explanatory strength not only from identifying patterns of events (for example from statistical associations), but also by drawing on theoretical insight and stakeholders’ own sense-making of an issue. (2,16) In our example around unmet postpartum care needs of recent migrant women in Canada, relationships described in stakeholder cognitive maps show how stakeholders made sense of their experience in the context of evidence from the literature. They named many social and structural influences, and situated these in relation to key outcomes. The subsequent weighting by stakeholders helped inform where to focus subsequent analysis. (36) Quantitative and qualitative evidence together with stakeholder reasoning described in the fuzzy cognitive maps served as the raw material, which together with a theoretical understanding, served to explain

how specific factors and relationships between them contribute to relevant outcomes. (2,12,37,38) Updating map across different stakeholder perspectives facilitated the identification of areas of shared and different understanding. We developed this approach as a rigorous method to incorporate patient and other stakeholders' perspective in the design and evaluation of health services, with a particular focus on incorporating perspectives from marginalized populations, often under-represented in biomedical and clinical practice. (27) While this remains our primary interest, we foresee multiple uses for this method in evidence synthesis, quality improvement science and health services evaluation as a way to ground systematic reviews in local stakeholder knowledge and can serve as a tool for priority setting by assessing the credibility of evidence for a specific context.

Discussion

Bayesian methods are often criticized for undermining any element, or illusion, of objectivity in conventional frequentist methods. Expert judgments about the relevance or likelihood of an event are often seen as overly subjective, while generating meaningful representations of prior beliefs is a challenging process, with few clear guidelines. (10) We believe fuzzy cognitive mapping to be an important tool to support the development of rigorous and transparent priors, addressing a long-standing challenge in the development of meaningful priors for the Bayesian analyst. (10) Bayesian updating offers a transparency and replicability rarely accessible through other tools. Pivotal here is the reduction to a common scale (-1,+1) of formal measurement (odds ratios, relative risks, risk differences, or regression coefficients) and of stakeholder knowledge sets (scales of 1-5 or other graded responses). By then framing these as knowledge networks that can "speak" to another, one makes explicit several assumptions that are otherwise left implicit. For example, the prioritization of one knowledge set over others is part of framing the research question: how are conventional knowledge syntheses affected when stakeholder opinions are taken into account? We could also ask, for example, how the knowledge set of policy makers and resource allocators might change if they took account of the knowledge synthesis and the perspectives of other stakeholders. In that case, we would update the knowledge network of the policy makers with the systematic review and other

stakeholder knowledge sets. Our method requires detailed clarification of how this prioritization should occur, making this reasoning explicit, and therefore more open to scrutiny.

(34)

Annex 1

Equation 1: Bayes Rule

$$\text{posterior distribution} = \frac{\text{likelihood of the data} \times \text{prior distribution}}{\text{marginal likelihood of the data}}$$

$$\text{or } f(\theta|x) = \frac{f(x|\theta) \times f(\theta)}{f(x)}$$

Equation 2: Combining Equivalent Perspectives

$$AVG = \frac{\mu_A + \mu_B}{2}$$

Equation 3: Weighted average (AVG_w):

$$AVG_w = \mu_A(w_A) + \mu_B(w_B), \text{ where } w_A \text{ and } w_B \text{ are assigned weights (Eq 3a)}$$

$$AVG_w = \mu_A\left(\frac{n_A}{N}\right) + \mu_B\left(\frac{n_B}{N}\right), \text{ where } n_A + n_B = N \quad (\text{Eq3b})$$

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Appendix 10: PhotoVoice exhibit as knowledge translation strategy to support findings from application of *Weight of Evidence* with pregnant and parenting adolescents

This appendix presents the final products of the PhotoVoice project carried out as a knowledge translation strategy following the application of the Weight of Evidence. The focus was on defining supportive relationships with pregnant and parenting adolescents. Materials distributed at the event and reactions from those who attended the exhibit are also shared.



You Are Invited

To a Community Photo Exhibit by Young Mothers
Exploring What It Means to Support Young Parents in Ottawa

Thursday June 27th, 2019

4:00-5:30pm

St. Mary's Home 780 de l'Église St. Ottawa

613 749-2491

This event is free and open to the community

This project has been generously supported by:





My flowers are so precious to me. Thinking about them damaged, hurt, burnt- it is an irreversible damage to something so beautiful. That was symbolism for what I experienced when I was with my abuser because once I endured those experiences, there were irreversible changes- I would never be the same after that- just like the flower.

I grew those flowers, and I cared for them. I watched them thrive and then I destroyed them. And it was like a piece of me, which I guess is a way to interpret what I experienced.

That put me in the position of the abuser because I burnt the flower. But thinking as the flower, it was only a small part of the plant, the rest of the plant could still continue to grow and bloom and replenish the piece of itself that it lost.

When we experience trauma it leaves us with scars and it leaves us burnt. It leaves us a little bit broken but we manage to heal from that and overcome it, and just like that flower, it will still bloom and it will still thrive, and it will mend itself. And even though that particular flower is gone, the entirety of the plant is still intact. It is still there. It is still going to survive. That is symbolism for over-coming.



Stillbirth is a taboo subject and a lot of moms feel isolated and alone in their loss and they can't really find emotional support that gages that loss.

More people need to be aware and understand that it is a possibility in any pregnancy, they might not always have a typical pregnancy. There is a lot of shame and guilt when those things happen, and mothers feel like it is on them, when it is just a natural occurrence. There is a lot of shame

when there doesn't need to be- it isolates the mom and dad, and it makes them closed off and alone in those feelings.....

It may not be easy to see or to hear, but just listening helps keep their child alive in their memory because its really all they have. They don't get to watch their child grow older, their child just stays like that forever, and its not talked about. And its not shameful that their baby has passed, because it is still their baby- they have the clothes, the pictures, the ashes and they just stay that way forever. And its hard.

People are so concerned with the mother being content and happy and worry free, but it doesn't really prepare them for the reality that sometimes things go wrong, there is not the proper funding in medical centres for circumstances like that, there is not enough time, there is not enough space, there is not enough medical supplies to maintain the level of care for the mother emotionally and mentally afterwards.

There should be more awareness and more support systems in place for families who have bereaved loved ones because sitting in silence is deafening.

It is weird when we experience the best days of your life, when you have a daughter, a living daughter, and then the worst days when we lost our child. You've experienced these two colossal events with the same person. It is also very isolating because you feel so helpless because nobody really understands it until they go through it.

It is a piece of yourself, and you are never really the same.





This is a picture of me and my fiancé. I am pregnant with our rainbow baby and this is our gender reveal photos for her. We took them early because we had to get genetic testing done to ensure that this pregnancy would have been healthy, opposed to my last pregnancy, where there were severe complications.

We were super happy, and optimistic and we were excited because we really wanted to have a girl because of the daughter we lost.

For us, there is no correct way to cope with a loss. I was so stricken with grief that I immediately wanted to try again because I thought that that was the only way that we would be okay. It turns out it wasn't that simple.

It was hard because every step of the way, there was anxiety, there was fear, there was worry, there were extra appointments. I didn't know if she was kicking enough, I didn't know if spotting was normal, I didn't know if I should not be eating a certain food, or if that puts me at a predisposition to miscarry or have another stillbirth. We were very happy, but we were very guarded. And to this day, I still am with my kids because I am so scared of their of their mortality.

Not all women have the luxury of experiencing a healthy pregnancy with a supportive partner. I was really thankful for it, because I couldn't have imagined it the first time around. I didn't know that it was real, but there are fathers that do want to be there, and do step up and do support the mothers, even if those kids aren't biologically theirs. It was like a fairy tale.





moments where I'm down on myself.

This is a photo of me and my best friend. I was 18 and she 17.

We have tons of pictures and videos together but this is one of my favourites.

I chose this picture to represent an important positive relationship in my life. My best friend has been all I could ever ask for and much more. We've been friends for 9 years now (and counting). She resembles a sister more than a friend. Her and her family have taken me as their own. She has stood by me during my toughest times. She's not afraid to speak her mind and tell me when and where I need to improve. She helps push me towards my goals and away from things that aren't beneficial.

In my opinion everyone should have someone they can count on in life. Someone that motivates them and encourages them to be a better version of themselves. This is exactly what she is to me. She loves me even in the

This is a picture of me and my Dad. I am sitting in his lap and it is my 4th birthday. This is the only picture I have of me and my father together. I chose this picture for that very reason.

I grew up without my father present in my life. After this birthday, he wasn't there for the many that followed. We never celebrated 'Father's Day' together or any other holidays. There were a few reasons for this; falling on both him and my mother. Growing up without him left me with a huge void. I knew his background yes, but desperately wanted to know more. I knew I had a grandmother on his side but that was it. I didn't know my paternal family. The sad part was that he and them resided in the same city as me. They were so close yet completely out of reach.

Not having a father in your life leaves you questioning so much. I was well aware of the fact that he had other children. That alone left me wondering if there was something wrong with me. If it was that he didn't love me or that I wasn't good enough for him to want to raise or support. I found myself trying to fill that void with many other things; most that were not healthy nor added anything to me but only dug a deeper hole. Creating much more hurt than what was there originally. The main issue being boys; immature, lacking perspective or any kind of vision for their own futures. Many took advantage of my emotional vulnerability, that I would easily open up because of the brokenness that I harbored. I didn't have much of an example of what a 'good man' was. Nor did I know what a healthy relationship looked like. My father not being there and my mother having numerous unstable relationships over the years.

My father and I still do not have the 'best' relationship. We speak and are civil with one another, yet he is not yet someone I feel as though I can fully confide in. I truly hope we can one day reach that point but I am also well aware that any and every relationship is as they say 'a two way street'.

I believe that parents can take away from this. That their absence is not a small thing. It is something that deeply affects children at every age. That it is important to build relationships with your children. I believe that parents should be open to having heart to heart conversations with their children; allowing them to ask the 'hard to hear' questions. Giving them the opportunity to express how the absence (of either father or mother) made them feel and how it affected them throughout various stages of their life.



This is a picture of me and my mom standing side by side. I am about 3 years old and my mom is 21.

I have many photos of me and my mom. This is one of my favourites; alongside another where she can be seen holding me as I sleep at only a few months old.

I chose this picture because this and the few years that followed was a time where me and my mom were in a good place. Though I don't remember much I do know that as I grew beyond 10 years old that's when things began to go sideways. I emotionally did not feel supported. We did not grow closer throughout my preteen/teen years. We unfortunately grew apart. Not only that but we both endured hardships of our own creating stress and tension; which in turn led to me leaving home at 17 years of age.

Now, 2 years later our relationship has become something that is positive and rewarding. Never had I thought that we'd be able to mend or build our relationship. I thought that we were maybe too far gone. It was still rocky to start, but we had all the difficult conversations that we had tried to avoid or bottle up for years. We expressed our emotions and for once in my life I truly felt like I was heard by her. It meant a lot, and took a great deal of strength on both of our ends.

I love my mom tremendously, I always have. No matter how far we found ourselves. I am proud of how far we've come in months compared to years of a broken relationship.

I believe that many parents can take away from my experience. That it is important to build relationships with your children from the time that they're young. Not only that; it is never too late to build one with your children as long as you're both willing to put in effort. Its vital for them to be heard and taken seriously. They should have the freedom to express their feelings and even how the actions and/or words of their parents affects them.



June 2, 2019

To the Honourable Minister Elliot,

I am writing to you because I am concerned about the lack of support for medically vulnerable child in Ontario. This is my cousin Jordan, he has a genetic disorder (Miller Dieker) which limits his mobility, speech and ability to eat. Most children with this diagnosis will die before the age of 10 years- Jordan is now 7. Jordan has multiple seizures and risks aspiration daily.

Jordan may not be able to communicate “normally” but he connects through his heart. This photo is of him and his mother. Recent budget cuts to home care and support for medical equipment introduced by your government have left Jordan without critical support for home care and medical equipment. Jordan’s mother is forced to wear multiple hats and bares this stress on her own. I chose this photo because it

expresses how much he means to her regardless of their struggles he is still the absolute best part of her life.

Although there are some good supports for my cousin and her medically compromised son, additional areas in desperate need of support are funding for out of home respite, special services at home, allotted hours of nursing care provided by the south east LHIN services and better support for the medical equipment needed to keep Jordan alive. Jordan’s family no longer has adequate support from a relief worker, leaving his mother to manage supporting her young family, while also coordinating Jordan’s care needs, including coordinating multiple medical appointments, coordinating with nurses to set up respite in the future, ordering medications and feeds, and much more. This leaves no room for the importance of self-care especially with a child who has high needs that naturally would cause worry and stress. Jordan’s brother is a very loving and accepting big brother but as an adult I know it can be hard to watch Jordan go through this so the eyes of his brother I can only imagine the pain he faces.

Financial support for medical equipment needed to keep Jordan alive is renewable only once every 5 years. In my cousin’s experience, this equipment rarely last more than 3 years. Jordan is currently using a gravity feeding bag. Because of this Jordan can face the risk of being fed at the improper speed, compromising his levels of oxygen and being at risk for aspiration pneumonia. There is limited help with medical equipment such as feeding pumps and suction units.

This photo gives 2 faces of the many that struggle due to medical budget cuts. This photo shows a life to “terms of the cutbacks” that potentially can be fatal for his situation. This face shows us exactly why we need to fix and improve our government’s budget crisis’s. Jordan deserves to live as normal of a life as he can, and financial setbacks shouldn’t be what hinders him from a successful life. Jordan deserves to live and eat in a way that is best for him. What many of us take for granted, his mother struggles daily by the guilt and worry she faces every time she feeds her son, or goes to sleep, fearing the worst in the unknown.

I cannot support a government that balances the budget on the backs of children. I ask you to restore funding levels for medical equipment and in-home support for Jordon's family and families like his across Ontario. I look forward to hearing about your government commitments to supporting families of children with rare diseases across Ontario who bear exorbitant financial costs to care for their children.

Thank you for taking the time to read my letter/email and I look forward to your response.

Sincerely,

Talyssa Yellowknife



This is my daughter Alyzabelah and my son Aleczavier. She resides with my mother in our hometown 2 hours away and my son resides in Ottawa with me. It is my favourite photo of them because it captures their relationship perfectly.

She naturally leaned over to admire her brother who she only sees for a few hours a week. She had been expressing how much she loves and misses him.

My son and daughter have a natural bond. Even with the hardships of us living at St. Mary's and her living in Brockville she still holds so much love and pride as a big sister. This is the happier moments of our situation. What this photo doesn't show is the heartache and hardship each week when they have to say goodbye to each other as well as when she has to say goodbye to me, or the guilt I feel leaving her behind as I walk away with my son.

Recommendations to improve support for young families like mine:

- We need more transportation support if CAS has chosen to move a parent away from their child
- Coping classes for children who have a sibling at home when they are not able to be
- Options to reassess parents to explore opportunities to have child returned to their parents.
- Recognize and appreciate the bond between children in other care and the family they are away from
- How to co-parent effectively with your own parent without being undermined as a parent yourself
- How to draw a line of when my parent should be my mother, and when she should be considered the caregiver of my child where both my mother and I can clearly know the difference for each situation we face
- Making resources and supports more commonly talked about and readily available.





St Mary's Residence and Centre have become my strongest support since pregnancy with Aleczavier.

I learn daily how to become a more successful parent for Aleczavier predominantly but also tools I can use with my oldest as well.

The staff at St. Mary's go out of their way to make sure we can succeed. Dixie provides someone I can trust to watch my son, so I can focus on becoming a better parent to him.

Dixie also provides childcare for the on-site school for clients 21 and under. This means they can work on their education in a strong-willed environment and trust in their childcare provider. I feel this is important because it gives clients a chance to graduate and continue on to have great accomplishments.

This photo shows my support system. My home, and those I have come to trust in with my son, so I can better myself as a person and parent.

Even with all the programs available, there are some that would be cool to have but funding has been an issue. For example, we as clients suggested an infant CRP program, however, lack of funding has so far limited our access to these programs.



When you see a young parent....

1. **REFLECT** on your first impression. Why did you have it?
2. **DON'T JUDGE** a parent by a moment
3. **NEVER ASSUME** you know someone's story
4. Not all disabilities are visible
5. Remember that children are little people with **BIG FEELINGS**
6. Aesthetics **DO NOT DEFINE** parenting ability
7. Poverty **DOES NOT DEFINE** my parenting. Love is free
8. Accessing help is not shameful- it is a sign of **RESOURCEFULNESS**
9. My **IDEAL FAMILY** does not have to be the same as yours

Suggestions made by young mothers as part of a community research project

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Building Family despite.....

- **Poverty:** Young mothers are 4 times more likely to live in poverty than adult mothers (Al Sahab, 2015) Poverty limits opportunities and erodes safety nets. Young parents need financial security to build their own futures and that of their children.
- **Fragmented Families:** Families need more supports and resources for successful parenting while experiencing child protection orders. (Dumbrill, 2006) Young parents need greater access to support for parenting, transportation, and counselling, among others while navigating parenthood while experiencing child protection involvement.
- **Experiencing Abuse:** Young pregnant or parenting people are 2-4 times more likely to have experienced abuse compared to adults. (BORN, 2018) Sometimes being separated from unhealthy relationships is the best option. Don't assume that partners and family members are always safe, wanted or helpful.

If young parents do not feel **seen and heard** by those meant to support them, then they may lose trust in those relationships.

Believe young parents when they tell you that they are unsafe or scared.

Stigma has important impacts on mental health and the access to and use of services. (Benoit, 2018) **Recognize and reduce stigma against all families-everyone deserves support!**

Staying Human Through Tough Situations

- Preparing young parents and care providers for unexpected outcomes, including a greater understanding of short and long-term needs around loss and unexpected outcomes for young parents
- Many young parents lose social support from friends, partners and sometimes family. Young parents need supportive relationships- people who will help, but not take over, and learn together with them, even if it means asking "hard to hear" questions.

Grounding Quality Improvement in the Experience of Young Mothers

Over 20 young mothers have contributed to a 15-month participatory research project focused on improving perinatal care for young women in Ottawa.

After collectively reviewing published evidence, women in this study identified the experience of being judged, particularly as it relates to being identified as a child-protection risk, as a priority concern. Adapting published literature on factors contributing to child-protection investigations among young families served to broaden our understanding of risks and understand how health and social service systems may better support young families in the Ottawa area.

Supportive relationships were identified as a source of resilience and strength for young mothers throughout pregnancy and early parenting. This photo exhibit showcases the work of 4 young mothers, examining important relationships in their lives and what it means to support young families in Ottawa.

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