Who should be responsible for supporting individuals with mental health problems? Perceptions of multiple stakeholders

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March 2016

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master of Science (MSc) in Psychiatry

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Acknowledgements

I am indebted to a number of individuals for their guidance, assistance, support and encouragement throughout my Master's training. I wish to first and foremost thank my supervisors, Dr. Ashok Malla and Dr. Srividya Iyer, for their guidance and mentorship not only during my graduate studies, but ever since I began working at PEPP nearly 8 years ago. My professional and academic life has taken shape here due to the enormous wealth of opportunities they have both given me to learn, develop important skills, and broaden my horizons through travel, and in tandem, I have experienced great personal growth. Their wisdom, compassion, vision, and dedication to improving the lives of individuals affected by mental illness continually inspire me with awe and deep respect and have profoundly shaped who I am as a person. For this, I could never sufficiently express my gratitude to them.

I wish to thank my advisory committee members, Dr. Jai Shah and Dr. Marie-Josée Fleury, for their guidance and thoughtful input; Heleen Loohuis and Shruthi Venkataraman for their assistance with data collection and analysis, respectively; and Marie-Christine Rondeau for her help with translations.

I am very grateful to Gerald Jordan for enriching this thesis with his unique and valuable perspectives and insights and for his unwavering and overwhelming support and encouragement throughout this process.

I am grateful to both CIHR and FRQS for their generous financial support throughout my training.

Finally, I am deeply grateful to all of my study participants – PEPP patients, families, and treatment providers as well as policy and decision makers – for generously giving their time and for sharing their invaluable insights, which I hope I have done justice to in this thesis.

Contribution of Authors

As first author of both manuscripts, I (**Megan Pope**) made a significant contribution to the design of the project, data collection and analyses, interpretation of results, and writing of both manuscripts.

Dr. Srividya Iyer provided overall supervision and guidance on the design of the project, data collection, and analyses, and contributed significantly to the interpretation of results and revisions of both manuscripts.

Dr. Ashok Malla provided overall supervision and guidance on the design of the project and contributed significantly to the preparation and revisions of both manuscripts.

Gerald Jordan contributed significantly to data analysis and interpretation of the results for the second manuscript.

Shruthi Venkataraman contributed significantly to data analysis and interpretation of the results for the second manuscript.

Heleen Loohuis contributed significantly to data collection for the second manuscript.

ABSTRACT

Background: Individuals with mental health problems have many support needs that are often inadequately met. Youth with first-episode psychosis (FEP) represent a group with particularly great needs for support. While various parties are currently involved in supporting persons with mental health problems, perceptions of who should be responsible for meeting the various needs of these individuals remain unexplored. This is an important knowledge gap, as varying perceptions among different stakeholders could be the cause of unmet needs for support. **Objectives:** The objectives of the following studies were (1) to discover what is known about perceptions of locus of responsibility for supporting individuals with mental health problems, what factors shape these perceptions, and how these factors relate to one another; and (2) to explore various key stakeholders' perceptions of who should be responsible for supporting individuals with mental health problems. **Methods:** A critical literature review was conducted, in which the conceptual contributions and limitations of relevant works were critically evaluated and a concept map was created. A qualitative descriptive study was then undertaken. Focus groups were conducted with FEP patients, their families, and treatment providers and individual interviews were conducted with mental health policy/decision makers. Transcripts were analyzed thematically. **Results:** The critical review identified salient concepts from literature on public attitudes towards the welfare state and views of individual versus governmental responsibility for need provision and health; the morality of caring; and attributions of responsibility for mental illness. A conceptual framework was built from these findings. The qualitative study revealed that individuals with mental health problems themselves; stakeholders in the immediate and extended social networks of these individuals; macro-level stakeholders with influence; and society as a whole were perceived to have a wide range of responsibilities for supporting persons with mental health problems. Themes relating to the structure and nature of roles and responsibilities were also identified. **Discussion:** The critical review and resulting concept map have shed light on the different factors that may shape perceptions about locus of responsibility for supporting individuals with mental health problems, while the qualitative study has revealed that key stakeholders ascribe a wide range of roles and responsibilities to various parties. Together, these studies fill a large knowledge gap about perceptions of who should be responsible for supporting individuals with mental health problems, and the findings have significant implications for mental health practices, policies, and research.

RÉSUMÉ

Contexte: Les personnes ayant des problèmes de santé mentale ont de nombreux besoins de support qui sont souvent remplis de manière inadéquate. Les jeunes avec un premier épisode psychotique (PEP) représentent un groupe avec des besoins particulièrement grands de soutien. Bien que différentes parties prenantes sont actuellement impliquées dans le soutien des personnes ayant des problèmes de santé mentale, les perceptions de qui devrait être responsable de répondre aux différents besoins de ces personnes restent inexplorées. Ceci est un manque important dans les connaissances, puisque des perceptions variées entre les différentes parties prenantes pourraient être la cause des besoins non satisfaits en matière de soutien. **Objectifs:** Les objectifs des études suivantes ont été (1) de découvrir ce qui est connu sur les perceptions du lieu de la responsabilité pour soutenir les personnes ayant des problèmes de santé mentale, quels facteurs façonnent ces perceptions, et comment ces facteurs sont liés les uns aux autres; et (2) d'explorer les perceptions des différents acteurs clés sur qui détient la responsabilité de soutenir les personnes ayant des problèmes de santé mentale. **Méthodes:** Une revue critique de la littérature a été réalisée, dans laquelle les contributions conceptuelles et les limites de travaux pertinents ont été évaluées de façon critique et une carte conceptuelle a été créé. Une étude descriptive qualitative a ensuite été entreprise. Des groupes de discussion ont été menés auprès de patients avec PEP, leurs familles, et les fournisseurs de soins et des entretiens individuels ont été menés avec les preneurs de décisions sur les politiques en santé mentale. Les transcriptions ont été analysées thématiquement. **Résultats:** La revue critique a identifié des concepts saillants de la littérature sur les attitudes du public envers l'État-providence et les vues de la responsabilité individuelle versus gouvernementale de répondre aux besoins et en matière de santé; les obligations interpersonnelles/l'éthique du "care"; et les attributions de responsabilité pour la maladie mentale. Un cadre conceptuel a été construit à partir de ces résultats. L'étude qualitative a révélé que les personnes ayant eux-mêmes des problèmes de santé mentale; les parties prenantes dans les réseaux sociaux immédiats et extérieurs de ces personnes; les parties prenantes avec de l'influence au niveau macro; et la société dans son ensemble ont été perçus comme ayant un large éventail de responsabilités dans le support aux personnes ayant des problèmes de santé mentale. Les thèmes relatifs à la structure et à la nature des rôles et des responsabilités ont également été identifiés. **Discussion:** La revue critique et la carte conceptuelle résultante ont mis en lumière les différents facteurs qui peuvent façonner les perceptions au sujet du lieu de responsabilité à soutenir les personnes ayant des problèmes de santé mentale, alors que l'étude qualitative a révélé que les intervenants clés attribuent un large éventail de rôles et de responsabilités aux différentes parties prenantes. Ensemble, ces études comblent un vide important de connaissances sur les perceptions de qui devrait être responsable de soutenir les personnes ayant des problèmes de santé mentale, et les résultats ont des implications importantes pour les pratiques de santé mentale, les politiques et la recherche.

CHAPTER 1

Background and Objectives

Individuals with mental health problems have many support needs which are often inadequately met (Mental Health Commission of Canada [MHCC], 2012; World Health Organization [WHO], 2013). Individuals with psychotic disorders, considered to be among the most serious mental illnesses, face particularly great challenges and consequently have an especially high need for a number of supports. Psychotic disorders, characterized by delusions, hallucinations, disorganized behaviour, changes in mood and personality, and impaired cognitive functioning, are among the leading causes of disability worldwide (WHO, 2008) as they affect functioning in virtually every sphere of life, from disrupting school and work activities to impairing the affected person's ability to find adequate, affordable housing or pay for medications (Health Canada, 2002). Given that psychotic disorders, like most mental disorders, typically emerge during adolescence and early adulthood (Kessler et al., 2007; Tandon, Keshavan, & Nasrallah, 2008), a period of developmental transition when youth begin to chart important social, educational, and occupational trajectories, needs may be greatest among youth experiencing a first episode of psychosis (FEP).

1.1. Support needs of individuals with FEP

Individuals with FEP have a wide range of support needs, but those that tend to pose the greatest challenges at the systems level include the need for housing support; help initiating or resuming work and school activities; general financial support; help covering the costs of medications, mental health services, and substance abuse treatment programs; and support for stigma reduction (MHCC, 2012).

1.1.1 Housing support

According to the Mental Health Strategy for Canada (MHCC, 2012), people with mental health problems often lack access to safe and affordable housing. The ability to find and maintain adequate housing is compromised for individuals with a psychotic illness, and this in turn has a negative effect on their mental health. Having better quality, independent housing (as opposed to living in a residential setting) is associated with better social relationships and supports, which are often lacking among people with psychotic disorders, as well as with better quality of life (Browne & Courtney, 2007). In fact, independent living is seen by patients to be an important aspect of recovery, because finding a place to live requires effective interpersonal skills and represents independence and empowerment (Browne & Courtney, 2007). The Mental Health Strategy for Canada identifies the need to increase access to safe, affordable, and supported housing for people with mental illnesses, even stating that "assistance with rent should be provided where necessary" (MHCC, 2012, p. 72). Housing for individuals with mental health problems has been identified as an unmet need in other countries as well. Indeed, some Australian researchers recently suggested that the proportion of individuals using mental health services who have access to stable housing should be a key performance measure of Australian mental health care (Rosenberg, Hickie, & Mendoza, 2009).

1.1.2 Support in initiating or resuming school/work activities

Another area where individuals with FEP need support is in initiating or resuming school or work activities (MHCC, 2012). Psychosis typically strikes during a stage of life where youth are often either completing school and entering the workforce or pursuing higher education (Killackey, Jackson, Gleeson, Hickie, & McGorry, 2006). As a result, work and school functioning is often disrupted. There is a high rate of unemployment among FEP youth compared with their same-age peers in the general population, and this trend tends to worsen over time (Killackey et al., 2006; Marwaha & Johnson, 2004). Individuals with psychotic illnesses face several barriers to going back to work, including the stigma associated with mental illness, discrimination from employers, the financial disincentive of losing one's disability benefits, and lack of professional support (Marwaha, 2005; Marwaha & Johnson, 2004). While there is a large evidence base for the effectiveness of the Individual Placement and Support (IPS) model of vocational reintegration in helping FEP patients find employment or return to school (Killackey, Jackson, & McGorry, 2008; Nuechterlein et al., 2008; Rinaldi et al., 2004), IPS and other supported employment programs are not offered in many mental health services, in part due to difficulties integrating these programs into existing services (Killackey & Waghorn, 2008; Killackey et al., 2006; Marwaha & Johnson, 2004; Rinaldi, Miller, & Perkins, 2010).

1.1.3 General financial support

Because many FEP patients are unemployed, they often lack a stable source of income and must therefore rely on family members and/or social assistance for financial support (Killackey et al., 2006). This places a large burden on families and the economy (Awad & Voruganti, 2008; Rossler, Salize, van Os, & Riecher-Rossler, 2005). Furthermore, it has been shown that financial strain is significantly and independently associated with poorer clinical outcome five years after a first psychiatric admission for FEP, having a negative impact on both physical and mental health (Mattsson, Topor, Cullberg, & Forsell, 2008). General financial support is thus an important need of individuals with FEP.

1.1.4 Support for the costs of medications & mental health services

FEP patients must also bear specific illness-related costs, such as the costs of mental health services and psychiatric medications. In Canada, provincial and territorial governments are responsible for providing health care within the dictates of the Canada Health Act (the national health insurance program), which includes covering the costs of medically necessary hospital and physician services for all eligible residents (Health Canada, 2012). In addition, provinces and territories each administer their own health insurance plans offering varying levels of additional insurance. However, because these different plans do not insure all individuals and services equally, FEP patients often have to pay out-of-pocket or through private insurance for medications and mental health services (MHCC, 2012). Considering that antipsychotic medication is usually a central component of treatment for psychosis (Health Canada, 2002) and that the newer "second-generation" antipsychotics can be very expensive (Alessi-Severini et al., 2008; Gardner, Baldessarini, & Waraich, 2005; Ilyas & Moncrieff, 2012), the remainder that is left to pay is still too much for many patients (MHCC, 2012). In addition, psychologist and counselling services delivered outside of a hospital or institutional setting are not covered by the public healthcare system and are underfunded by private health insurance (Cohen & Peachey, 2014), putting the cost burden on individuals with FEP.

1.1.5 Support for the costs of substance abuse treatment programs

The treatment of comorbid substance use problems, which are highly prevalent in FEP (Archie et al., 2007; Pope, Joober, & Malla, 2013), presents another need for support for FEP patients. Although substance use in FEP can be effectively reduced by early intervention services using standard case management (Archie et al., 2007; Pope et al., 2013), FEP patients with more serious substance abuse or dependence problems often require more specialized services offered by substance abuse treatment and rehabilitation programs. However, these programs often lack government funding (National Treatment Strategy Working Group, 2008), requiring individuals with FEP to occasionally have to pay for services directly or through private health insurance.

1.1.6 Support for stigma reduction

Reducing stigma and building awareness of ways to prevent mental ill health have been identified as priority areas by the Mental Health Strategy for Canada (MHCC, 2012). The stigma associated with mental illness is widespread and has many harmful consequences for individuals with psychotic disorders (Hocking, 2003; Rossler et al., 2005): for example, it acts as a barrier to returning to work and finding housing and diminishes perceived quality of life (El-Badri & Mellsop, 2007; Marwaha & Johnson, 2004). There is growing recognition that all members of society must contribute to combatting societal-level discrimination and stigmatizing attitudes (MHCC, 2012; Hocking, 2003).

1.2 Objectives

It is well-established that various needs of individuals with mental health problems, particularly serious ones such as psychosis, are unmet or inadequately met. Although the Canadian healthcare system provides for several of these needs, gaps in health insurance coverage across provinces and territories have led a number of other stakeholders (families, community organizations, etc.) to become formally and informally involved in supporting these individuals (Institute of Health Economics, 2010), and in some cases, individuals with mental health problems are left to support themselves.

One possible cause of unmet or inadequately met needs for support may be disagreement among various stakeholders as to who should be responsible for meeting the needs of individuals with mental health problems. Furthermore, different stakeholders' perceptions of their own and each other's responsibilities may iteratively shape and be shaped by the roles and responsibilities assumed by each. For example, a person with mental health problems may expect more support from their treatment team if they receive minimal family support.

To date, no other studies have explored relevant stakeholders' perspectives about locus of responsibility for supporting individuals with mental health problems. Since varying perceptions of responsibility across stakeholder groups could shape the extent and type of support received by these individuals, this is an important knowledge gap that must be addressed.

To address this knowledge gap, we conducted two studies. The objective of the first study was to critically review the relevant literature in order to discover what is known about perceptions of responsibility for supporting individuals with mental health problems and to create a conceptual framework of factors shaping these perceptions.

The objective of the second study was to directly explore key stakeholders' perceptions of who should be responsible for supporting individuals with mental health problems and their views of the precise roles and responsibilities of these parties. The second study had a narrower, more specific scope than the first study because it explicitly explored, using a qualitative approach, perceptions of relative responsibilities for meeting the support needs of individuals with mental health problems among various stakeholders in the Quebec context.

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CHAPTER 2

Methods

2.1 Critical literature review

A critical literature review was first undertaken to discover what is known about perceptions of who should be responsible for supporting individuals with mental health problems and the factors shaping these perceptions. An extensive, librarian-assisted review of literature spanning multiple disciplines was conducted in four phases: a planning phase, a search phase, a selection phase, and an evaluation phase. Relevant articles were selected and appraised for their ability to inform the review questions, and salient concepts were extracted in order to build a conceptual framework of the topic.

2.2 Qualitative descriptive study

Given the lack of research directly investigating perceptions of who should be responsible for supporting individuals with mental health problems, a qualitative descriptive study was conducted with the aim of exploring key stakeholders' perceptions of who should be responsible for supporting individuals with mental health problems and their views of the roles and responsibilities of these parties.

Focus groups were conducted with FEP patients, their families, and treatment providers from the Prevention and Early Intervention Program for Psychoses in Montreal, Quebec (PEPP-Montreal), and individual interviews were conducted with institutional- to regional-level mental health policy and decision makers. Focus groups and interviews were audio recorded and the transcripts were analyzed thematically.

Greater detail on the methodology employed in the critical review and in the qualitative study is included in the chapters that follow.

CHAPTER 3

Manuscript #1: Who should be responsible for supporting individuals with mental health problems? A critical literature review

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3.1 Abstract

Background & objectives: Individuals with mental health problems have many support needs that are often inadequately met; however, perceptions of who should be responsible for meeting the various needs of these individuals have been largely unexplored in the literature. The objective of this review was to critically evaluate the relevant literature in order to determine who different stakeholders feel should be responsible for supporting individuals with mental health problems, what factors shape perceptions of who should be responsible for supporting individuals with mental health problems, and how these relate to one another. **Methods:** Following an initial planning phase, an extensive librarian-assisted literature search was undertaken. Relevant literature was selected and read in full, after which the conceptual contributions of each work were critically evaluated in the context of the review questions. A concept map was then created to build a conceptual framework of the topic. **Results:** Three main areas of research were found to offer important conceptual understandings of the review questions: public attitudes towards the welfare state and views of individual versus societal/governmental responsibility for need provision and health; morality of caring and social/interpersonal responsibilities; and attributions of responsibility for mental illness. The contributions and limitations of significant works within these research themes and the theoretical links between concepts are discussed. **Discussion:** Varying perceptions of who should be responsible for supporting individuals with mental health problems could be the cause of unmet support needs among this group. By critically evaluating the relevant literature and creating a conceptual framework of factors influencing perceptions of responsibility for supporting individuals with mental health problems, we have enhanced our understanding of the

different factors that may play a role in shaping these perceptions. However, research directly assessing the perceptions of key stakeholders is needed.

3.2 Introduction

Individuals with mental health problems have many support needs that are often inadequately met (MHCC, 2012; WHO, 2013): for example, the need for help with covering specific illness-related costs, such as the costs of some medications and mental health services (including substance abuse treatment programs) (MHCC, 2012), the need for help with returning to or initiating work or school activities (Rinaldi et al., 2010), and the need for help with sensitizing others to and reducing the stigma surrounding mental illness (Hocking, 2003).

Different governments provide for the needs of people with mental health problems to different degrees, with important gaps in health care coverage in many cases. Given the variation in coverage offered by different governments across countries and even across regions within the same country, many of the needs of individuals with mental health problems are taken up by other parties, such as family members or community organizations (Awad & Voruganti, 2008; MHCC, 2012), or these individuals are left to support themselves, at least with respect to some specific needs. Thus, mental health care at the individual patient level and at the systems level is organized around a formal and informal division of roles and responsibilities among various stakeholders (e.g., families, treatment providers, government, community organizations, patients themselves, etc.).

While the support needs of individuals with mental health problems are well documented, perceptions of who should be responsible for meeting these needs remain largely unexplored in the literature. This is a significant knowledge gap, as people's perceptions of their responsibility for supporting individuals with mental health problems could influence whether or not they provide them with support. If, for example, a family member feels that it is the responsibility of their mentally ill relative to pay for their own medication, then they may be less inclined to provide this support themselves. Moreover, how individuals with mental health problems themselves seek to meet their support needs may differ depending on their own perceptions of responsibility. Considering that different parties are involved in supporting people with mental health problems, understanding relevant stakeholders' views of the *relative* responsibilities of these parties and the factors shaping these views would be particularly informative as they iteratively influence and reflect the complex division of roles and responsibilities within health care.

Interestingly, strategic directions outlined by key national and international bodies (e.g., the Mental Health Commission of Canada’s 2012 Mental Health Strategy for Canada; the World Health Organization’s Mental Health Action Plan 2013-2020) emphasize fostering collaboration between the different levels of government, the private and voluntary sectors, and individuals with mental health problems themselves and their families in order to transform mental health systems (MHCC, 2012; WHO, 2013); in essence, promoting a vision of shared responsibility for mental health care across stakeholder groups. Considering that a balance of responsibility is seen as ideal and a goal to strive for, it is all the more important to examine key stakeholders' perceptions of responsibility and uncover any disparate views.

Given these important knowledge gaps, the purpose of this review was to critically evaluate the literature in order to answer the following questions: 1. Who do different stakeholders feel should be responsible for supporting individuals with mental health problems? 2. What factors shape perceptions of who should be responsible for supporting individuals with mental health problems, and how do these relate to one another?

3.3 Methods

Given the paucity of information on this topic, a critical literature review was undertaken in order to create a conceptual framework (Grant & Booth, 2009; Jesson & Lacey, 2006). Critical reviews are a type of literature review in which the literature is researched at length and the conceptual contributions, strengths, and limitations of significant works are critically evaluated (Grant & Booth, 2009). These reviews differ from more systematic approaches to reviewing the literature (such as systematic or scoping reviews) in that there are no formal search, appraisal, or analysis guidelines; the literature search is extensive but not exhaustive; and a relatively small yet representative sample of the relevant literature is evaluated, with a focus on key works (Grant & Booth, 2009). Critical reviews are appropriate in situations where little is known about a subject area and there is a need to identify salient concepts and build a conceptual framework or model with which to guide further inquiry. As such, the major strength of critical reviews lies in their ability to create conceptual links and thereby promote conceptual innovation and theory development (Grant & Booth, 2009).

Review methodology

The present review occurred in four phases: a planning phase, a search phase, a selection phase, and an evaluation phase. In the planning phase, the first author consulted with mental health experts (including senior authors S.I. and A.M.) in order to collaboratively identify areas of research that could shed light on the review questions. Several domains of inquiry were deemed relevant, including research on the morality of caring and on stigma and attributions of responsibility for mental illness.

In the search phase, the first author consulted with university librarians to select appropriate search terms to be used in several electronic databases and in a general Internet search (Google Scholar). The following subject headings and key words were used in various combinations in searches of MEDLINE, PsycInfo, and Web of Science and in a Google Scholar search of peer-reviewed English-language literature with publication dates ranging from 1960 to

2015: health, mental health, mental illness, mental disorders, mentally ill persons, mental health services, responsibility, social responsibility, perceptions of responsibility, attributions of responsibility, locus of responsibility, interpersonal responsibility, moral responsibility, moral obligations, morality of caring, stigma, political ideology, welfare state, distributive justice, and social justice. The references and citations of relevant works were also hand-searched using backward and forward citation tracking search techniques, and expert recommendations of pertinent literature were also pursued.

In the selection phase, titles and abstracts of articles retrieved during the search phase were screened and articles were selected based on their relevance and ability to inform the review questions. A paper was deemed relevant if it could shed light on the questions in an important way (e.g., a study dealing with political orientation and views of the government's role was selected because it offered an explanation of how political ideology can shape general views of government responsibility for need provision). Quantitative, qualitative, and mixed methods research studies as well as reviews and theoretical papers were reviewed with equal consideration.

Finally, in the evaluation phase, selected articles were read in full and the conceptual contributions, strengths, and limitations of each were noted in detailed memos and critically evaluated in the context of the review questions. Articles were sorted into different groups based on the main themes or concepts addressed and a concept map was created using knowledge modeling software (CmapTools) in order to organize the most salient concepts from the literature and graphically display the relationships between them (Figure 1).

The first author consulted with the senior authors (S.I. and A.M.) regularly during the selection and evaluation phases, particularly regarding the thematic classification of selected articles and the development of the concept map. The concept map and initial review findings were also presented to and discussed with peer and expert audiences during several seminars held at the authors' affiliated mental health university institute and at an international conference, helping to further validate and refine the results.

It is important to note that the phases of this review were conducted in an iterative fashion, with the results of the selection phase sometimes pointing to new and relevant areas of research to be explored, which then resulted in a new search phase. Occasionally, searches yielded no relevant results and required reformulation of search terms. As such, this review is the result of not one but several literature searches.

3.4 Results

While none of the articles assessed in the evaluation phase directly examined the question of who should be responsible for supporting individuals with mental health problems, several papers stemming from a wide range of disciplines and orientations (including social, cross-cultural, and developmental psychology; health ethics; social justice; political science; psychiatry; gerontology; etc.) discussed responsibility for health in general or offered distinct and important conceptual understandings of the factors that may shape perceptions of who should be responsible for meeting the needs of individuals with mental health problems. These works can be broadly categorized into three main themes: public attitudes towards the welfare state and views of individual versus societal or governmental responsibility for need provision and health; morality of caring and social or interpersonal responsibilities; and attributions of responsibility for mental illness.

Public attitudes towards the welfare state and views of individual vs. societal/governmental responsibility for need provision and health

Several works discussed public attitudes towards the welfare state and views of individual versus societal or governmental responsibility for need provision and health. At a fundamental level, there are conflicting opinions as to who should bear the greater responsibility for health: the government/society as a whole or individuals themselves. In a seminal review article, Rothstein (2010) puts forth arguments in favour of universal welfare state systems (which include universal health care) based on empirical evidence that the more generous and comprehensive the welfare state, the higher the subjective well-being of its citizens and the greater the level of social cohesion, equality, and trust. Indeed, public satisfaction with health care is high in countries with universal health care systems (e.g., France, Germany, Canada, and Great Britain) (Brown, 2003). Most Canadians, for instance, are highly supportive of the values on which the national health care system is founded (Mendelsohn, 2002) and the overwhelming majority favour a strong government role in health (EKOS Research Associates Inc., 2012).

However, critics of the welfare state argue that the government's and medical establishment's involvement in individual health is too far-reaching and that this impinges on personal freedoms and undermines the responsibility of individuals for their own health (Resnik, 2007; Szasz, 1963; Wikler, 1978). Applied to mental health, arguments against state over-involvement in health are closely aligned with the concept of the “therapeutic state”, a term coined by psychiatry critic Thomas Szasz (1963) to refer to the state’s control of the populace through the medicalization of social problems and undesirable behaviours. For example, Pupavac (2001) contends that providing psychosocial interventions to war-affected populations by international governments and health agencies, while seemingly beneficent, actually individualizes social problems and pathologizes normal reactions to trauma. Furthermore, it reduces the legitimacy of local coping strategies and erodes natural support networks, such as those of families and communities (Pupavac, 2001). In a related vein, research within the field of gerontology has explored the "crowding out" phenomenon, in which the formal supports provided by generous welfare state systems have long been thought to interfere with, or crowd out, informal, natural community supports and shift the responsibility for caring for the elderly from families and communities to the state (Künemund & Rein, 1999; Moor et al., 2013).

Arguments in favour of individual responsibility for health are largely predicated on the recognition that lifestyle factors contribute to the development of many illnesses (Minkler, 1999; Resnik, 2007; Wikler, 2002). According to the argument, a person who makes lifestyle choices known to be detrimental to health should be held personally responsible for any ill health they experience as a consequence. This argument may be especially influential in the case of mental health problems, as mental illnesses (such as substance abuse and psychosis) are considered by the public to be more personally controllable than physical illnesses (Corrigan, 2000; Corrigan et al., 2003; Corrigan & Watson, 2003), despite improvements in public mental health literacy and the greater emphasis in recent years on the biological bases of mental disorders (Schomerus et al., 2012). Others, such as Morrisette et al. (2015), argue in favour of greater personal responsibility for health because they disagree with the notion that health is a fundamental right.

Some theorists caution that a danger inherent in overemphasizing individual responsibility for health is that the state risks becoming paternalistic and overly punitive towards those who knowingly adopt unhealthy behaviours, denying the same care and support to these individuals that they would offer to individuals experiencing ill health through no apparent fault of their own (Minkler, 1999; Wikler, 1978; Wikler, 2002). Moreover, it limits the responsibility of government for the health of its citizens and raises difficult questions: which health behaviours are ever truly voluntary and which health conditions are ever fully preventable

(Minkler, 1999; Wikler, 2002)? For these reasons, several theorists encourage a balanced view of responsibility for health, with individuals doing their best to improve their own health and governments addressing the larger-scale social determinants of health through sound policies and the creation of environments conducive to good health: in other words, individual responsibility within the context of broader social responsibility (Minkler, 1999; Resnik, 2007; Wikler, 2002). Of note, Devisch (2012) dismisses the individual-government dichotomy as reductionist and goes beyond the notion of shared responsibility for health to propose co-responsibility: intertwined, inseparable individual and societal responsibilities for health.

Several articles revealed that attitudes towards the welfare state and views about government responsibility for need provision and health are shaped by multiple factors, including political ideology, national and cultural context, gender, age, and the extent to which an internal versus external locus of causality is emphasized. A qualitative study conducted in the United States exploring public views about determinants of and attributions of responsibility for health found that participants largely spoke of individual responsibility for health, but some identified “layers” or domains of responsibility and could conceive of multiple parties sharing responsibility (Lundell et al., 2013). Importantly, participants' views were influenced by political ideology, with political conservatives tending to appeal to notions of individual responsibility for health more than liberals and being more opposed to government involvement in health, which they viewed as a threat to individual freedom in light of the restrictions placed on lifestyles. Liberals, meanwhile, tended to identify more ways in which the government could play a role in improving public health other than lifestyle regulation. The authors caution that the public's tendency to locate responsibility for health within the individual can undermine efforts to increase awareness of the social determinants of health and gain public support for policies aimed at reducing health inequalities.

In a comparative study of 24 nations in Europe, Oceania, North America, Asia, and the Middle East, Blekesaune and Quadagno (2003) found that public attitudes toward welfare state policies vary across nations due to contextual and ideological factors. Specifically, while policies for the sick and elderly were viewed very favourably across nations, the public was somewhat less supportive of policies for the unemployed and there was greater national variation in support for these policies. This variation was found to be attributable in part to contextual or situational factors, in that nations experiencing high levels of unemployment tended to favour policies directed at reducing unemployment; but mainly to ideological factors, with nations (and individuals) espousing an egalitarian ideology tending to support income redistribution more than those who did not. Conversely, the authors reason that the greater uniformity in attitudes towards policies for the sick and elderly reflected self-interest more than contextual or ideological factors, because everyone expects to get old and experience health problems with advancing age. Moreover, women and older people were more supportive of welfare state policies than men and younger people; again, largely due to their greater espousal of an egalitarian ideology. These gender findings are corroborated by other studies showing that women tend to support social welfare programs and equal rights more than men due to their greater egalitarian ideology (Pratto et al., 1997).

The extent to which an internal versus external locus of causality is emphasized can also affect judgments about whether the government or individuals themselves should be more responsible for providing for basic needs. In a cross-cultural study examining the effects of internal-external causal attributions, culture, gender, and political ideology on attitudes towards welfare policies for the poor, Shirazi and Biel (2005) found that people who believe that poverty is the result of external, situational factors (e.g., lack of available jobs or educational opportunities) rather than internal, dispositional factors (e.g., reckless spending habits or laziness) are more likely to feel that the government should provide for basic needs, such as health and child care, for the poor. Political liberals and females ascribed greater responsibility to the government for need provision than conservatives and males, but causal attributions largely mediated these effects. Furthermore, culture also played a role in shaping views, with some nations (the USA, Australia, South Africa, and Canada-Ontario, which was considered separately from Canada-Quebec) assigning significantly less responsibility to government for need provision than the other nations surveyed; some nations (Norway, Sweden, France, Ireland, and Israel) assigning significantly more responsibility to government; and other nations (the Netherlands, New Zealand, Japan, Jamaica, and Canada-Quebec) assigning an average level of responsibility to government.

While these papers help situate public attitudes towards the welfare state and show how views of individual versus societal/governmental responsibility for need provision and health can be influenced by several factors, they are limited in a number of ways. For instance, although they tell us something about public attitudes towards government support of the sick, elderly, unemployed, and poor, they do not address attitudes towards government support of people with mental health problems specifically. This is an important limitation, as more general social welfare policies may be less controversial and polarizing than policies for the mentally ill. Indeed, a recent systematic review of changes in public attitudes towards mental illness over time reveals that social acceptance of people with mental health problems is the same (i.e., poor) or even worse than it used to be decades ago, despite improved mental health literacy

(Schomerus et al., 2012). This suggests that public attitudes towards government support of these individuals may be less favourable than to general welfare provision.

These papers also tend to focus on absolute rather than relative judgments of government responsibility, in that they do not consider the responsibilities of other parties who play a role in supporting people in need besides the government or individuals themselves (e.g., families). While several theorists (Minkler, 1999; Resnik, 2007; Wikler, 2002) encourage a balance of responsibility for health between individuals and governments, they do not consider that seriously ill individuals, such as many individuals with serious mental health problems, are often unable to meet their own support needs and may require support from other parties, including family members, community organizations, and mental health treatment providers.

Finally, methodological weaknesses in some of the studies reviewed limit the relevance of the findings and conclusions drawn. For example, Shirazi and Biel (2005) sampled only undergraduate students for their 2005 study. Given that students are known to hold more liberal political views, this could have restricted the range of their findings on cross-cultural differences in political ideology.

Morality of caring and social/interpersonal responsibilities

A very different area of inquiry looking at the morality of caring and social or interpersonal responsibilities and their effect on helping behaviours was found to provide a distinct and valuable perspective on the review questions. The morality or ethics of caring refers to the moral responsibility to be attentive to the needs of others (Miller, 1994). When deciding whether or not to help a person in need, this type of morality emphasizes the maintenance of harmonious interpersonal relationships and consideration of the needs of others and is contextually sensitive (i.e., considers the details of the situation case-by-case), unlike decision-making based on the ethics of justice, which emphasizes impartial, universal, and contextually insensitive rules (Botes, 2000; Miller, 1994).

Individuals’ views of their interpersonal responsibilities (the moral obligations they feel towards others) have been found to influence their decisions about whether or not to help a person in need, and further, these views may be shaped by cultural context. In a theoretical paper, Miller (1994) argues that perceptions of interpersonal responsibilities are culturally bound, a stance supported by her own empirical research. In a study of moral reasoning about social responsibilities in India and the United States by Miller et al. (1990), Hindu Indians tended to view helping a person in need as a moral imperative, or duty, regardless of how well they knew the person (be they a parent, best friend, or stranger) or how serious the need (from minor to life-threatening). In contrast, Americans tended to view helping a person in need as a moral imperative only in cases where the need was extreme or where they had a close relationship with the person in need (e.g., parent, child, or close friend); otherwise, the decision about whether or not to help a person in need was viewed more as a matter of personal choice. Miller (1994) argues that these cultural differences in helping behaviour reflect different cultural conceptions of the self, with Hindu Indians viewing the self as interdependent and embedded within society and Americans viewing the self as independent, autonomous, and distinct from society.

Similar results to Miller and colleagues' have been found when comparing moral reasoning about interpersonal responsibilities between individuals from other independent/individualistic and interdependent/collectivistic cultures. Chinese (collectivistic) youth have been found to consider altruistic and interpersonal concerns more often than Icelandic (individualistic) youth when asked to reason about a hypothetical moral conflict (Keller et al., 1998). Likewise, Janoff-Bulman and Leggatt (2002) found that Latin American undergraduate students perceived helping others as both more obligatory and more personally desirable than Anglo undergraduate students, although it is unclear how "Anglo" was defined in this study. Moreover, people with a higher personal collectivistic orientation have been shown to be more likely to comply with a simple request than people with a higher personal individualistic orientation, and this, more often for altruistic, selfless reasons than for personal, self-serving reasons (Barrett et al., 2004).

Taken together, these findings suggest that the degree to which an individual feels morally obligated to help a person in need varies depending on the extent to which their culture emphasizes independent versus interdependent values (or on their personal level of individualism/collectivism), and that this can have a bearing on whether or not that individual actually helps a person in need.

While these studies contribute to our understanding of how views about the morality of caring and social/interpersonal responsibilities can shape perceptions of who should be responsible for supporting individuals with mental health problems, they are not without limitations. First, they discuss moral reasoning about interpersonal responsibilities in the context of helping behaviour in general, not with respect to helping a person with mental health problems specifically. This is an important limitation, as there is undoubtedly a difference between deciding whether or not to help a person with a relatively minor need, such as the need to borrow class notes, versus a major need, such as the need for stable, affordable housing or help with covering the costs of medications over an extended period of time. Miller et al. (1990) did examine the effect on participants' moral reasoning of varying the magnitude of need experienced by individuals in hypothetical scenarios (from minor to life threatening), however all scenarios involved a one-time-only commitment to help on the part of the helper. In contrast, the needs of individuals with mental health problems may demand a greater and more long-term commitment to help and may therefore involve more complex moral decision-making.

Only one article dealing with moral responsibility towards individuals with mental health problems specifically was identified. In a qualitative study conducted in the United States, Karp and Watts-Roy (1999) showed how family caregivers' views of their moral responsibilities to a mentally ill relative evolve over the course of the illness. A large number of in-depth interviews revealed that caregivers moved through different phases, or "interpretive junctures", in which their understanding of the illness changed and consequently, so did their views of their obligations to their ill family member. Specifically, caregivers shifted from having no or porous boundaries between themselves and their ill relative at the beginning of the illness and feeling a strong moral obligation to care to having firmer boundaries and greater expectations of their ill relative later on in the illness. With the realization that their relative's illness (depression, bipolar disorder, or schizophrenia) was a chronic condition likely to persist despite their efforts, caregivers reassessed their own obligations and began to place more responsibility on their ill relative to help themselves get better. A recurrent theme in caregivers' narratives was that of having to draw a line between themselves and their ill relative in order to preserve their own health and identity.

This study is pertinent in that it deals specifically with moral judgments about responsibility to help a person with mental illness, however the findings are limited in terms of their generalizability across cultures. Nowhere do the authors mention Miller and colleagues' work on the morality of caring, and limited attention is paid to cross-cultural variations in moral reasoning. As a result, the authors do not fully acknowledge the predominantly Western emphasis in caregivers' narratives on weighing their personal needs against interpersonal responsibilities and of being bound by personal choice rather than duty when deciding whether to help their ill family member. Indeed, the majority of participants interviewed were white Americans.

Moreover, none of these studies directly address the larger question of *who* should be helping people in need. No distinctions are made between what an individual is willing to do (or feels morally obligated to do) personally for someone in need and what they may feel other relevant stakeholders should be obligated to do to help a person in need. This considerably limits our ability to answer the review questions, because when asked who should be responsible for helping a person in need, individuals may identify other parties as having a role to play in addition to themselves and may thus reveal a more nuanced and relative view of interpersonal responsibilities.

Attributions of responsibility for mental illness

A final and more directly relevant theme touched on by several articles involves attributions of responsibility for mental illness. Research on mental illness stigma, led in large part by the work of Patrick Corrigan and colleagues, reveals that the cognitive processes underlying stigma can be understood using attribution theory, a social psychological theory that describes how people explain the causes of behaviours and events (Weiner, 1980). Research on attribution theory has shed some light on how causal and controllability attributions can shape decisions about locus of responsibility and consequently, helping behaviour. For example, in a study applying attribution theory to general helping behaviour, Higgins and Shaw (1999) found that helping behaviour is determined by both individual-level and situational-level variables. By varying the controllability of a hypothetical person's need for help, the authors found that participants with a general tendency to perceive others' problems as being caused by factors outside of their control (termed a "supportive attributional style") exhibited helping behaviour regardless of whether the target's need for help was controllable or not. Conversely, participants with a tendency to perceive others' problems as being caused by factors *within* their control (termed an "unsupportive attributional style") exhibited helping behaviour only when the target's need for help was out of their control. These findings reveal that helping behaviour is not only influenced by people's judgments about the controllability of an event or behaviour based on situational cues, but also by individual-level factors such as attributional style. Of note, these results are similar to Shirazi and Biel's (2005) findings about internal-external locus of causality and support for welfare state policies, with unsupportive and supportive attributional styles resembling internal and external loci of causality, respectively.

In an article advancing an attribution model of mental illness stigma, Corrigan (2000) explains the link between attributions of controllability, perceptions of responsibility, and emotional and behavioural responses to individuals with mental illness. According to the model, people assign responsibility and blame to individuals for behaviours or conditions viewed as personally controllable; hence, people who think that individuals with mental illness can control their illness or its symptoms are likely to feel that these individuals are personally responsible for their condition. A directional, causal relationship between attributions of illness controllability, perceptions of responsibility, and emotional and behavioural responses to individuals with mental illness is well supported by research, including Corrigan's own work (Corrigan, 2000; Corrigan et al., 2003). Specifically, people who believe that individuals with mental illness can control their illness tend to react emotionally with anger and behaviourally in a punitive and discriminatory fashion; for example, by denying them important supports and opportunities. Conversely, believing that mental illness is *not* under the afflicted person's control leads to feelings of pity and to helping and supportive behaviours. Importantly, controllability attributions appear to exert their effects on emotional and behavioural responses largely via responsibility beliefs (Corrigan et al., 2003). Corrigan has also found that male gender, higher level of education, older age, and white ethnicity are associated with a greater tendency to believe that people with mental illness are personally responsible for their condition, a reduced likelihood of offering help or support, and greater support of coercive measures (such as forced hospitalization) and segregation (Corrigan, 2000; Corrigan et al., 2003), and he cites research by others showing that culture moderates controllability attributions.

These findings from research on stigma and attribution theory make an important contribution to our understanding of the review questions and have practical implications, as attributions are perceptions or beliefs that are not necessarily rooted in fact. The heuristic process of attributing causes to events and behaviours can thus result in errors, such as the fundamental attribution error of overestimating the influence of internal, dispositional factors on others' behaviour and underestimating external, situational factors; a well-established psychological phenomenon (Ross, 1977). This kind of attribution bias may have an impact on whether and to what extent people feel that they or other parties should be responsible for supporting individuals with mental health problems. Policymakers may be less likely to allocate resources to programs and services for people deemed personally responsible for their problems, such as people with mental illnesses, who are considered by the public to be more personally responsible for their condition than people with physical illnesses (Corrigan & Watson, 2003). Here too, however, political orientation plays a role, with political conservatives tending to withhold resources from programs and services serving people they deem responsible for their problems and liberals tending not to make judgments of controllability or responsibility and to be more sympathetic (Corrigan & Watson, 2003).

Paradoxically, while Corrigan cites strong research support for the attribution-emotion-behaviour model and has through his own research demonstrated its predictive ability (Corrigan et al., 2003), the increased emphasis in recent years on the biological determinants of mental disorders and the implicit message that these disorders are largely out of the control of afflicted individuals has been ineffective in reducing stigma and preferred social distance from individuals with mental illnesses, and may have even worsened public attitudes towards mental illness (Schomerus et al., 2012). This calls into question the uncontrollability attribution-pity-helping behaviour arm of the model. Furthermore, while attribution theory helps explain how people decide whether to help or punish a person with mental health problems, it does not tell us about stakeholders' views of who should in fact be responsible for supporting these individuals or what their support role should be.

3.5 Discussion

The purpose of this critical review was to critically evaluate the literature in order to discover who different stakeholders feel should be responsible for supporting individuals with mental health problems; what factors shape perceptions of who should be responsible for supporting individuals with mental health problems; and how these factors relate to one another. Our literature search yielded no studies directly investigating stakeholders' perceptions of who should be responsible for supporting individuals with mental health problems. However, several works were found which debate whether individuals or governments should be more responsible for general health, with some arguing in favour of a strong government role in health (EKOS Research Associates Inc., 2012; Mendelsohn, 2002; Rothstein, 2010), some arguing for greater individual responsibility for health or reduced government involvement (Morrisette et al., 2015; Pupavac, 2001; Szasz, 1963; Wikler, 1978), and others calling for a balance of responsibility between individuals and governments (Minkler, 1999; Resnik, 2007; Wikler, 2002) or intertwined responsibilities (Devisch, 2012).

Research on public attitudes towards the welfare state and views of individual versus societal or governmental responsibility for need provision and health; the morality of caring and social or interpersonal responsibilities; and attributions of responsibility for mental illness was found to shed light on some of the different factors shaping perceptions of responsibility. While these themes have thus far been examined as distinct bodies of research, the main concepts from each can be seen to relate to each other in a number of ways. To graphically display the relationships between concepts, CmapTools, a knowledge modelling software, was used to create a concept map (Figure 1). Concept maps are useful tools for organizing and presenting knowledge in a way that facilitates the creation of new knowledge, as they enable the novel bridging of ideas (Novak & Cañas, 2008).

As Figure 1 shows, perceptions of who should be responsible for supporting individuals with mental health problems may be influenced by each of the three factors discussed so far, which are in turn linked to each other in several ways. For example, public attitudes towards the welfare state and views of locus of responsibility for need provision and health have been shown to be influenced in part by political and egalitarian ideology (the former broadly dichotomized into politically conservative vs. liberal) (Lundell et al., 2013; Shirazi & Biel, 2005). Political ideology also influences policymakers' attributions of responsibility for mental illness, and subsequently, their policy decisions (Corrigan & Watson, 2003).

Attributions of responsibility for mental illness, for their part, may also be influenced by individuals' attributional styles (Higgins & Shaw, 1999). Attributional style is a concept very similar to that of internal/external locus of causality, which has been shown to influence attitudes towards welfare state policies (Shirazi & Biel, 2005). Culture and national context, meanwhile, influence views about the morality of caring and interpersonal responsibilities (Barrett et al., 2004; Janoff-Bulman & Leggatt, 2002; Keller et al., 1998; Miller, 1994) as well as attitudes towards the welfare state (Blekesaune & Quadagno, 2003; Shirazi & Biel, 2005) and attributions of illness controllability (Corrigan, 2000). These examples reveal the extent of interconnection between the different concepts from the literature. It is important to note, however, that the links shown in this concept map are not derived from path analyses and do not constitute statistical evidence of mediation or moderation, but rather theoretical relationships between concepts.

Furthermore, it is also important to note that the three research themes represent different levels of analysis. Attitudes towards the welfare state and government responsibilities represent a macro level of analysis and may influence views of broader social or systemic supports, while views about the morality of caring and attributions of responsibility for mental illness are more micro-level and may influence individual-level helping behaviours and supports. This distinction is important, as stakeholder perceptions may vary depending on whether they are considering responsibility for support needs at the macro systems level or at the individual patient level. Also, at the individual patient level, stakeholder views of their own responsibility relative to that of different stakeholders are likely to be much more dynamic and responsive to how other stakeholders perceive or act in their roles. For example, a family member may feel minimal responsibility for helping an ill family member find employment due to the treatment provider's emphasis on the ill family member's autonomy and primary responsibility for functional recovery. In addition, stakeholders' perceptions may vary depending on the type of support need: while a stakeholder may be in favour of a strong government role in providing housing for individuals with mental health problems, they may not support government funding for substance abuse treatment programs.

Given the paucity of research on locus of responsibility for the support of people with mental health problems, the results of this critical review and the creation of a concept map linking relevant concepts from diverse disciplines help build a much-needed conceptual framework of the topic. This serves as a first step towards answering the question: who should be responsible for supporting individuals with mental health problems? Understanding the various factors shaping perceptions of responsibility is important, because these perceptions could influence whether or not relevant stakeholders provide individuals with mental health problems with support, as well as the nature of support provided. To our knowledge, this is the only critical review examining this question.

Although this review is the product of multiple librarian-assisted literature searches, it is not exhaustive. Due to time and resource constraints, predominantly English-language published articles were reviewed. As such, while the results of this review give us an idea of the range and interplay of factors shaping perceptions, there are likely other factors at play as well. For instance, personal experience of interacting with the health care system generally or mental health care system specifically could influence a person's views about locus of responsibility in important ways. Even second-hand experience, such as hearing stories about difficulty accessing appropriate mental health services or of individuals “manipulating” the system, could affect people's perceptions about who should be responsible for supporting individuals with mental health problems.

Opinions about locus of responsibility for the support of people with mental health problems likely differ from views about locus of responsibility for general health, as mental illness continues to be highly stigmatized and individuals with mental illnesses tend to be held accountable for their illness more than persons with physical illnesses (Corrigan & Watson, 2003; Schomerus et al., 2012). Consequently, deciding whether or not to help a person with mental health problems may involve additional considerations. Moreover, the individual-government responsibility dichotomy is simplistic and ignores the wide range of other actors involved in supporting people with mental health problems (e.g., families, community organizations). Thus, while the articles included in this review contribute to our understanding of the review questions, an investigation of the perceptions of various relevant stakeholders as to who should be responsible for supporting people with mental health problems specifically is needed, and their relative, rather than absolute, judgments of responsibility should be elicited. An investigation of this sort is timely given recent debates in several countries (e.g., Canada, the Netherlands, etc.) (Ter Meulen & Jotterand, 2008; Ter Meulen & Maarse, 2008) over the increasing privatization of health care and the appropriate role of the government in health care, with opponents of privatization warning of a two-tier system that threatens to unfairly disadvantage the most vulnerable members of society and shift the burden of responsibility for health to individuals themselves.

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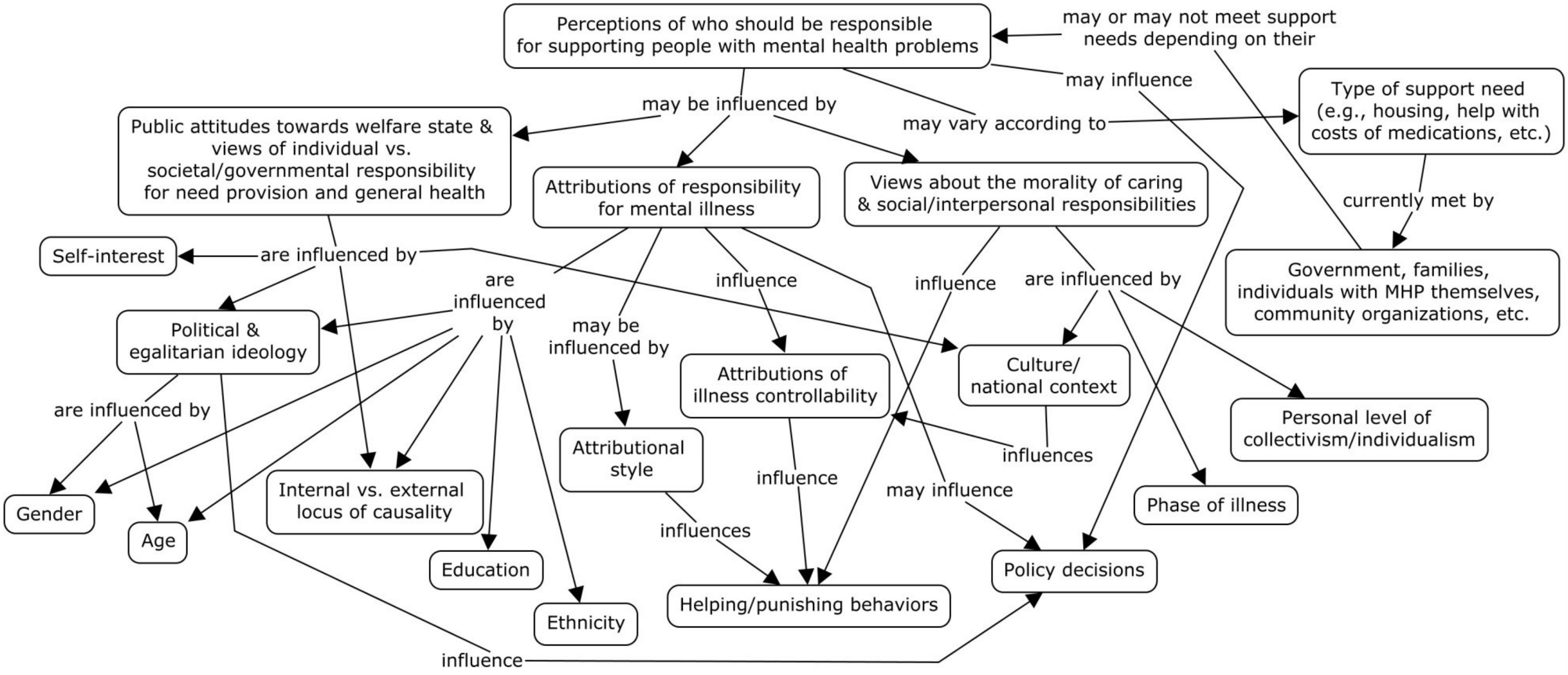
3.7 Figures

Figure 1. Concept map of factors influencing perceptions of who should be responsible for supporting people with mental health problems.



CHAPTER 4

Manuscript #2: Who should be responsible for supporting individuals with mental health problems? A qualitative descriptive study exploring the perceptions of multiple stakeholders

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4.1 Abstract

Background & objectives: Individuals with mental health problems, particularly those with serious mental illnesses such as first-episode psychosis (FEP), have many support needs that are often inadequately met. Relevant stakeholders' perceptions of who should be responsible for meeting the various needs of these individuals have not been investigated; yet, varying perceptions of who should be responsible for supporting individuals with mental health problems could be the cause of unmet support needs within this group. The objective of this study was to explore the perceptions of youth with FEP, their families, treatment providers, and mental health policy and decision makers as to who should be responsible for supporting individuals with mental health problems and to discover what responsibilities they ascribe to these parties.

Methods: A qualitative descriptive design was used. Focus groups were conducted with patients, families, and treatment providers from a specialized early intervention program for psychosis. Individual interviews were conducted with mental health policy/decision makers. Thematic analysis was used to analyse transcript data. **Results:** Participants assigned roles and responsibilities to individuals with mental health problems themselves; stakeholders in the immediate and extended social networks of these individuals; macro-level stakeholders with influence; and society as a whole. Themes relating to the structure and nature of roles and responsibilities were also identified. **Discussion:** Participants from all stakeholder groups largely agreed that individuals with mental health problems, their families, hospitals/treatment providers, and the government should be responsible for supporting individuals with mental health problems. This suggests that varying perceptions are unlikely to be the cause of unmet support needs. Furthermore, many participants perceived roles and responsibilities as being hierarchically structured, with some stakeholders playing a more important role than others, and/or as being shared among different stakeholders each with distinct strengths to contribute. Participants (particularly treatment providers) also often perceived roles and responsibilities to be conditional or to have certain limits or boundaries. The implications of this study for shaping policy, services, and future research are discussed.

4.2 Introduction

Individuals with mental health problems are known to have many support needs which are often inadequately met (MHCC, 2012; WHO, 2013). Given that psychotic disorders are among the leading causes of disability worldwide (WHO, 2013) and affect functioning in many spheres of life (Health Canada, 2002; WHO, 2013), it is not surprising that youth with first-episode psychosis (FEP) represent a group with an especially great need for a number of supports. For example, many of these individuals lack access to safe, affordable, and supported housing; need help reintegrating into school or work; and have difficulty covering the costs of needed psychiatric medications and mental health services (e.g., psychotherapy and substance abuse treatment programs) (MHCC, 2012). In Canada, the government provides for several of these needs through the national health insurance plan and through province- and territory-specific health insurance plans (Health Canada, 2012); however, this coverage is not all-encompassing and inevitably, many of the needs of individuals with serious mental illnesses are taken up by other parties or are simply not met (MHCC, 2012).

One possible cause of unmet needs for support is varying perceptions about who should be responsible for supporting individuals with mental health problems. Research suggests that different stakeholders may diverge in their opinions about who should support these individuals (Iyer, Pope, Loohuis, Rangaswamy, & Malla, 2014; Iyer et al., 2015). Disagreement between stakeholders may contribute to unmet needs for support.

Different stakeholders' perceptions of their own and each other's responsibilities may also iteratively shape and be shaped by the roles and responsibilities assumed by each. For example, families may feel less of an obligation to support their mentally ill loved one financially if their loved one is receiving social assistance or disability benefits from the government, while the ill person him or herself may take a less active role in searching for employment. In this way, roles and responsibilities are likely to be seen in relative rather than absolute terms.

Several recent major mental health policy documents (e.g., the World Health Organization's Mental Health Action Plan 2013-2020; The Mental Health Commission of Canada's 2012 Mental Health Strategy for Canada) have recommended that stakeholders from various sectors (e.g., public, private, philanthropic; service users themselves and their families) should share responsibility for transforming mental health care in order to improve outcomes. Yet, no study to date has investigated different stakeholders' perceptions of their own and others' roles and responsibilities. This is an important knowledge gap, as these perceptions may need to be understood in order to effectively foster collaboration.

Objective & research questions

The objective of this study was therefore to explore the views of young people with FEP, their families/carers, treatment providers, and mental health policy and decision makers as to who should be responsible for supporting individuals with mental health problems. These key stakeholder groups were specifically chosen because as users, providers, and organizers of services, they directly and indirectly shape clinical practice and mental health policy.

Specifically, our research questions were: who do key stakeholders believe should be responsible for supporting individuals with mental health problems, and what responsibilities do they ascribe to these parties?

4.3 Methods

Study design

A qualitative descriptive research design (Sandelowski, 2000, 2010; Sullivan-Bolyai, Bova, & Harper, 2005) was used in order to answer our research questions. The purpose of qualitative description is to provide a comprehensive description of experiences, events, and processes using the language of participants; in essence, painting a detailed portrait of the phenomenon of interest (Green & Thorogood, 2009; Sandelowski, 2000). Qualitative descriptive designs are especially well-suited to exploratory studies asking 'who' and 'what' questions and they assume a naturalistic orientation to inquiry, studying phenomena in their natural, unaltered state (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). Because qualitative description involves a commitment to discover the facts about a phenomenon, researchers using this approach stay closer to the surface meanings of their data than in other types of qualitative research (e.g., grounded theory or phenomenology); however, meaningful interpretation of the findings is still necessary as data are not seen to speak for themselves (Sandelowski, 2000, 2010; Sandelowski & Barroso, 2003; Sullivan-Bolyai et al., 2005).

This research design was ideal for our investigation because it permitted a rich description of key stakeholders' views of who should be responsible for supporting individuals with serious mental health problems, a topic that has received virtually no previous attention in the literature. Moreover, because qualitative description uses a low level of inference that remains faithful to participants' own renderings of their experiences, it produces findings that are accessible to various stakeholders and highly influential for changing healthcare practices and policies (Sullivan-Bolyai et al., 2005).

Philosophical assumptions and conceptual framework

Qualitative description is considered to be the least theoretical of the qualitative approaches because it did not grow out of any particular disciplinary or philosophical traditions

(Sandelowski, 2000); however, underpinning the qualitative descriptive design is the assumption that the description or “portrait” produced by the researcher is an accurate representation of reality. The emphasis on minimally interpreting the data also assumes that a more faithful account of participants’ experiences is more reflective of the truth. As such, this research design has a post-positivistic ontological position.

Given that this was a largely uncharted area of research, no formal theoretical or conceptual framework guided our investigation. However, since the literature and the combined clinical experience of the researchers pointed to several key areas where individuals with serious mental health problems are known to need, and often lack, support (namely, housing, work/school reintegration, covering the costs of medications and services, stigma reduction, general financial support), these areas were taken into consideration when developing our interview guide. In addition, it is important to note that we had certain assumptions: for instance, that different stakeholders were likely to have different perceptions about locus of responsibility, and that these perceptions were likely to vary depending on the type of support considered (for example, housing support versus support for the costs of substance abuse treatment programs).

Study setting & context

This study took place at the Prevention and Early Intervention Program for Psychoses (PEPP-Montreal), a specialized early intervention service for youth experiencing a first untreated episode of psychosis located at the Douglas Mental Health University Institute in Montreal, Quebec. The program is structured around a case management model of service and offers two years of comprehensive medical and psychosocial treatment to youth between the ages of 14 and 35 with a primary diagnosis of affective or non-affective psychosis. PEPP operates on an open referral system whereby any person may make a direct referral to the program, including a family member of a youth experiencing psychosis or the young person him or herself, and referrals are responded to within 72 hours. Once accepted to the program, every patient receives personalized treatment and follow-up from the same case manager and psychiatrist for the duration of the program. Case managers, members of a multidisciplinary team comprising psychologists, social workers, nurses, and other mental health professionals, are the patient's primary treatment provider and coordinate all aspects of their care.[1]

Data collection for this study was completed just two months prior to the official launch of a major reorganization of the healthcare system in Quebec intended to streamline services, facilitate public access to treatment, and improve the quality of services (Bill 10, 2015). As a result of the reorganization, which was highly publicized in the preceding months, the Douglas Institute was amalgamated with several other institutions within the same region to form a large network known as the Montreal-West Island Integrated University Health and Social Services Centre. This restructuring also modified and eliminated many decision-making positions within the healthcare system, including those of some of the policy/decision makers previously interviewed for the purposes of this study.

Participants & sampling strategy

We recruited FEP patients between the ages of 18 and 35 receiving services at PEPP-Montreal; patients' family members (first- or second-degree relatives, spouses or partners); treatment providers (case managers and psychiatrists from PEPP-Montreal and from an affiliated FEP early intervention program within the McGill University Health Centre); and mental health policy/decision makers at the institutional or regional level.

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[1] For a more detailed overview of the PEPP-Montreal program, see Iyer, Jordan, MacDonald, Joober, and Malla (2015).

Patients and their family members were selected according to a purposive sampling strategy in which information-rich participants were chosen deliberately (Green & Thorogood, 2009; Sandelowski, 2000; Schwandt, 2007). Specifically, they were selected according to a maximum variation sampling strategy (Sandelowski, 2000; Sullivan-Bolyai et al., 2005) in order to represent differences in age, sex, ethnic background, and in the case of family members, relationship to the patient (mother, brother, etc.), as we hoped to elicit a variety of opinions and perspectives. Only patients who had received at least 6 months of treatment and who were deemed by their treatment team to be stable enough to participate were considered for the study.

Because we had access to a limited number of treatment providers and policy/decision makers, these participants were selected according to a convenience sampling method (Green & Thorogood, 2009); that is, based on availability and drawing from the researchers' existing professional networks.

Data collection

In order to elicit the perspectives of a large number of participants in a short amount of time and because we were interested in the discussion and negotiation of opinions that would take place in a group setting, we opted to conduct focus groups with FEP patients, their family members, and treatment providers. However, individual interviews were conducted with policymakers as it was infeasible to assemble a group of these stakeholders together at one time and place. Seven focus groups were conducted: two with FEP patients (English and French), two with family members of FEP patients (English and French), two with case managers (English and French), and one in English only with psychiatrists. Each group included 5-7 participants. Separate focus groups were conducted with case managers and psychiatrists to prevent any perceived power imbalance from dissuading case managers from expressing divergent views from those of psychiatrists. Individual interviews were conducted with six policy and decision makers. Focus groups lasted between 1 ½ and 2 ½ hours and took place in a conference room at the PEPP clinic while interviews ranged from 30 minutes to an hour in length and took place in policymakers' work offices.

As the focus groups were being conducted within the scope of a larger study for which there were time constraints for data collection, the number of focus groups was predetermined and not guided by theoretical saturation considerations (Green & Thorogood, 2009; Schwandt, 2007). However, recurrent themes were nonetheless identified.

We developed a semi-structured interview guide with open-ended questions to discover who participants felt should be responsible for supporting individuals with serious mental health problems and what responsibilities they attributed to these parties. Participants were also asked about their concerns and priorities as mental health stakeholders as well as their perceptions of the needs of people with serious mental health problems; this data was collected within the purview of a larger study being conducted by authors A.M. and S.I. The interview guide (Appendix) was developed with input from multiple stakeholders with expertise and/or experience in early psychosis and its treatment, including clinicians, researchers, patients, and family members, in an effort to maximize the validity of the questions. The guide was then pilot tested in separate interviews with a FEP patient and a family member and the questions were further refined before being used in the final focus groups and interviews.

The semi-structured format of the interview guide enabled us to cover specific topics informed by the literature and our clinical experience while also being unstructured enough to permit spontaneous discussion through which unprompted insights could emerge. This semi-structured format is typical of interview guides used in qualitative descriptive designs (Sullivan-Bolyai et al., 2005).

All focus groups were facilitated by the same two fluently bilingual researchers (authors M.P. and H.L.) and author M.P. conducted all individual interviews with policymakers. Both researchers wrote reflexive notes after each focus group or interview, recording their thoughts and insights on the discussions and documenting their personal impact on the research process. Focus groups and interviews were audiotaped and transcribed verbatim.

Relevant demographic information (e.g., age, sex, political orientation) was collected from all participants using a brief questionnaire created for the purposes of this study (available upon request to the authors).

Data analysis

Thematic analysis was used to analyse focus group and interview data (Braun & Clarke, 2006; Green & Thorogood, 2009; Sullivan-Bolyai et al., 2005). This type of qualitative data analysis involves identifying recurrent themes or “repeated patterns of meaning” (Braun & Clarke, 2006, p. 86) in the data. Thematic analysis is an appropriate data analysis method for qualitative descriptive studies because it is not tied to any particular theoretical framework or epistemological position and it provides a rich description of data without a high degree of interpretation or transformation of the data (Braun & Clarke, 2006).

Transcripts were first read in their entirety and carefully verified against the audio recordings to ensure accurate transcription by two researchers working independently (authors M.P. and S.V.). In the process, memos about coding ideas and other reflections on the data were noted and discussed (Braun & Clarke, 2006). Initial codes were then created by both researchers based on this first reading of the transcripts and were discussed with senior author S.I., and a coding manual including clear definitions of each code was developed. Using computer-assisted qualitative data analysis software (Atlas.ti version 7.5.10), authors M.P. and S.V. then independently assigned the initial codes and any new codes inspired by emerging insights to content deemed important and relevant to the research questions (Braun & Clarke, 2006). Throughout the coding process, author M.P. kept analytic memos containing questions about the data, ideas for themes and future merging of codes, and reflexive thoughts about the process and her role in shaping the data (Green & Thorogood, 2009). For example, the author noted that having worked closely with treatment providers, patients, and families at the PEPP clinic for several years may have shaped her interactions with each of these stakeholders during the focus groups and influenced the resulting data.

We used a combination of inductive and deductive coding but favoured inductive coding, a data-driven approach in which codes, concepts and themes are identified from the data rather than imposed on them from a pre-existing theoretical or conceptual framework (Braun & Clarke, 2006). We favoured the inductive approach because the purpose of the study was to discover stakeholders' views about locus of responsibility for the support of people with serious mental health problems, which have as of yet not been explored. However, a small number of deductive codes were created based on the literature and our prior clinical knowledge, which pointed to several support needs being important for individuals with serious mental health problems and to several stakeholders potentially playing an important role in the satisfaction of these needs.

In line with the aims of qualitative description, coding occurred primarily at a semantic or surface level; however some coding of latent meaning occurred as well (Braun & Clarke, 2006). For example, if a participant did not explicitly state that it was the role of a particular party to fulfil a certain responsibility but both coders agreed that this was strongly implied, it was coded as the responsibility of that party. Care was taken to code for both convergence and divergence of opinions.

After the first round of coding of all transcripts, the coders (M.P. and S.V.) iteratively compared and discussed their codes, re-coded certain excerpts, and added, removed, or modified codes as needed. Following the steps proposed by Braun and Clarke (2006), author M.P., assisted by authors G.J. and S.V. and guided by S.I., then combined codes that appeared to be meaningfully related to create potential categories, sub-themes, and themes and verified the coherence of themes by comparing them against the coded transcript excerpts. The ‘external heterogeneity’ of themes was also verified by ensuring that themes were clearly distinct from one another. Finally, after revising and modifying themes as necessary, the final themes were defined and labelled.

Validity

We strove to maximize the rigour and validity of our study in multiple ways. Feedback from multiple pertinent stakeholders (service users, families, researchers, and treatment providers) was incorporated in the interview guide, thereby helping validate its content and scope, and facilitators were fluently bilingual in English and French and embedded in the same cultural context as the participants, thus minimizing the chance of misinterpreting meaning. In addition, focus groups and interviews were audio recorded, transcribed, and the transcripts carefully read and cross-checked against the audio recordings to ensure that participants’ words were accurately captured. Triangulation of data and of investigators further enhance the validity and trustworthiness of our findings (Creswell & Plano Clark, 2011). Collecting data from different stakeholders permitted a more holistic understanding of the research questions, and having several researchers code transcripts and collaboratively develop and refine themes ensured a more robust interpretation of the data. Validity and rigour were further strengthened by having facilitators keep reflexive notes to help account for their pre-existing biases and impact on the research process. Finally, the use of minimally interpretive data analysis methods reduced the likelihood of misinterpreting participants or misrepresenting their views.

Ethics

The Douglas Institute Research Ethics Board granted ethics approval for this study and all participants provided informed consent to participate. Participants were compensated $60 to offset the costs of travelling to the focus group location, or, in the case of treatment providers and policymakers for whom focus groups and interviews took place during work hours, to compensate for the loss of wages.

4.4 Results

Sample characteristics

Detailed characteristics of the sample can be found in Table 1. The majority of participants were Canadian-born and politically left-leaning. Most patients were young males living with their family or spouse/partner. Roughly half claimed welfare as their primary source of income and were neither employed, in school, nor caring for children or dependent adults. Patients and family members were ethnically diverse, with almost half of patients and over half of family members belonging to a visible minority group. Treatment providers, who represented a variety of different mental health professions, were a much more ethnically homogenous group (mostly Caucasian). Half of the family members we recruited were mothers to an ill person receiving PEPP services, and for the majority, their ill relative was living with them or with other family members. Most policymakers had previously worked as general or mental health treatment providers.

Themes

Our analysis yielded several themes cutting across all stakeholder groups (Figure 1). Five main themes were identified pertaining to who participants felt should be responsible for supporting individuals with mental health problems and what roles and responsibilities they attributed to these parties. Participants identified roles and responsibilities of individuals with mental health problems themselves; stakeholders in the immediate social network of the individual with mental health problems (their families, friends, and communities); stakeholders in the extended social network of these individuals (healthcare institutions and treatment providers; community, non-governmental, and non-profit mental health organizations; educational institutions, researchers, and workplaces/employers); macro-level stakeholders with influence (the government, the private sector, philanthropic organizations, and the media); and society as a whole. These themes roughly correspond to different spheres of an individual's social world, and the stakeholders within each of these spheres or networks can be distinguished from one another by their levels of influence and by the degree of formality of the supports they provide.

In addition, we identified overarching themes relating to how roles and responsibilities were perceived to be structured (i.e., hierarchically according to importance and/or collectively shared) and how they were perceived to be often conditional or limited in nature.

Theme 1: Perceived roles and responsibilities of individuals with mental health problems

Participants from all stakeholder groups assigned responsibility of some kind to individuals with mental illnesses themselves. There was strong agreement between patients themselves and other participants that individuals with mental health problems are ultimately responsible for their own lives because they are the ones living their experience and only they can truly determine the course of their lives. Indeed, a few participants described persons with mental illnesses as the “conductors” of their own lives.

> Case manager 8: Mais si on revient dans – en général, ok, mettons, la crise aiguë est passée, tu sais, on peut voir ça d’un point de vue de rôle et responsabilité, on peut voir ça comme, il n’y a personne qui peut marcher leur chemin pour eux. On ne peut pas le tirer ou pousser pour qu’il marche leur chemin. C’est un peu comme chacun d’entre nous: est-ce que j’ai un rôle particulier dans ma vie? Évidemment, c’est ma vie. […]

> *Case manager 8: But if we come back to – in general, ok, let’s say the acute crisis has passed, you know, we can look at this from the point of view of roles and responsibilities, we can see this as, no one can walk their path for them. We can’t pull or push them to walk their path. It’s a bit like each of us: do I have a particular role in my life? Of course, it’s my life. […] (Translated)*

There was consensus among several participants (including patients) that while others can offer support, no one can help an individual with mental health problems who is not willing to help themselves: this was seen as a basic precondition. Taking responsibility for one’s own life was seen by some to include the recognition and acceptance of oneself as having an illness.

Many patients and other participants felt that individuals with mental illnesses must take responsibility for their own mental health treatment and recovery by actively participating in treatment and by doing what they can themselves to get better; for example, taking prescribed medications, independently searching for housing (with assistance if needed), or if capable, paying for their own substance abuse treatment. Engaging in treatment was seen by some patients, treatment providers, and policymakers to mean more than merely complying with the doctor’s orders; it meant being an active and integral member of the treatment team. One policymaker explained that taking responsibility for one’s own recovery is actually in and of itself indicative of health and recovery.

> Patient 4: I think the person himself should be responsible and actually taking the medication, taking good habits, not just going there and sitting and coming back and taking medication, you have to do some effort on your own.

Patient 1: Oh, yeah, absolutely.

Patient 4: And think on your process, because I think the doctor cannot do nothing if you don’t want to do it yourself.

Patient 1: Yeah.

Patient 3: Yeah, you can’t help somebody that doesn’t want to be helped.

Patient 1: Yeah, you’re the first person who should take ownership of your recovery.

Another role attributed to individuals with mental health problems was that of advocating for their needs and those of others with mental illnesses and being involved in mental health policy and decision making. Several participants (mostly policymakers and treatment providers but also a few patients) expressed that individuals with mental illnesses should not only help their treatment team understand their needs and be involved in decision-making pertaining to their own treatment, but also directly contribute to the development of larger-scale policies affecting all individuals with mental illnesses, both by helping create these policies and by ensuring that they continue to serve their interests over time.

Policymaker 6: […] families and patients certainly need to act – not only the initiation of these policies because they should be involved in it, but at the same time in making sure that they’re done in an appropriate fashion. So, it’s an iterative process, nothing stays solid forever, and things can always be improved, and that's where patients and families need to interact to ensure that what we have in place is appropriate for that period of time.

Interviewer: Ok, so their role is a bit more of like an advocacy role to make sure that policies are being upheld.

Policymaker 6: Yes and even as an integral part of the development of these policies because they have a perspective which is different but at the same time can add to the development of these policies so that they make sense. So it’s not only advocacy, it’s also being part of the decision making process.

A few participants also felt that individuals with mental health problems should help destigmatize mental illness, with two participants (a treatment provider and a policymaker) expressing that destigmatization efforts often carry more weight when coming from individuals with lived experience of mental illnesses themselves.

Theme 2: Perceived roles and responsibilities of stakeholders in the individual's immediate social network

Participants identified families of persons with mental illnesses, their communities or neighbourhoods, and their friends and peers as having roles to play in supporting people with mental health problems. Together, these stakeholders can be seen to form part of the individual’s immediate social network and to have more informal, relationally-driven roles than other stakeholders.

2.1 Roles and responsibilities of families

As the stakeholders closest to the individual, families (including parents, siblings, spouses or partners) were perceived by participants from all stakeholder groups (including families themselves) to play a pivotal role in supporting individuals with mental health problems. Indeed, families were described by two policymakers as the anchor of society and the social fabric supporting the individual even when all other stakeholders are gone. While many participants went into detail about how families can help support their ill relative, families themselves tended to speak about their own responsibilities in more general terms, stating the importance of being involved, being responsible for their ill loved one, being there for them and accompanying them in their illness.

There was consensus among many participants that families should be involved in their ill loved one’s treatment and should support them as much as possible in their recovery process. Participants felt that families should be active members of the treatment team with a responsibility to be aware of and assist in their ill relative’s treatment plan (e.g., by reminding their ill loved one to take their medications, encouraging social outings, etc.). Families were expected to be attentive to changes in their ill relative’s clinical state and to provide the treatment team with updates and information that could help treatment. Two policymakers and one treatment provider expressed that while families play an essential role in supporting their ill relatives, they must above all "do no harm"; for example, by blaming the person for unusual behaviour caused by their illness. To this end, families were expected to learn about their loved one's illness and attend psychoeducation sessions offered by the treatment centre.

> Psychiatrist 2: I think they [families] have a major, major, major role. I think the role of family is fundamental in the treatment of people, young people specifically with psychotic disorder, but they need to be equipped because most of the time if they are not equipped then they will you know intervene or they will help in a way that is not necessarily the adequate way to do things. […]

Families were by and large the stakeholder group perceived to have the greatest responsibility for providing emotional support, which included accepting their ill relative, illness and all; showing love and affection; spending time with the ill loved one and helping them grow as a person; and knowing when to step back and let their ill relative take responsibility. Families were also seen as responsible for providing instrumental supports such as financial assistance, housing (typically by having their ill relative live with them), and help liaising with schools and employers.

> Facilitator: Et quel devrait être le rôle de la famille dans le soutien des personnes avec une maladie mentale d'après vous?
>
> Family member 9: Les accompagner, s'informer.
>
> Family member 8: Le plus de soutien possible.
>
> Family member 7: C'est ça. Soutenir le maximum qu'on peut.
>
> Family member 8: Oui.
>
> Facilitator: Du côté émotionnel ou pratique?
>
> Family member 7: Du mieux qu'on peut dans tous les sens.

> *Facilitator: And what do you feel the role of the family should be in supporting individuals with mental health problems?*
>
> *Family member 9: Accompanying them, informing yourself.*
>
> *Family member 8: As much support as possible.*

Family member 7:	*That's it. Supporting as much as we can.*
Family member 8:	*Yeah.*
Facilitator:	*Emotionally or practically?*
Family member 7:	*The best that we can in every way. (Translated)*

A few participants identified families as having a role to play in the prevention and early identification of mental health problems, chiefly by fostering good mental health among family members and directing or accompanying a loved one to care at the first signs of mental ill health. Policymakers in particular also expressed that families should advocate on behalf of their ill loved one by communicating that person's needs and strengths to the treatment team, by endeavouring to reduce stigma, and by promoting the cause of mental health; and that they should be directly involved in mental health policy and decision making.

> Policymaker 2: I think families are uniquely positioned to understand what the strengths of that individual are and were before the individual got sick. And acceptance of the individual as a member of the family despite the fact that he or she may be ill and helping the patient who begins to get treatment for the biological illness in their brain reconnect to those strengths that they knew that the person had. And also explaining to the healthcare team what those strengths are. And participating and developing a plan of care that focuses on the strengths of the individual. I think that that's a unique role that families play and can play.

In addition to supporting individuals with mental health problems, a number of participants, particularly treatment providers, identified families as having some responsibility to help themselves and other families cope with their loved one's illness; for instance, by searching for resources and illness-related information on their own and by organizing family support groups.

A minority of patients were reluctant to assign too much responsibility to families, stating that families already do enough for them and to ask for anything more would burden them.

Facilitator:	[…] Est-ce que vous pensez que la famille a une responsabilité à satisfaire à certains besoins?
Patient 10:	Non je pense pas.

Facilitator: Pourquoi?

Patient 8: La famille en fait déjà une grosse partie, on peut pas exiger plus. Ça va les fatiguer, ça va les drainer, ils voudront pas aider après.

Patient 10: Ça va trop leur demander d'énergie.

Facilitator: […] Do you think the family has a responsibility to meet certain needs?

Patient 10: No I don't think so.

Facilitator: Why?

Patient 8: The family already does a big part, we can't ask for more. It will tire them, it will drain them, they won't want to help after.

Patient 10: It will take too much of their energy. (Translated)

2.2 Roles and responsibilities of friends/social network and the community

A smaller number of participants from all stakeholder groups assigned responsibilities to the friends and social network of the individual with mental health problems and to the individual's community or neighbourhood.

Friends were primarily seen to play a role in providing emotional and moral support to the individual with mental illness as well as helping them grow and develop as a person and giving them more autonomy. One policymaker explained that simply sticking by a friend with mental health problems through their illness can be greatly helpful:

Policymaker 3: Et aussi besoin de support des pairs, des proches. […] Moi, ma fille, qui a été schizophrène, j'en ai deux; elle, ses amis sont restés d'une fidélité incroyable, tu sais? Ils savaient qu'elle faisait une crise puis que – mais ils sont restés ses potes là puis ils sont encore ses potes et ça c'est – moi je les admire ces petits jeunes-là, ils l'ont beaucoup aidé dans son cheminement.

Policymaker 3: And also need support from peers, from loved ones. […] Me, my daughter, who was schizophrenic, I have two; her, her friends remained incredibly loyal, you know? They knew that she was in crisis and that – but they remained her buddies and they're still her buddies and that's – I admire those kids, they helped her a lot in her journey. (Translated)

Participants felt that communities or neighbourhoods could facilitate the individual's recovery by providing local opportunities for them to meet and relate to peers and by creating wellness or recovery programs. Communities were also seen to play a role in preventing mental health problems and promoting good mental health. For example, one treatment provider highlighted the ideal responsibility of members of a community to take care of and support one another.

In addition to supporting individuals with mental health problems themselves, two participants (a family member and a treatment provider) identified the community as having a role to play in supporting these individuals' families.

Theme 3: Perceived roles and responsibilities of stakeholders in the individual's extended social network

Participants also attributed responsibilities to healthcare institutions and treatment providers; community, non-governmental, and non-profit mental health organizations; and educational institutions, researchers, and employers/workplaces for supporting individuals with mental illnesses. These stakeholders represent institutions, organizations, and establishments situated within the individual's extended social network that are involved in formally treating, supporting, and facilitating the recovery of individuals with mental health problems.

3.1 Roles and responsibilities of healthcare institutions and treatment providers

A large number of participants from all stakeholder groups identified hospitals and healthcare institutions and the treatment providers working within these institutions as having important roles to play in supporting individuals with mental health problems. Providing mental health services and assisting the recovery of people with mental illnesses was seen to be one of the main roles of these stakeholders. Policymakers made reference to the organization of the Quebec healthcare system when describing how healthcare institutions are responsible for offering different levels of services tailored to the level of need. These services were said to range from generic first-line services (i.e., general practitioner care) to more specialized second- and third-line services such as work reintegration programs, intensive community follow-up, hospitalization and inpatient care, and early psychosis programs.

Within this framework, participants from all stakeholder groups (including treatment providers themselves) assigned a wide range of medical and psychosocial roles to hospitals and treatment providers; however treatment providers (particularly case managers) gave more specific examples of their own responsibilities than other participants. These were seen to include providing medications and monitoring the ill person's physical health; helping the individual understand their illness and medications; assisting their reintegration into work, school, recreational and social activities and society in general; providing social and peer support opportunities; helping the individual find housing; liaising with the individual's family, government bodies, and other institutions on their behalf; referring to community-based supports whenever possible; keeping the individual informed and offering them a menu of treatment options; preventing hospitalizations while also invoking the legal system when necessary (i.e., imposing treatment and hospitalization orders); listening and providing emotional support; accompanying and guiding the individual in their recovery; reassessing the individual's needs over time and adjusting their own level of involvement as needed; and letting the individual take some responsibility and encouraging autonomy.

> Case manager 1: Our role is a good long list. It's like helping them understand their illness and how to manage it, what happened to them, help, you know, process all of that, help them understand their medication, stay on their medication. If, like, a lot of substance abuse stuff comes up then helping them navigate around that. These are all more like therapy type stuff, like connecting with friends, family, leisure activities, getting back to work, school, and then all the practical stuff like filling out forms, housing.

Of note, there was some disagreement between treatment providers regarding their role in managing patient crises. Two case managers stressed the importance of being available to patients by phone any time of day or night in order to prevent hospitalizations, however most disagreed with the suggestion that case managers should be "on call" and thereby replace emergency services.

In addition, participants from all stakeholder groups felt that healthcare institutions and treatment providers should advocate on behalf of individuals with mental illnesses and help influence policy. Advocacy efforts were seen to include communicating the individual's needs and interests to families, employers, schools, government, and other parties and promoting the cause of mental health by increasing awareness, helping reduce stigma, and enlisting the financial backing of stakeholders with influence. A few participants (primarily policymakers and treatment providers) expressed that hospitals and treatment providers have a duty to help influence mental health policy by lobbying the government, by participating in and promoting clinically relevant research, and by directly involving patients and families in decision-making at the institutional level.

> Policymaker 4: Les établissements [de santé mentale] ont une responsabilité de faire participer les personnes qui ont des problèmes de santé mentale et leurs familles dans les comités décideurs. Quand on veut changer les choses dans nos façons de faire, il faut impliquer les patients; ils ont souvent des réponses à nos questions. Ça c'est notre responsabilité en tant qu'institution pour la santé mentale de le faire. […] Il faut les habituer tranquillement à faire partie des petits comités et ensuite les faire monter dans les comités de direction pour qu'ils prennent de l'ampleur et qu'ils puissent aider à la prise de décision. C'est à nous à leur laisser la place.

> *Policymaker 4: Institutions [of mental health] have a responsibility to involve people with mental health problems and their families in decision-making committees. When we want to change the way we do things, we must involve patients; they often have answers to our questions. It's our responsibility as a mental health institution to do so. […] We have to slowly get them used to being part of small committees and then have them move up into management committees for them to carry more weight and so that they can help with decision-making. It's up to us to give them this place. (Translated)*

Related roles of hospitals and treatment providers included supporting the production of research, sharing research knowledge with other healthcare institutions, teaching, and educating the public about mental health problems.

> Psychiatrist 1: I think it should be in our [treatment providers'] hands to be able to psycho-educate the population through, you know, giving general talks to friends and families like we do here. Maybe going around schools, educating people in general.

One policymaker also expressed that hospitals and healthcare institutions, particularly first-line services, have a role to play in prevention and early identification of mental health problems.

Only policymakers identified aspects of institutional management as roles of healthcare institutions and treatment providers. They assigned responsibility to these stakeholders for developing treatment and management guidelines; informing institutional strategic directions based on clinical experience; managing access to and quality of housing resources; ensuring local implementation of government policies; liaising with and referring patients to other institutions and services (e.g., from first-line to second-line services); and ensuring that different mental health professionals (e.g., psychologists, psychiatrists, social workers) work together to manage mental health care at the institutional level.

> Policymaker 3: […] Donc moi je pense qu'il faut un – une collaboration clinico-administrative là. Des gestionnaires, bien sûr, qui connaissent les ressources humaines puis tout ça, les finances puis tout, mais aussi des spécialistes de la psychiatrie. Puis pas juste des médecins. Des infirmières spécialisées, des psychologues, des travailleurs sociaux spécialisés là-dedans. Et donc moi le clinico-administratif puis le médico-administratif aussi. Il faut absolument que les psychiatres soient associés à la gestion des soins de santé mentale. […]

> *Policymaker 3: […] So I think we need a – a clinical-administrative collaboration. Managers, of course, who know human resources and all that, finances and everything, but also specialists in psychiatry. And not only doctors. Specialized nurses, psychologists, social workers who are specialized in that. And so to me clinical-administrative and medical-administrative as well. It is essential that*

> *psychiatrists be involved in the management of mental health care. […](Translated)*

Finally, participants perceived that healthcare institutions and treatment providers play a role in engaging families in their ill loved one's treatment and supporting families; for example, by helping them understand their loved one's illness.

3.2 Roles and responsibilities of community, non-governmental, and non-profit organizations

Community, non-governmental, and non-profit mental health organizations were identified by a number of participants as having roles to play in supporting individuals with mental health problems. One of the main roles attributed to these groups (by treatment providers, patients, and one policymaker) was that of advocating on behalf of mentally ill individuals and helping influence policy. These organizations were deemed responsible for helping to reduce stigma; representing the interests of individuals with mental illnesses to the government in order to inform the development of policies better suited to meeting their needs; and ensuring that mental health becomes a government priority.

> Policymaker 6: […] It's very easy for mental health to not be a priority for historical reasons within the allocation of budgets, within the development of policies, et cetera. And there families and patients and other organizations, community organizations, need to continually push that mental health becomes a priority like other health care issues in our society.

Several policymakers expressed that community organizations, non-governmental organizations (NGOs), and non-profits play an important role in providing support services and resources to individuals with mental health problems and assisting their reintegration into various domains of life, from work and school to recreational activities. One policymaker also highlighted the role of community organizations in preventing mental health problems.

> Policymaker 1: […] The community groups also have a role to play 'cause they're support

> services, they help a great deal and in some neighbourhoods they're very, very involved. They're very involved even in preventing, in preventing problems and being there before things get out of hand. So they're also very, very important. […]

However, the most important role participants assigned to community organizations was that of supporting *families* of individuals with mental illnesses, as evidenced by the large number of participants from all stakeholder groups endorsing this role.

Facilitator:	Okay. What about community organizations… do you see a role for them at all in helping meet the needs of people with mental health problems?
Family member 6:	Not people with mental health but for the family. I went there [AMI-Quebec; community organization providing services for families of persons with mental illnesses] to get some emotional support. So for me it was very helpful.
Family member 5:	I went to AMI-Quebec too, it was pretty helpful, to support the families.

3.3 Roles and responsibilities of educational institutions, researchers, & employers/workplaces

A small number of participants, mostly policymakers, assigned responsibilities to educational institutions, researchers, and employers or workplaces for supporting individuals with mental health problems. As institutions and establishments where individuals with mental illnesses work and study, these stakeholders were seen to play a role in their functional recovery.

Participants expressed that educational institutions and the researchers affiliated with them are responsible for producing clinically relevant research and sharing this knowledge with healthcare partners across the province in an effort to improve mental health services.

> Policymaker 6: […] within the framework of the RUIS [Réseau Universitaire Intégré du Santé], the faculty [of medicine] plays a role in facilitating the transfer of information along the lines of the themes we're talking about to other health care partners so that they also can use the expertise that we have as a university and in our tertiary care centers and our academic health care centers, that they can use the expertise to develop their own resources for their local communities.

A few participants mentioned that researchers play an important role in improving mental health care by researching treatments and best practices for serious mental illnesses and that universities have a role to play in improving training for mental health professionals; for instance, by reinstating mental health internships where they have been eliminated and by training clinicians to have a more holistic approach to treating individuals with mental health problems.

Researchers were also said to be responsible for including key stakeholders such as patients, families, and clinicians in their research in order to produce more relevant and politically influential findings.

> Policymaker 4: […] Je pense qu'on va réussir à influencer politiquement encore plus lorsque les projets de recherche vont impliquer encore plus les familles. Faut que la recherche travaille encore plus avec la clinique pour pouvoir influencer. Il se fait des projets de recherche locaux. Mais au niveau psychosocial, je pense qu'il y a quand même une amélioration à faire à ce niveau-là. Plus on va être en mesure d'avoir cette collaboration-là, patient, famille, intervenant et chercheur, plus on va être en mesure d'influencer politiquement les gouvernements.
>
> *Policymaker 4: [...] I think we'll have greater political influence once research projects involve families more. Research has to work even more with the clinic in order to have influence. There are some local research projects. But at the psychosocial level, I think that there is nonetheless improvement to be made at that level. The more we will be able to have that collaboration, patient, family, clinician and researcher, the more we will be able to influence governments politically. (Translated)*

One policymaker explained that educational bodies and researchers can influence decision-making within healthcare institutions by informing institutional practices and play an important role in developing evidence-based mental health initiatives that can go on to form government policies.

A few participants felt that educational institutions and employers or workplaces can play a role in helping individuals with mental illnesses resume role functions disrupted by their illness. Specifically, these stakeholders were seen to help by working closely with the individual's treatment team and by making accommodations (such as permitting a flexible work or school schedule) to facilitate the individual's reintegration into school or work.

Family member 11: Bien moi mon fils était un bout de temps après les fêtes, il manquait beaucoup [de travail]; il manquait comme une journée par semaine. Là son travail commençait à lui peser, fait que là ils savent qu'il est malade mais ils avaient pas comme rien d'information probablement. Puis là il y a eu un avis disciplinaire parce que là il manquait trop [de travail]. Moi j'ai téléphoné à [gestionnaire de cas au PEPP] et puis je lui ai demandé s'il pouvait arranger de quoi. Fait que ils ont écrit une lettre comme quoi que [mon fils] avait des problèmes. Ils ont mis ça dans le dossier donc ils sont plus tolérants. Là ils savent que de temps en temps il a besoin d'une journée de décrochage, surement là, parce que ça doit être dans lui. Ça doit être dans sa maladie s'il a besoin de pas travailler une journée il se sent pas bien. Ça ça l'a aidé. Ça c'est bien, ça.

Family member 11: Well for a while after the holidays, my son was missing a lot [of work]; he was missing like one day per week. Then his work started to weigh down on him, so they know that he's sick but they probably had like no information. So then he got a warning because he was missing too much [work]. I called [case manager at PEPP] and I asked him if he could arrange something. So they wrote a letter to the effect that that [my son] had problems. They put that in the file so they are more tolerant. Now they know that from time to time he needs a day off, surely, because it must be in him. It must be in his illness if he needs to not work on a day that he doesn't feel well. That helped him. That's good. (Translated)

One policymaker also expressed that schools should be responsible for formally educating people about mental health problems and that both educational institutions and workplaces should contribute to preventing the exacerbation of mental ill health by destigmatizing mental illness (thereby making it easier to talk about and seek help for mental health problems).

Theme 4: Perceived roles and responsibilities of macro-level stakeholders with influence

Participants described a number of macro-level stakeholders with significant political, financial, and cultural influence as having roles to play in supporting individuals with mental health problems; namely, the government, the private sector, philanthropic organizations (including foundations and charities), and the media.

4.1 Roles and responsibilities of the government

One of the stakeholders mentioned the most frequently by participants from all stakeholder groups was the government, which was referred to both in general terms as a single entity and in specific terms as one of the levels of government (federal, provincial, or regional/municipal). One policymaker also included all of the institutions and organizations that receive funding from the government in their definition of government, such as hospitals, local community health and service centres, and some community organizations.

The government was seen by most participants to be the stakeholder responsible for creating a basic mental health infrastructure. Setting up and organizing programs and services for individuals with mental health problems, including hospitals, substance abuse treatment programs, work and school reintegration programs, and housing resources (e.g., low-cost housing, supervised apartments, etc.), was considered to be a fundamental and distinct role of the government. Treatment providers also deemed the government responsible for creating legal mechanisms intended to help and protect individuals with mental illnesses, such as trusts and court orders for treatment, psychiatric evaluation, or confinement.

> Policymaker 6: The basic infrastructure needs to be set by government and its partners. It's not for patients and families to set that up. For example, housing resources are not things that families set up, though they can voice their support for such resources. In the end, government has to take a role in actually initiating programs that are rational and logical and meet the needs of the patients concerned. So I think government has to play a major role in having a thoughtful approach to this and there needs to be an infrastructure to put it into place. […]

Another role assigned to the government was that of funding mental health programs and services, subsidizing the costs of medications and services, and providing direct financial assistance to individuals with mental health problems. According to many participants, in addition to setting up and organizing services, the government must fund them adequately to enable them to deliver the best possible mental health care. The government's funding role was seen to include helping fund some community and non-profit organizations and NGOs serving individuals with mental health problems and paying the salaries of mental health service providers. Indeed, increasing the salaries and the number of treatment providers (specifically, case managers) was seen by some to help improve the quality of care delivered by treatment providers, in part by reducing caseloads.

The government was also described as responsible for subsidizing the costs of services so that individuals and their families need not pay to receive mental health care. A few participants recognized that the healthcare system currently covers the costs of many services and were in favour of this; however, several participants (a family member, patient, and some policymakers) mentioned that psychologist services and substance abuse treatment programs are not always covered by the government and felt that they should be. Likewise, while a few participants acknowledged that the government currently covers part of the costs of many psychiatric medications (and covers them fully for individuals receiving welfare), several family members, policymakers and one treatment provider felt that the government should subsidize these medications to a greater extent. One treatment provider suggested that the government could also subsidize the costs of healthy foods for individuals with mental health problems, given the high incidence of metabolic complications among those taking psychiatric medications.

> Case manager 2: When it comes to access to care and maybe the medication, I think it should be the government, mostly.
>
> Facilitator: And what do you mean by access to care?
>
> Case manager 2: So everyone should have equal access to care, even people who don't have insurances or people out of the country, international students and stuff. And also when it comes to medication, I think it should be just free, free for the client.

The government was also said to be responsible for providing direct financial assistance to individuals with mental illnesses in need; for example, by providing financial supplements to help pay for rent. However, one patient disagreed with the idea of direct financial assistance on the grounds that it discourages people from helping themselves.

Another major role of the government identified by participants was that of creating mental health policies and strategic directions and improving services; in essence, roles related to the government's vision for mental health. A number of participants expressed that it is the unique responsibility of the government to create policies, set priorities, and outline regulations related to mental health, although these should be informed by relevant stakeholders, including individuals with mental illnesses and their families.

> Policymaker 6: […] the government must play a role as it does with other health care services in ensuring that the minimum requirements are met and that the appropriate policies are in place so that patients can transit the health care system in an appropriate fashion.

Government policies were said to have important short- and long-term consequences on mental health care; for instance, their decisions relating to the future privatization of health care were described by one treatment provider as having potentially detrimental effects for individuals with mental health problems. In addition, participants expressed that the government has a role to play more generally in maintaining the priority of mental health issues on the political agenda.

The government was also said to be responsible for identifying the unmet needs of individuals with mental health problems and making changes to services in an effort to better meet their needs. One policymaker described how by doing this, a government body had been recently able to draft a service transformation plan aiming to improve housing resources. Treatment providers and policymakers expressed that it is the government's responsibility to improve services; for example, by making mental health services more accessible (e.g., less costly, easier and quicker to access) and by changing the way welfare and disability benefits are administered such that they do not become a disincentive for individuals with mental illnesses to return to work or school.

Participants from all stakeholder groups believed that the government has a role to play in increasing the visibility of mental health issues and raising the public's awareness of mental illness. Specifically, the government was seen as responsible for creating information campaigns, websites, "mental health" days or walks and other publicity initiatives in order to educate the public about the symptoms of different mental illnesses, reduce the stigma attached to these conditions, and promote the cause of mental health. A few participants noted that to date, publicity campaigns have tended to focus on depression, substance abuse, and other more common mental health disorders and felt that they should expand to include more serious and less well-known mental illnesses, such as psychosis. Indeed, several patients and family members expressed that not enough was known about their or their loved one's condition and that this made the process of seeking help all the more challenging.

> Facilitator: We have touched upon this about advocacy, but is there anything else more concretely that you think the government should be doing specifically?
>
> Patient 5: I think so when you talk about making people aware. For example, in my situation
>
> we had no idea, absolutely, whatsoever, what was going on with me. It was a shock and my husband didn't know what was going on. They called the police and there was a huge mess. So I think that if TVs, there are speeches, or posters, anything that could inform people that it happens and it happens to anyone, any age. But we should be aware of what can happen to us.

A final role assigned to the government by families, treatment providers, and policymakers was that of supporting families of people with mental health problems. Treatment providers and policymakers acknowledged that caring for a loved one with a serious mental illness is demanding and requires formal recognition and support from the healthcare system. They mentioned various ways in which the government should support families, including enabling family members to take paid time off work to care for their ill relative and in so doing preventing the young person from being hospitalized; helping reduce the burden associated with organizing family support groups (a task usually undertaken by families themselves); for example, by offering financial support; and acknowledging the oftentimes highly stressful and labyrinthine process of help-seeking that families engage in by offering them extra support once they finally access appropriate care.

4.2 Roles and responsibilities of the private sector

A few participants, mostly treatment providers, named the private sector in general and pharmaceutical and insurance companies in particular as having roles to play in meeting the support needs of individuals with mental health problems. Some participants expressed that pharmaceutical companies can help by subsidizing the costs of psychiatric medications for patients with limited means or by offering free samples, while others highlighted the important role played by insurance companies in covering (at least partially) the costs of medications and psychologist services, given the necessity of these treatments for many people and the difficulty many would otherwise have paying for them entirely out of pocket.

> Facilitator: […] So you’ve mentioned families and the government, are there any other people or any other groups that you think should be involved in supporting - helping with the needs of people with mental health problems?
>
> Family member 2: Well maybe the companies that make the medications, I don’t know if they’re involved or not in any way. Pharmaceutical companies, maybe they could be of help somehow. We buy their products; so maybe - I don’t know if they do, I’m not aware. Maybe they can do some funding for people who need it. […]

4.3 Roles and responsibilities of philanthropic organizations

Philanthropic organizations, including charities and foundations dealing not with individual patients or families but with higher-level efforts to fund research and/or services or shape policy, were described by a few policymakers and one treatment provider as having a responsibility to support individuals with mental health problems; specifically, by funding programs, projects, and services and by helping to reduce stigma. Participants explained that by donating money to mental health institutions and organizations, philanthropic organizations help them realize projects or implement programs or resources that may not have otherwise been possible without this funding.

> Policymaker 1: Yeah, I think philanthropic organizations they get involved in projects and they contribute to make certain ideas, certain projects happen, that would not happen if they had not given the financial part. I think that in other provinces and part of the world there, the philanthropic organizations are very involved. I think in Quebec there's less of that but there's still some that happens and they help by funding certain projects, by funding resources, by funding programs. Yeah, they're part of it and that's very good when they get involved.

By leveraging their power and influence, philanthropic organizations were also said to play a role in helping reduce the stigma of mental illness.

4.4 Roles and responsibilities of the media

The media were identified as an important stakeholder by two participants (one patient and one treatment provider) due to the role they can play in increasing the visibility of mental health issues, educating and informing the public about mental health problems, and reducing the stigma associated with these conditions.

> Psychiatrist 3: But they would need to make it [mental illness] more visible in the media also. […] So maybe pushing it towards the media and then maybe that's also the responsibility of the media, the media are responsible - to be held responsible. I think that would be important also because there's a lot about depression and suicide. And that's good but I don't think there's much about psychosis. […]

Theme 5: Perceived roles and responsibilities of society as a whole

A few participants representing most stakeholder groups went beyond specific individuals, institutions, or organizations to name society as a whole as having a responsibility to support individuals with mental health problems. Most of these participants discussed the role all of society plays in directly and indirectly funding mental health services and initiatives. One patient described how citizens can donate money to support mental health initiatives, while treatment providers and one policymaker pointed out that because the Canadian healthcare system is publicly funded, ultimately it is tax-paying citizens who contribute the majority of funding for mental health services.

> Case manager 1: I mean families are responsible [for housing] in terms of like maybe having the person live with them. But in terms of independent living in an appropriate housing resource, I see that as the government putting money into the system to have those places, like supported, supervised and… subsidized.
>
> Case manager 5: Yeah because at the end of the day it's the taxpayers are paying that. It's not the government, it's us.
>
> Case manager 1: Yeah, yeah.
>
> Case manager 5: It's the parents of those kids.
>
> Case manager 2: Yeah we say government but…
>
> Case manager 5: It's us and the parents of those kids. So at the end of the day it's us.

Two participants (a patient and a policymaker) also expressed that it is the role of all members of society to advocate on behalf of individuals with mental illnesses by rallying together to represent their interests to the government, help influence mental health policies, and destigmatize mental illness.

More fundamentally, policymakers expressed that it is the duty of all citizens to care about mental health and support people with mental health problems. At an individual level, this was said to entail being attentive to the signs of mental illness in others and helping an individual who is unwell get the treatment they need, while at a societal level this was described as providing individuals with mental illness the resources they need to get better.

> Policymaker 4: […] En tant que société on a un devoir de procurer aux gens les moyens pour y

arriver. Une personne qui a vécu un problème de santé mentale et qui est laissée à elle-même, pour se trouver un logement, pour se trouver un travail, c'est pas tellement garant d'un succès. Une fois qu'on a donné les moyens à une personne, c'est pour la soutenir. […]

Policymaker 4: […] As a society we have a duty to provide people with the means to get by. A person who has experienced a mental health problem and who is left to themselves, to find housing, to find a job, it's not very conducive to success. Once we have given a person the means, it's about supporting them. […] (Translated)

Theme 6: Perceived structure and nature of roles and responsibilities

When discussing their opinions of who should be responsible for supporting individuals with mental health problems, participants often described roles and responsibilities in terms of their structure (hierarchical or shared) and nature (conditional or limited/bounded), adding depth and dimension to their views about responsibilities.

Many participants from all stakeholder groups made direct reference to or alluded to the notion of there being a structure to roles and responsibilities; specifically, that there is a hierarchy of roles (i.e., an order of importance) and/or that roles are or should be shared. Most participants who spoke of a hierarchy felt that individuals with mental illnesses themselves or their families or caregivers have the most important role in supporting individuals with mental health problems. Participants' explanations for these attributions largely centred on the fundamental responsibility of individuals for their own health and lives and on the essential role of families and loved ones as those closest to the individual, both in terms of emotional bonds and proximity. Among the participants who endorsed individuals themselves as having the most important role (a group which included patients, treatment providers, and policymakers), several perceived that families are next in the hierarchy; however, a few participants felt that the treatment team or the government are second in importance. Likewise, among participants endorsing families as most important (a group including family members, treatment providers, and policymakers), the treatment team and the government were variously perceived to be second in order of importance.

> Patient 1: I think the government has to put the right regulations in place and that the family's support is very important, but the first responsibility is the patients themselves. We have to take ownership of our recovery and be responsible for it.

> Policymaker 4: D'après moi c'est les familles. Les familles qui jouent le plus grand rôle. Comme je te dis j'englobe les amis là-dedans et tout ça. C'est sûr que la personne elle-même c'est important, ton autonomie, ta force et tout ça. Il faut que le tissu social des personnes soit très fort, pour les aider à se rétablir. Sinon ce sera les équipes interdisciplinaires qui doivent pallier à ça. Mais c'est jamais comme les familles et les proches. Pour moi ça c'est clair. C'est la famille et les proches qui sont le plus importants pour le patient.

> *Policymaker 4: To me it's families. Families who play the biggest role. As I said I include friends in there and all that. For sure the person him or herself is important, your autonomy, your strength and all that. Peoples' social fabric has to be very strong to help them recover. Otherwise it will be the interdisciplinary teams who will have to compensate for that. But it's never the same as families and loved ones. To me that's clear. It's family and loved ones who are the most important for the patient. (Translated)*

Less commonly, the government, the treatment team, or the individual's social network were described as having the most important role.

A number of participants (treatment providers, one patient, and one policymaker) felt that no one stakeholder can be said to have the most important role, but rather that each stakeholder has a different role to play and different strengths or competencies to contribute. These participants preferred to think of a partnership or sharing of roles rather than a hierarchy of roles. Indeed, a large number of participants across all stakeholder groups expressed that responsibility for supporting individuals with mental health problems should be shared among various stakeholders. This was taken to mean either that different parties should share the responsibility for meeting a particular support need (e.g., treatment providers and employers should partner together to facilitate a patient's return to work) or that they should have distinct but complementary responsibilities with the common goal of supporting individuals with mental health problems (e.g., the government should lay the foundation by creating effective mental health policies while families should provide moral and emotional support). In the latter view, the roles of both stakeholders are important but different and reflect the unique strengths of each stakeholder.

Facilitator: T'allais dire tantôt à propos du gouvernement…?

Case manager 9: Bien juste que ça devrait être complémentaire. Parce qu'à la base je pense que chaque rôle devrait se chevaucher, si c'est comment on dit ça, parce que, même si on a peut-être une façon différente d'adresser un problème, le rôle de chacun c'est de soutenir l'individu, d'aider l'individu à accomplir son objectif. Donc on travaille tous sur le même objectif, c'est de trouver comment on – c'est comme un casse-tête; on amène tous les morceaux du casse-tête pour pouvoir avoir un résultat finale. Donc dans l'idéal, tous les différents joueurs ça serait comme – il y aurait un chevauchement et tout le monde pourrait s'entraider dans un but ultime.

Facilitator: You were going to say before about the government…?

Case manager 9: Well just that it should be complementary. Because basically I think that every role should overlap, if that's how you say it, because, even if we maybe have a different way to address a problem, the role of each is to support the individual, to help the individual accomplish their goal. So we're all working on the same goal, it's a question of finding how we – it's like a puzzle; we bring together all the pieces of the puzzle to get a final result. So ideally, all the different actors would be like – there would be overlap and everyone would help each other towards an ultimate goal. (Translated)

Of note, some participants conceived of roles as having a hierarchical structure while also underlining the need for a sharing of roles, as expressed by one policymaker:

Policymaker 6: […] I think maybe that's a theme of what I've been saying is that there has to be a partnership here of all the groups; however, there's certainly a leadership role that again government with all of the organizations it supports must play, because that's where the expertise is, that's where the training has occurred to deal with mental health issues, but it has to be bolstered by the implication and involvement of patients and families.

Participants from all stakeholder groups also described roles and responsibilities in terms of their conditional nature and in terms of their limits or boundaries. Many participants expressed that stakeholder roles and responsibilities vary case by case depending on the specific needs of the individual with mental health problems, their capacity to support themselves, their diagnosis, their stage of life or personal development, and the phase of the illness. As such, participants perceived that in an individual case, different stakeholders can play a more or less important role depending on these different factors.

> Interviewer: […] Do you see any major difference in the roles of these different groups or do you see one group as having a more important role or responsibility than the other groups?
>
> Policymaker 2: Well, I guess it depends which phase the person is at in their recovery. I think that when a person is acutely ill, the family and the healthcare providers have a more important role to play. I think when the person is starting to recover then I believe that community organizations and communities can create places for individuals. […] I think when the person's recovering then families need to change roles from the more intense caregiver to joining the healthcare team, understanding what the plan is and supporting the recovery of the individual. I think there needs to be changing roles on everybody's part. […]

In addition, several participants (predominantly treatment providers) perceived that there are role boundaries, or limits to the extent of responsibility that certain stakeholders can or should assume. Specifically, the roles of families, individuals with mental illnesses, treatment providers, and the government were described as limited (or needing to be limited) in various ways. For example, several treatment providers described how their role is often “parenticized”, or the line blurred between what they feel their responsibilities and those of the ill person’s family should be, and policymakers conveyed that families cannot be expected to be more involved in their ill loved one’s treatment if confidentiality rules or other institutional barriers prevent them from doing so.

> Policymaker 1: […] What happens is that often, families have no access to information, no access

> to this, no access to that, the doors are closed and you cannot turn around and then ask them to assume certain responsibilities when the door has been shut for so many, for being more involved. […]

4.5 Discussion

The purpose of this study was to explore key stakeholders' perceptions about who should be responsible for supporting individuals with mental health problems and to discover what responsibilities they ascribe to these parties. We found that participants identified individuals with mental health problems themselves; stakeholders in the immediate and extended social networks of these individuals; macro-level stakeholders with influence; and society as a whole as having a wide range of roles and responsibilities. Furthermore, we discovered that many participants variously perceived roles and responsibilities as being hierarchical in structure, with some stakeholders playing a more important role than others, and/or as being shared among different stakeholders each with distinct strengths to contribute. Participants (particularly treatment providers) also often perceived roles and responsibilities to be conditional and to have certain limits or boundaries.

There was consensus among participants from all stakeholder groups that individuals with mental health problems, their families, healthcare institutions and treatment providers, and the government have important roles to play in supporting individuals with mental health problems.

Given that persons with mental health problems, their families/carers, and treatment providers are the stakeholders at the core of most mental health encounters, it is perhaps intuitive that they would be identified by participants from all stakeholder groups as having significant responsibilities. Treatment providers, including general practitioners, psychiatrists, and other mental health professionals from a variety of disciplines (e.g., social workers, nurses, psychologists, etc.), are formally involved in supporting patients by providing them with medical and psychosocial care, and general practitioners are often the first point of contact for young people seeking help for mental health problems (Anderson, Fuhrer, & Malla, 2010; Rickwood, Deane, & Wilson, 2007). That being said, since our study participants included patients and families receiving services at PEPP, an early intervention program for psychosis affiliated to a mental health institution, this may have framed their thinking about roles and responsibilities to necessarily include hospitals and mental healthcare providers. Had they been recruited from a different context, such as a peer support group or community organization, these participants may not have placed as much importance on healthcare institutions and treatment providers. Furthermore, FEP patients and families who dropped out of treatment because of dissatisfaction with services may have been less likely to endorse these stakeholders. Meanwhile, it is not surprising that treatment providers would identify themselves and the institutions they work in as having important roles to play in supporting individuals with mental health problems.

Families, including parents, siblings, and spouses or partners, are also frequently involved in providing informal care and supports and often initiate the process of help-seeking (Anderson, Fuhrer, & Malla, 2013). Moreover, as mentioned by several participants, they are usually the closest stakeholder to the person with mental health problems in terms of emotional ties, knowing the person well (their needs, strengths, etc.), and being with them often. This is particularly the case among youth with FEP, who are young and often living at home with their families when the illness emerges (Addington & Burnett, 2004). The high endorsement of families among participants may also be a reflection of the study setting. Family involvement in treatment is a critical component of specialized early intervention services such as PEPP (Iyer et al., 2015). Since we recruited PEPP treatment providers, patients, and families for this study, these participants would have all been sensitized to the importance of family involvement in treatment and as a result, may have been more likely to assign roles and responsibilities to families.

As the persons experiencing the illness and in need of support, individuals with mental health problems are not only the recipients of care, but also active agents who are able to satisfy some of their own support needs. Participants' frequent appeals to the fundamental responsibility of individuals with mental illnesses for their own lives, health, and recovery may also reflect the cultural context of this study, as autonomy, independence, and self-sufficiency are highly valued in individualistic Western societies such as our own (Miller, 1994). Indeed, the role of persons with mental health problems is minimized in some cultural settings endorsing more collectivistic and interdependent values (Iyer et al., 2014; Iyer et al., 2015). The strong consensus on the role of individuals with mental health problems may also testify to the growing recognition that consumers of mental healthcare should be active partners in their own treatment as well as advocates for their own needs and those of others with mental illnesses (WHO Regional Office for Europe, 2010).

As the stakeholder formally mandated with organizing and funding the healthcare system, the government was identified by many participants across stakeholder groups as having responsibilities for supporting individuals with mental health problems. Indeed, setting up the mental healthcare infrastructure, funding programs and services, and creating policies were three of the major domains of responsibility attributed to the government. The strong consensus on the role of the government among participants from various stakeholder groups reflects the cultural and historical context of this study. Canada has had a mostly publicly funded and administered universal healthcare system since 1984 (Health Canada, 2012) which is a source of national pride and a defining element of the Canadian identity (Mendelsohn, 2002). The vast majority of

Canadians are strongly in favour of the current system and of the government's role in health care, and in fact, most Canadians would like the federal government to become *more* involved in improving the healthcare system (EKOS Research Associates Inc., 2012). Participants' views of the government's role may have differed greatly had this study been conducted in the United States, for example, where opinion on the role of the government in society in general and health care in particular is much more divided. Additionally, the high endorsement of the government reflects the largely left-leaning political orientation of most participants (Table 1).

There was less consensus among participants on the roles and responsibilities of friends and the community/neighbourhood; community organizations, NGOs, and non-profits; educational institutions, researchers, and employers/workplaces; philanthropic organizations/foundations; the private sector; and the media. There may be several reasons for this.

First, many of these stakeholders may not be very visible in terms of their support roles. The express purpose of educational institutions and workplaces, for instance, is not to support individuals with mental health problems, and the ways schools and workplaces were perceived by participants to provide support were often indirect. For example, the effects of producing clinically relevant research and sharing this knowledge to improve mental health care are not immediate and may not be visible to most people. Philanthropic organizations, the private sector, and the media also do not have a formal mandate to support persons with mental illnesses, and their responsibilities again tended to involve more indirect supports (e.g., funding programs and services, increasing mental health awareness). Community organizations, NGOs, and non-profits may not have been endorsed frequently because they may not be well publicized. Indeed, our focus groups and interviews revealed that patients and families are often unaware of where to turn when they are in need of mental health care. The services offered by these organizations may also be perceived to be inadequate for individuals experiencing a serious mental illness such as FEP.

Second, the stakeholders less frequently cited as having responsibilities tended to be identified mainly by policymakers and/or treatment providers, who may be more aware of the different parties currently involved in supporting people with mental health problems. By virtue of their occupations, one would expect policy and decision makers to be knowledgeable about the mental healthcare system, including which organizations are mandated to fulfil which functions and which sectors of society could be more involved. Likewise, PEPP treatment providers (particularly case managers) regularly liaise with other stakeholders such as schools, government agencies, employers, and community organizations in the context of their professional duties and are by necessity aware of the different resources and supports available to patients.

Finally, it may be that some of the less frequently mentioned stakeholders would have been shown to have a larger role had we specifically probed about them during the focus groups and interviews. While we directly asked about the roles of individuals with mental health problems, their families, and the government when these groups were not mentioned spontaneously, we did not specifically inquire about the role of the media or friends, for instance.

There may also be other more specific reasons why some stakeholders were less frequently cited by participants as having roles and responsibilities.

Friends of the individual with mental illness and their communities or neighbourhoods were seldom mentioned, with only one patient acknowledging the role of their social network in providing motivation and support; however, this is in line with research showing that youth with

FEP have minimal social contact outside of their families and few close friends or confidants (Gayer-Anderson & Morgan, 2013). Participants may have also been inclined to think about instrumental supports (e.g., help paying for medications and services) more than emotional supports during the focus groups and interviews, which do not appear to be the type of support most often provided by friends in this age group. Additionally, some participants may have conceived of friends and families as one group (as one policymaker explicitly mentioned).

Since the school and work activities of youth with FEP are often disrupted when they begin to experience mental health problems, patients and families might have been expected to perceive schools and employers as having a greater responsibility to help them transition back into their functional roles. However, since Individual Placement and Support (IPS) (Becker & Drake, 1993) vocational rehabilitation services are integrated into the PEPP program and offered to all patients in need of these services, patients and families may have perceived work reintegration support to be the domain of treatment providers.

Community organizations, NGOs, and non-profits were identified by a larger number of participants from different stakeholder groups, though mostly for their role in providing support to *families* of individuals with mental health problems. The community organization most frequently cited by participants, AMI-Quebec, is dedicated to families of mentally ill persons, suggesting that participants may have perceived that community mental health organizations primarily cater to families. Since mainly policymakers saw a role for community organizations in providing support services to individuals with mental health problems, it may also be that patients, their families, and treatment providers, thinking of their own experiences at PEPP, did not perceive that patients require much support outside of what they already receive at PEPP. PEPP, like most specialized early intervention programs, offers a wide range of services in addition to case management, such as cognitive-behavioural therapy, work reintegration support, group psychoeducation, and physical activity, nutrition, and social meet-up groups, to name a few (Iyer et al., 2015). Meanwhile, community-based supports may have been seen as more appropriate for families, suggesting perhaps that fewer family-focused services and interventions are available at PEPP.

That the private sector was not mentioned by many participants may reflect the prevailing wariness among Canadians about industry involvement in healthcare. A 2002 review of the evolution of Canadian public opinion on healthcare since 1985 revealed that most Canadians strongly oppose the privatization of healthcare (Mendelsohn, 2002). Interestingly, policymakers and treatment providers were more vocal in their endorsement of the private sector's role than patients or families, which may reveal a value difference between these groups. Of note, however, one treatment provider cautioned that privatization of healthcare threatens to most unfairly disadvantage individuals with mental health problems.

Finally, while a small subset of participants expressed that society as a whole has a responsibility to support individuals with mental health problems, "society as a whole" is an abstract concept that can be seen to encompass all of the other institutions and organizations mentioned by participants.

By conceptualizing roles as hierarchical/shared and conditional/limited, participants revealed nuanced, relative views of roles and responsibilities. The hierarchy described by many participants illustrates the central roles of individuals with mental health problems and their families, and to a lesser extent, those of the government and treatment providers. Perhaps not surprisingly, the groups deemed most important (individuals with mental illnesses, their families, the government, and hospitals/treatment providers) were also those that were endorsed most frequently by participants across stakeholder groups, and interestingly, they correspond to the stakeholder groups interviewed. That patients often recognized their own role in supporting themselves and families often identified themselves as having important responsibilities suggests that these stakeholders agree with their roles and responsibilities. It is noteworthy that no patients named families as having the most important role and vice versa: both groups seemed reluctant to attribute too many responsibilities to each other. Indeed, a few patients minimized the role that families should play for fear of burdening them, and some family members appeared hesitant to assign too much responsibility to patients, particularly at the beginning of their illness, citing their reduced capacity to care for themselves.

The view held by numerous participants from all stakeholder groups that roles and responsibilities should be shared echoes several national and international mental health policy documents (MHCC, 2012; National Treatment Strategy Working Group, 2008; WHO, 2013) which recognize that a partnership or coordination of efforts among various stakeholders will produce greater systemic change than each stakeholder working independently could. For instance, two policymakers expressed that greater collaboration between different mental health professionals (e.g., nurses, social workers, psychiatrists) leads to better quality, more integrated and holistic services that address a broader range of support needs (e.g., substance abuse treatment, psychotherapy, work/school reintegration, housing). This endorsement of the idea of shared roles and responsibilities stands in contrast with the current silo-like compartmentalization of mental health services and professions (Hall, 2005; Kilbourne, Fullerton, Dausey, Pincus, & Hermann, 2010; Linden, 2015). Substance abuse treatment, for example, is delivered by multiple sectors (hospitals, private programs, etc.) and is rarely integrated into more general mental health services, often resulting in a lack of communication and collaboration between different service providers separately treating an individual's substance abuse problems and other mental health problems (National Treatment Strategy Working Group, 2008).

The idea (endorsed by many treatment providers) that stakeholder roles and responsibilities vary depending on multiple factors such as the age of the individual with mental health problems, the phase of their illness, and their specific needs suggests that roles are dynamic and sensitive to context. This in turn reveals that many participants were thinking about roles at an individual patient level. Conversely, the notion that there are or should be limits to certain stakeholders' roles implies the perception that some responsibilities cannot or should not be assumed by specific stakeholders. Notably, several treatment providers (particularly case managers) discussed the need for boundaries in their own professional roles; for example, between their responsibilities and those of other mental health professionals. These views attest to the attempts of different health professions historically to define and delimit their roles, which some scholars believe has led to the creation of professional siloes (Hall, 2005).

The specific responsibilities assigned by participants to different stakeholders are equally revelatory. Some responsibilities were largely seen to be specific to a particular stakeholder group. For example, emotional support (e.g., showing love, affection, and acceptance) was usually seen as a distinct responsibility of families, while formal mental health care (e.g., providing medication and psychotherapy) was seen as the exclusive domain of hospitals and healthcare providers. However, several responsibilities mentioned recurrently by a number of participants were attributed to various stakeholder groups. Responsibilities for advocating for the needs of individuals with mental health problems, reducing stigma, and/or being involved in policy and decision making were assigned to persons with mental illnesses; their families;

hospitals and treatment providers; community organizations, NGOs, and non-profits; educational institutions and researchers; philanthropic organizations; and society as whole. Meanwhile, responsibilities for prevention and early identification of mental health problems and for increasing the visibility/public awareness of mental health problems were attributed to families; the communities and friends of individuals with mental illnesses; hospitals/treatment providers; community organizations; educational institutions and researchers; employers/workplaces; the government; and the media. Several stakeholders were also said to be responsible for supporting families of individuals with mental health problems.

Altogether, this suggests that these are key responsibilities that various stakeholder groups with different levels of influence can and should collectively assume. In particular, the recurring notion that service users and their families should be involved in research and mental health policy and decision making, domains that they have traditionally been excluded from, reveals a shift in thinking about roles and responsibilities and in expectations of persons with mental illnesses and their families. That researchers were said to have a responsibility to involve key stakeholders (patients, families, and clinicians) in research in order to influence policy while few to no clinicians, families, or patients identified any role for researchers or educational institutions also points to the need for a shift towards more participatory research and more effective knowledge translation. In this way, research will be able to impact actual clinical practices and service users and their families will be more aware of and able to use research knowledge.

Some discrepancies exist between participants' views of roles and responsibilities and current mental health policies and practices. For instance, many participants expressed that individuals with mental health problems are fundamentally responsible for their own lives and treatment and that no one can truly help an ill person who does not want to be helped; yet, the current practice of imposing court orders for treatment and confinement serve as examples to the contrary. Likewise, several participants felt that families should be involved in their ill relative's treatment and should be seen as an integral member of the treatment team; however, current policies on confidentiality and mental health practices that largely focus on the individual are incongruent with this role; a discrepancy highlighted by two policymakers.

Participants' perceptions of the roles and responsibilities of different stakeholders for supporting individuals with mental health problems may have been nuanced by a number of factors, such as their level of analysis or frame of reference. Some participants, particularly policymakers, tended to describe roles and responsibilities at a macro systems level, identifying the government and major institutions and organizations as important stakeholders, while other participants tended to describe roles and responsibilities at an individual patient level and to be sensitive to contextual factors.

Different conceptions of government, mental health problems, and even responsibility may also have nuanced participants' views. Government could have been interpreted as any of the different levels of government and it could have been seen (and in some cases, was seen) to include all publicly funded institutions and any organizations receiving government funding. Similarly, participants may have been thinking about different mental health problems associated with different support needs. A person with mild depression, for example, may not be perceived to have the same need for supported housing as a person with a psychotic disorder. Differing conceptions of responsibility could also shape perceptions. Responsibility could refer to the obligation to act in accordance with the law, the duty to act morally or ethically, or the expectations one must fulfil depending on one's role (Snelling, 2012). In the case of persons with mental illnesses, responsibility could also imply blame (Corrigan, 2000). Finally, participants' views may have been nuanced by whether they were thinking of the *actual* roles and responsibilities of various stakeholders or their *ideal* roles and responsibilities.

This study has several strengths. Until now, key stakeholders' perceptions of who should be responsible for supporting individuals with mental health problems and the roles they ascribe to these parties have never been investigated. By exploring the perspectives of multiple stakeholders involved in organizing, providing, and receiving mental health services using a qualitative design, we have discovered multifaceted, nuanced, and relative views of roles and responsibilities. Our study also serves as a model for the "de-siloization" of research and mental health care by virtue of taking into account the views of *all* stakeholder groups who play a role in mental health care. Our study was also methodologically rigorous, with care taken to incorporate service user, family, clinician, and researcher perspectives into the interview guide and several researchers contributing to data collection (M.P., H.L.), careful verification of transcripts (M.P., S.V.), and data analysis and interpretation of findings (M.P., S.V., G.J., S.I.).

This study also has some limitations. In general, policy and decision makers identified more stakeholders as having roles and responsibilities and provided more detailed descriptions of their responsibilities than did other participants. While this may be due to policymakers' greater knowledge of the healthcare system, the use of different data collection methods may have amplified this difference. Policymakers were the only stakeholder group interviewed individually (focus groups were conducted with all other stakeholder groups), which allowed them to take more time to answer questions and to elaborate their responses. Furthermore, there may have been less consensus on the roles of some stakeholders (e.g., the media) because we did not specifically inquire about them. Finally, the situating of our focus groups in the context of a specialized early intervention program for first-episode psychosis may have resulted in particularities in the views of patients, families/carers, and treatment providers, which may not be evident in other mental health care contexts.

Our study has important implications. Given the consensus among key stakeholders on the roles of the groups deemed most important for supporting people with mental health problems, varying perceptions are not likely to be the cause of unmet support needs. Now that we have discovered who pertinent stakeholders feel should be responsible for supporting individuals with mental illnesses and what their responsibilities are perceived to be, mental health policies can take this information into consideration. For example, greater opportunities can be made for service users and their families to be involved in clinical research and institutional policy and decision making.

Learnings from this study can also have implications for the design and delivery of mental health services, and ultimately, for the quality of care. For instance, explicitly declaring this avowed value of roles and responsibilities being shared among various stakeholders may facilitate less “siloed” and more collaborative practices. Given that the current reorganization of the healthcare system in Quebec is intended to improve the quality of health services, the knowledge imparted by this study may be particularly timely.

Finally, we have demonstrated that eliciting the perspectives of diverse stakeholders and drawing on numerous and varied sources (e.g., policy documents, the mental health literature, public opinion polls, clinical experience) to inform focus group and interview questions, data analysis, and interpretation of results can yield robust findings. This study thus illustrates the value of conducting interdisciplinary research involving multiple stakeholders.

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4.7 Tables

Table 1. *Selected sample characteristics*

Variable	Patients (*n* = 13)	Families (*n* = 12)	Case managers (*n* = 12)	Psychiatrists (*n* = 6)	Policymakers (*n* = 6)
	f(%) / M(SD)	*f*(%) / M(SD)	*f*(%) / M(SD)	*f*(%) / M(SD)	*f*(%) / M(SD)
Relationship to family member at PEPP					
Parent	-	*6* (50%)	-	-	-
Spouse/partner	-	*3* (25%)	-	-	-
Sibling	-	*2* (16.7%)	-	-	-
Other	-	*1* (8.3%)[a]	-	-	-
Gender (male)	*8* (61.5%)	*3* (25%)	*5* (41.7%)	*4* (66.7%)	*4* (66.7%)
Age	26.31 (6.21)	38.83 (15.11)	43.73 (10.16)	42.67 (7.60)	58.83 (9.10)
Highest level of education					
Less than high school	*6* (46.2%)	*0* (0%)	*0* (0%)	-	-
High school	*4* (30.8%)	*4* (33.3%)	*0* (0%)	-	-
College/vocational degree or diploma	*0* (0%)	*6* (50%)	*2* (16.7%)	-	-
University degree	*3* (23%)	*2* (16.7%)	*9* (75%)	-	-
Not specified	*0* (0%)	*0* (0%)	*1* (8.3%)	-	-
Previously worked as a treatment provider	-	-	-	-	*5* (83.3%)
Professional affiliation/discipline					
Social work	-	-	*4* (33.3%)	-	*0* (0%)
Nursing	-	-	*6* (50%)	-	*2* (33.3%)
Occupational therapy	-	-	*1* (8.3%)	-	*1* (16.7%)
Art therapy	-	-	*1* (8.3%)	-	*0* (0%)
Psychology	-	-	*0* (0%)	-	*1* (16.7%)
Internal medicine	-	-	*0* (0%)	-	*1* (16.7%)
Primary source of income					
Employment/salary	*3* (23.1%)	*11* (91.7%)	-	-	-
Welfare	*6* (46.2%)	*0* (0%)	-	-	-
Allowance from parent/guardian	*0* (0%)	*1* (8.3%)	-	-	-
Disability pension	*2* (15.4%)	*0* (0%)	-	-	-

Other	*2* (15.4%)[b]	*0* (0%)	-	-	-
Born in					
Canada	*12* (92.3%)	*8* (66.7%)	*8* (66.7%)	*4* (66.7%)	-
Outside Canada	*1* (7.7%)	*4* (33.3%)	*4* (33.3%)	*2* (33.3%)	-
Ethnicity					
Arab	*0* (0%)	*0* (0%)	*0* (0%)	*1* (16.7%)	-
Black	*3* (23.1%)	*1* (8.3%)	*0* (0%)	*0* (0%)	-
Chinese	*0* (0%)	*0* (0%)	*1* (8.3%)	*0* (0%)	-
Latin American	*2* (15.4%)	*2* (16.7%)	*1* (8.3%)	*0* (0%)	-
South Asian	*1* (7.7%)	*2* (16.7%)	*0* (0%)	*0* (0%)	-
West Asian	*0* (0%)	*2* (16.7%)	*0* (0%)	*1* (16.7%)	-
White/Caucasian	*5* (38.5%)	*3* (25%)	*10* (83.3%)	*4* (66.7%)	-
Other	*1* (7.7%)[c]	*1* (8.3%)[d]	*0* (0%)	*0* (0%)	-
Not specified	*1* (7.7%)	*1* (8.3%)	*0* (0%)	*0* (0%)	-
Occupational status[e]					
In school (full or part-time)	*4* (30.7%)	*1* (8.3%)	-	-	-
Working (full or part-time)	*3* (23.1%)	*8* (66.7%)	-	-	-
Volunteering	*1* (7.7%)	*0* (0%)	-	-	-
Caregiving for child(ren) and/or dependent adult	*3* (23.1%)	*3* (25%)	-	-	-
Neither in school nor working nor caregiving	*6* (46.2%)	*1* (8.3%)	-	-	-
Living situation					
Living alone	*3* (23.1%)	*0* (0%)	-	-	-
Living with family or partner	*10* (76.9%)	*11* (91.7%)	-	-	-
Living with friend/roommate	*0* (0%)	*1* (8.3%)	-	-	-
Living situation of family member at PEPP					
Living alone	-	*2* (16.7%)	-	-	-
Living with family or partner	-	*10* (83.3%)	-	-	-
Marital status					
Single	*6* (46.2%)	*2* (16.7%)	*0* (0%)	*1* (16.7%)	-
In a relationship or married/common-law	*6* (46.2%)	*8* (66.7%)	*9* (75%)	*5* (83.3%)	-
Separated or divorced	*1* (7.7%)	*2* (16.7%)	*3* (25%)	*0* (0%)	-

Political orientation[f]	4.46 (1.98)	4.60 (1.77)	4.00 (1.15)	3.16 (1.16)	4.40 (1.81)

[a] Nephew

[b] Support from brother (*n* = 1); not specified (*n* = 1)

[c] "Un mélange" / "A mix"

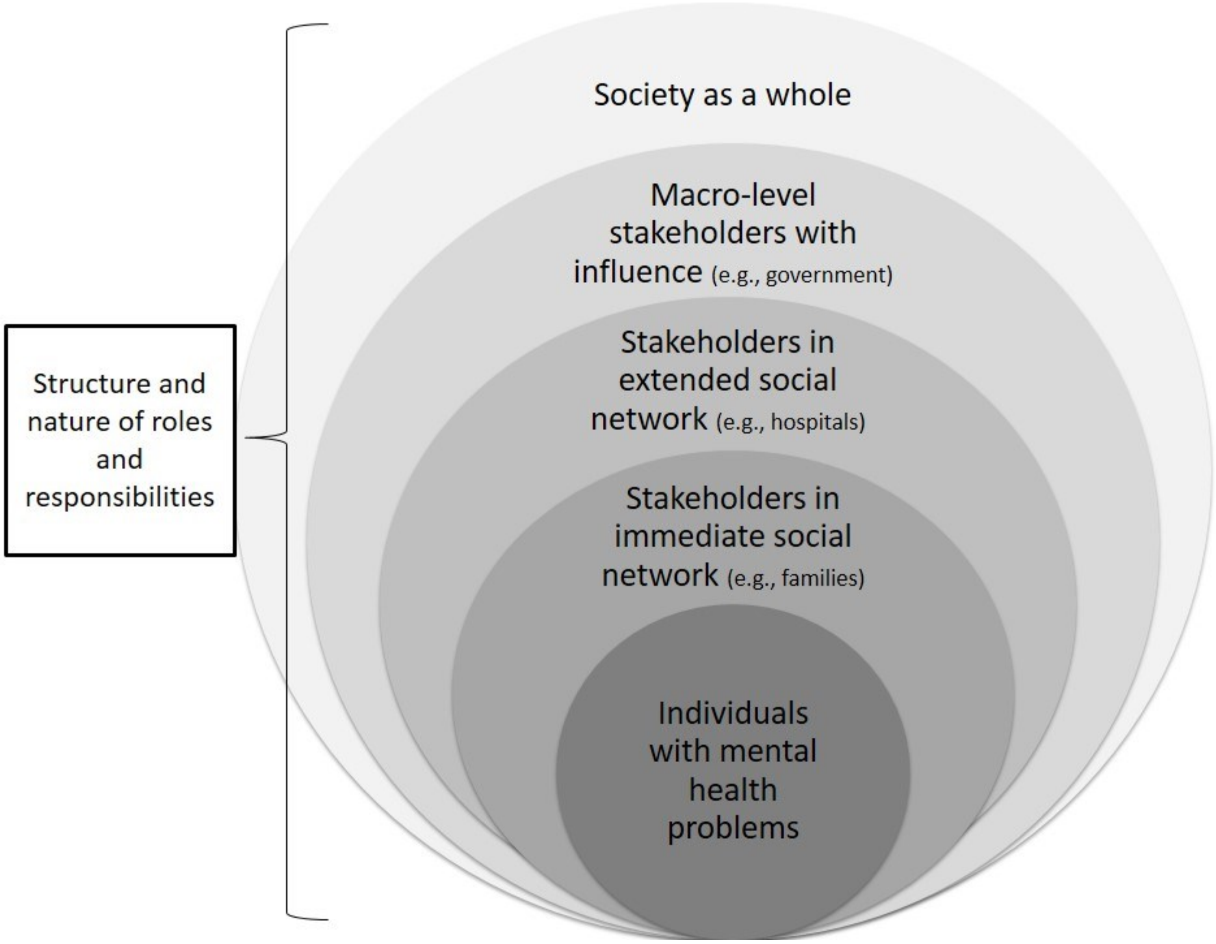
[d] African

[e] Percentages do not sum to 100 because some patients and family members were engaged in more than one occupational activity

[f] Rated on a scale from 1 to 10 where 1 = left-leaning and 10 = right-leaning

4.8 Figures

Figure 1. Final themes pertaining to who stakeholders feel should be responsible for supporting individuals with mental health problems and pertaining to the structure and nature of roles and responsibilities.



CHAPTER 5

General Discussion and Conclusions

5.1 Summary of main findings

The results of the critical review and of the qualitative study fill a large knowledge gap about perceptions of who should be responsible for supporting individuals with mental health problems. In the critical review we identified and linked salient concepts from the literature on public attitudes towards the welfare state and views of individual versus societal/governmental responsibility for need provision and health; morality of caring and social/interpersonal responsibilities; and attributions of responsibility for mental illness; creating a concept map of the different factors that may play a role in shaping perceptions about locus of responsibility. This served as a first step towards answering the question of who should be responsible for supporting individuals with mental health problems.

The qualitative study took our investigation further by directly exploring the perceptions of key stakeholders involved in shaping mental health practices and policies (youth with FEP, their families, treatment providers, and mental health policy and decision makers). We found that individuals with mental health problems themselves; stakeholders in the immediate and extended social networks of these individuals; macro-level stakeholders with influence; and society as a whole were perceived to have a wide range of responsibilities for supporting individuals with mental health problems. We also discovered that roles and responsibilities were variously perceived as being hierarchical or shared between different stakeholders and conditional or limited.

5.2 Synthesis of critical review and qualitative study findings

Taken together, the critical review provides a conceptual framework that enhances our understanding of several of the results of the qualitative study, while the qualitative study significantly adds to and extends the critical review findings.

In the critical review, we theorized that public attitudes towards the welfare state and views of individual versus societal or governmental responsibility for need provision and health may influence perceptions of who should be responsible for supporting individuals with mental health problems. Specifically, several works were found to present arguments in favor of the government's role in health, such as evidence of strong public support for and satisfaction with universal healthcare systems in many countries, including Canada. This finding is mirrored by the finding in our qualitative study that participants from all stakeholder groups strongly endorsed the role of the government in supporting people with mental health problems. Just as in the critical review we found that most Canadians would like the government to become *more* involved in health, many participants expressed that the government should do more to cover the costs of medications and mental health services, and several participants spoke favourably about how the Quebec healthcare system is designed to ensure that the vulnerable in society are cared for.

The critical review also identified several works criticizing the government and medical establishment's over-involvement in health on the grounds that it impinges on personal freedoms, undermines individuals' responsibility for their own health, and erodes or "crowds out" informal, natural support networks (such as those of families and communities). The first criticism brings to mind the discrepancy between the views of many participants in the qualitative study that individuals with mental health problems are the "conductors" of their own lives and are fundamentally responsible for their own health and the current practice of imposing involuntary, court-mandated hospitalization and treatment on these individuals, which can easily be seen as impinging on their freedoms. There is also evidence for the second criticism in the qualitative study. Several patients readily acknowledged the need to take ownership of their own health and recovery, and a few participants (including a patient and a policymaker) expressed that direct government financial assistance and welfare/disability benefits that are withdrawn as soon as one begins to work or go back to school act as disincentives for persons with mental illnesses to support themselves or return to work or school. This reveals that government support was indeed occasionally thought to undermine the responsibility of individuals for their own health. The third criticism, that welfare state systems erode or "crowd out" informal, natural support networks, may also help explain why communities, friends, and community organizations were not endorsed more frequently by participants in the qualitative study: it may be that the more informal supports provided by these stakeholders were not perceived to be as legitimate as the formal supports provided by the government and healthcare system. Moreover, families could be seen to be "crowded out" by mental health services which emphasize the primacy of the individual to the exclusion of families and by confidentiality laws which often restrict families from becoming more involved in their ill relative's treatment, a fact mentioned by a few policymakers.

In the critical review, views of the welfare state and of government responsibility for health and need provision were found to be shaped by numerous factors, including national or cultural context, political ideology, and self-interest. These factors may have shaped participants' views in the qualitative study as well. As discussed earlier, the strong consensus on the role of the government among participants (most of whom were Canadian-born) could be attributed in part to the national context, since Canadians are highly supportive of the healthcare system and of the government's involvement in health, and it could reflect the fact that most participants self-identified as politically left-leaning. Endorsement of the government's role may also have been motivated by self-interest, since policymakers and treatment providers directly and indirectly work for the government and patients and family members benefit from the services provided by the healthcare system.

Our finding in the qualitative study that a large number of participants described roles and responsibilities as being shared or needing to be shared among various stakeholders parallels the finding in the critical review that several scholars encourage a balance or sharing of responsibility for health between individuals and governments.

In the critical review, we also considered how the morality of caring and views of social and interpersonal responsibilities could influence perceptions of who should be responsible for supporting individuals with mental health problems. Several studies revealed that our views of our moral obligations to help others influence actual helping behavior and are shaped by cultural context, with people from collectivistic cultures feeling a stronger duty to help others and exhibiting more helping behavior than people from individualistic cultures, who are guided more by personal choice. This finding was echoed by a Latin-American mother in the qualitative study who spoke of the duty of families to be responsible for their ill loved one. The critical review also found that family caregivers' views of their moral responsibilities to a mentally ill relative evolve over the course of the illness, from initially feeling a strong duty to care to having greater expectations of their loved one later on and feeling the need to preserve their own health and identity. Likewise, in the qualitative study, several participants across all stakeholder groups expressed that roles and responsibilities vary depending on the stage of the individual's illness or recovery, with most participants assigning a larger role to families and treatment providers and a smaller role to the person with mental illness earlier on in their illness. In addition, one family member described the need of families/carers to recognize their own limits and refer to others for help when necessary; essentially, in order to preserve themselves.

Of note, views about the morality of caring may have been less salient in influencing the perceptions of other participants, particularly treatment providers and policymakers, who are formally mandated to support individuals with mental health problems (either through the direct provision of services or by setting up and funding them).

The final theme of the critical review involved the literature on attributions of responsibility for mental illness and how these could shape perceptions about locus of responsibility for supporting individuals with mental health problems. The main finding was that believing that an individual can control their mental health condition results in feelings of anger and punitive or discriminatory behaviors, and that this relationship operates via the belief that the individual is personally responsible for their illness. Interestingly, despite the consensus among many participants from all stakeholder groups in the qualitative study that individuals with mental health problems have an important responsibility for their own lives, health, and recovery, their views did not appear to stem from the belief that these individuals are to blame for their illness, but rather from the recognition that they know themselves and their own needs best.

In the critical review, we noted that stakeholder perceptions may vary depending on whether they are considering responsibility for support needs at the macro systems level or at the individual patient level. We theorized that attitudes towards the welfare state and the government's role in health represent a macro level of analysis and may influence views of broader social or systemic supports, while views about the morality of caring and attributions of responsibility for mental illness are more micro-level and may influence individual-level helping behaviours and supports. These hypotheses were largely confirmed in the qualitative study, in that some participants (particularly policymakers) tended to describe roles and responsibilities at a macro systems level, identifying the government and major institutions and organizations as important stakeholders, while other participants tended to describe roles and responsibilities at an individual patient level and to take into greater account the individual’s specific circumstances.

In the critical review we also theorized that stakeholders’ perceptions of who should be responsible for supporting individuals with mental health problems may vary depending on the type of support need being considered. Indeed, in the qualitative study, many participants expressed that roles and responsibilities are conditional or dependent on the specific person and the need in question, and some responsibilities were seen to be specific to particular stakeholders. For instance, most participants agreed that showing love and affection and providing emotional support is the domain of families, and all participants agreed that setting up the mental healthcare infrastructure is the government’s responsibility. However, we also found that many responsibilities were attributed to multiple stakeholder groups (for example, responsibilities for advocating for the needs of individuals with mental health problems, reducing stigma, and/or being involved in policy and decision making).

The qualitative study can be seen to build on the critical review in many ways and to address several of the limitations of the existing literature. First, we directly investigated perceptions of who should be responsible for supporting individuals with mental health problems among various relevant stakeholders, revealing nuanced and relative views of responsibility. Perceiving roles and responsibilities as varying depending on multiple factors, as more or less important than one another, and as needing to be shared among various stakeholders are just a few of the expressions of this relative thinking. Second, while most works in the critical review discussed locus of responsibility for general health, this study focused on perceptions of responsibility for mental health specifically. Third, our study moved beyond the simple, dichotomous view that either governments or individuals themselves must bear the greater responsibility for health to show that multiple stakeholder groups with different levels of influence and with formal and informal support roles are perceived to be responsible for supporting people with mental health problems, and that these stakeholders should in fact share responsibility. Finally, in addition to discovering who stakeholders thought should be responsible, we also discovered what specific responsibilities they assigned to these parties.

5.3 Implications and future directions

Together, findings from the critical review and the qualitative study contribute substantially to the literature and may inform and help improve mental health practices, policies, and research. Mental health services could facilitate the involvement of families in their loved one's care, for example, and policies could affirm the need for greater collaboration and sharing of responsibilities between different mental health professionals and between different stakeholder groups. Efforts could also be made to make more visible and accessible the range of supports available to persons with mental illnesses and their families, such as those provided by the community, schools, and workplaces. Mental health research could include more relevant stakeholders and could favour a more interdisciplinary approach.

Future investigations of this topic should explore different stakeholders' explanatory models for the causes of different mental illnesses to determine whether these have any bearing on perceptions of responsibility, as our critical review suggests that attributions of responsibility for mental illness may influence perceptions of who should be responsible for supporting people with mental health problems but our qualitative study did not directly address this. Given also that many participants in the qualitative study emphasized that roles and responsibilities vary case by case, it may be interesting to present stakeholders with case vignettes describing individuals with different mental health problems, different needs for support, and different circumstances or contexts to see where they locate responsibility in those specific cases.

Appendix

Interview Guide

TOPIC	QUESTIONS
The roles and responsibilities of various parties in helping people with mental health problems get better and move towards their valued goals	• As **young people receiving services for mental health problems**, what are your most important concerns and priorities? OR • As **family members of young people receiving services for mental health problems**, what are your most important concerns and priorities? OR • As **mental health professionals working with young people with mental health problems**, what are your most important concerns and priorities? OR • As a **policy/decision maker working within the field of mental health**, what are your most important concerns and priorities? ASK OF ALL GROUPS: • In your opinion, what are the needs of people with mental health problems? *(give examples if needed)* • Who should be responsible for meeting the needs of people with mental health problems? o How do you see the roles of these different parties? *(if different parties mentioned)* • How do you see the roles of people with

	mental health problems, their families, treatment providers, and the government in terms of meeting the needs of people with mental health problems? *(if these parties were not already mentioned)* • In what ways are the roles of these groups different? o Why? • Which of these parties do you see as being more important/playing the biggest role? o Why? • Who should be responsible for meeting the needs of *families* of a loved one with mental health problems?