

**“Everyone Has a Role”: Perspectives of Service Users With First-Episode Psychosis,
Family Caregivers, Treatment Providers, and Policymakers on Responsibility for
Supporting Individuals With Mental Health Problems**

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Abstract

Varying perceptions of who should be responsible for supporting individuals with mental health problems may contribute to their needs remaining unmet. A qualitative descriptive design was used to explore these perceptions among key stakeholders. Focus groups were conducted with 13 service users, 12 family members, and 18 treatment providers from an early psychosis intervention program in Montreal, Canada. Individual interviews were conducted with six mental health policy-/decision-makers. Participants across stakeholder groups assigned a range of responsibilities to

individuals with mental health problems; stakeholders in these individuals' immediate and extended social networks (e.g. families); macro-level stakeholders with influence (e.g. government); and society as a whole. Perceived failings of the healthcare system and the need for greater sharing of roles and responsibilities also emerged as important themes. Our findings suggest that different stakeholders should collectively assume certain responsibilities and that systems-level failings may contribute to unmet needs for mental health support.

Keywords

mental health and illness; responsibility; adolescents; youth; young adults; schizophrenia; psychosis; recovery; support needs; adaptation; coping; enduring; agency; families; policy; policy analysis; health; access to health care; teamwork; health care; power; empowerment; qualitative description; Canada

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). Psychotic disorders are among the leading contributors to disease burden worldwide (WHO, 2013) and affect functioning in many spheres of life (McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013). Persons with psychosis therefore have an especially great need for several supports. Many of them lack access to safe, affordable, and appropriate housing; need help reintegrating into school or work; and struggle to pay for medications and services (Browne & Courtney, 2005; Cohen & Peachey, 2014; Fossey & Harvey, 2010; Gardner, Baldessarini, & Waraich, 2005; Harvey, Killackey, Groves, & Herrman, 2012; Killackey, Jackson, Gleeson, Hickie, & McGorry, 2006; MHCC, 2012).

While some countries' governments provide for some of these needs, coverage is seldom all encompassing. The WHO's 2014 Mental Health Atlas reported that regardless of national income, governments allocated less than 5% of health expenditures to mental health (WHO, 2015). Funding disparities also exist within countries. In Canada, for instance, although universal healthcare is federally mandated, provinces and territories offer differing levels of healthcare coverage (Health Canada, 2018). Inevitably, many needs of persons with serious mental illnesses are addressed by other parties, or go unmet (MHCC, 2012; WHO, 2013).

Psychotic disorders typically emerge during adolescence and early adulthood (Kessler et al., 2007). Specialized early intervention services are recommended for the early stages of psychosis (Nordentoft, Rasmussen, Melau, Hjorthøj, & Thorup, 2014). A core component of such services is treatment by a multidisciplinary team comprising psychiatrists, social workers, nurses, and other mental health professionals. In addition to providing medications as needed,

treatment providers address a broad range of psychosocial concerns (e.g., return to work/school, housing, etc.) (Iyer, Jordan, MacDonald, Jooper, & Malla, 2015; Nordentoft et al., 2014).

As persons experiencing a first episode of psychosis are often young and living with family when the illness emerges (Addington & Burnett, 2004; McCann, Lubman, & Clark, 2011), families frequently assume the role of informal caregivers. Qualitative research reveals that families are involved in many aspects of treatment, from initiating help-seeking and accessing services to attending appointments, managing medications, and continually monitoring their loved one's state (Anderson, Fuhrer, & Malla, 2013; Lavis et al., 2015; McCann, Lubman, & Clark, 2011). Family caregivers experience a myriad of negative (e.g., distress, self-blame, and confusion) and positive (e.g., compassion, gratitude, and hope) emotions as they support their ill loved one and come to terms with changing roles (e.g., from parent/sibling to caregiver) (Lavis et al., 2015; McCann, Lubman, & Clark, 2009; Veltman, Cameron, & Stewart, 2002).

The few extant qualitative studies reveal that perceptions of responsibility for supporting an individual with mental health problems can vary over time, and between stakeholders. Family caregivers' views of their own and their ill loved one's responsibilities have been found to evolve over the course of the illness as their understanding of the illness changes (Karp & Watts-Roy, 1999). Informal caregivers and healthcare professionals have also been shown to hold differing views about the division of roles and responsibilities when caring for someone with health problems (Wittenberg, Kwekkeboom, Staaks, Verhoeff, & de Boer, 2018). Expectations around responsibilities for care are not always discussed between service users, caregivers, and professionals, which can result in a lack of clarity about roles and in conflictual, inequitable interactions among stakeholders (Ungar, Liebenberg, Landry, & Ikeda, 2012; Wittenberg et al., 2018). Moreover, despite their involvement in and feelings of responsibility for care, family

caregivers often feel undervalued by treatment providers and excluded from decision-making (Lavis et al., 2015; Lavoie, 2018; Stensrud, Høyer, Granerud, & Landheim, 2015). Although clinical guidelines often extol family support and involvement in treatment, in practice, multiple barriers limit the inclusion of families (Eassom, Giacco, Dirik, & Priebe, 2014).

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 instance, an individual with mental illness receiving government disability benefits may feel less compelled to find work and their family may feel less obliged to support them financially. Roles and responsibilities are thus likely to be seen in relative rather than absolute terms.

Although major mental health policy documents (e.g., the WHO Mental Health Action Plan 2013-2020) recommend that stakeholders from various sectors (e.g., public, private, service users and their families) share responsibility for mental healthcare, no study has explored key stakeholders' perceptions of their own and others' responsibilities for supporting individuals with mental health problems. Variances in stakeholders' views could contribute to support needs remaining unmet and need to be understood to effectively foster collaboration.

The purpose of this study was to explore the views of individuals with first-episode psychosis (FEP), their families/caregivers, treatment providers, and mental health policy-/decision-makers as to who should be responsible for supporting individuals with mental health problems, and what responsibilities they ascribe to these parties. The early phases of psychosis provide a valuable context within which to unpack these views. Individuals with FEP have many support needs because the illness and treatment experience is new and difficult for them and their families. For many families, this may also be the first time that responsibilities for support are negotiated.

Methods

Study Design and Theoretical Framework

We used a qualitative descriptive study design (Sandelowski, 2000, 2010; Sullivan-Bolyai, Bova, & Harper, 2005), which aims to provide a rich, detailed description of experiences and processes in participants' own language (Green & Thorogood, 2009; Sandelowski, 2000). Qualitative description assumes a naturalistic orientation to inquiry, studying phenomena in their natural, unaltered state (Sandelowski, 2000; Sullivan-Bolyai et al., 2005), and the resulting description is assumed to represent an objective truth or reality.

No established theoretical framework guided our investigation, as this was a largely uncharted area of research. However, since the literature and our experience pointed to several key areas where individuals with mental health problems need support (e.g., housing), questions about perceived locus of responsibility for these particular needs were asked. Data interpretation was also informed by literature on the social determinants of health and on recovery from serious mental illnesses, and by our critical review (Pope, Malla, & Iyer, 2018) of the literature on perceptions of responsibility for supporting individuals with mental health problems.

Study Setting and Context

This study took place at a specialized early intervention service for FEP, an outpatient and community-oriented program within an academic psychiatric institution in Montreal, Canada. The program offers two years of comprehensive medical and psychosocial treatment. A treatment team comprising a case manager and a psychiatrist delivers care. Case managers, mental health professionals from a variety of disciplinary backgrounds (social work, nursing, psychology, etc.), are the primary treatment providers and coordinate all aspects of care.

Participants and Sampling Strategy

We recruited service users, their family members, treatment providers (case managers and psychiatrists), and institutional- to regional-level mental health policy-/decision-makers. These stakeholders were chosen because as users, providers, and organizers of services, they directly and indirectly shape mental health practices and policies. Using a purposive sampling strategy (Green & Thorogood, 2009; Sandelowski, 2000), service users aged 18 to 35 who had been receiving treatment at the service for at least six months and their family members were invited to participate. A maximum variation sampling strategy was then employed (Sandelowski, 2000; Sullivan-Bolyai et al., 2005), whereby participants varying in age, sex, ethnicity, and in the case of family members, relationship to the service user (parent, sibling, etc.) were selected. Treatment providers were recruited from the FEP service. Because we had access to a limited number of policymakers, convenience sampling (Green & Thorogood, 2009) was used to recruit them from our existing professional networks. This study received institutional ethics board approval and all participants provided written informed consent. Interviews and focus groups were kept confidential and any findings shared with the clinical team were aggregated and anonymized to preserve participants' confidentiality. Researchers not involved in care provision conducted the focus groups.

Data Collection

As we were interested in group discussion and a range of perspectives, we conducted separate focus groups with service users, family members, and case managers (each in English and French), and with psychiatrists (in English only), for a total of seven focus groups. Each group comprised five to seven participants. Case managers and psychiatrists were separated to prevent any perceived power imbalance from dissuading case managers from expressing divergent views from those of psychiatrists. We interviewed six policymakers individually as it

was not feasible to assemble them at one time and place. The same two fluently bilingual researchers facilitated all focus groups and one of them conducted all policymaker interviews. Both researchers wrote reflexive notes after each focus group and interview. Focus groups and interviews were audiotaped and transcribed verbatim. We developed a semi-structured interview guide with input from service users, family members, clinicians, and researchers with experience in early psychosis. It comprised open-ended questions about who participants felt should be responsible for supporting individuals with mental health problems and what responsibilities they attributed to these parties.

Data Analysis

We used thematic analysis to identify recurrent and important themes (Braun & Clarke, 2006; Sullivan-Bolyai et al., 2005). Megan Pope and Shruthi Venkataraman first read and carefully verified transcripts for accuracy. We created initial codes, discussed them with co-authors, and developed a coding manual. Using Atlas.ti version 7.5.10, we independently coded all transcripts. We used a combination of inductive and deductive coding but favoured inductive coding (Braun & Clarke, 2006), such that we predetermined a small number of general codes but built up most codes from the data. After the first round of coding, we iteratively compared and discussed codes, re-coded certain excerpts, and added, removed, or modified codes as needed. Following Braun and Clarke's (2006) steps, we combined meaningfully related codes to create categories, sub-themes, and themes. We verified the coherence of themes by comparing them to coded excerpts. We considered as themes both frequently recurring content and infrequent yet significant and novel content (e.g., divergent perspectives voiced by one or two participants) (Braun & Clarke, 2006; Sandelowski & Barroso, 2003).

Validity

Rigour and validity were maximized in multiple ways. Our interview guide incorporated feedback from pertinent stakeholders and was pilot-tested in separate interviews with a service user and a family member, helping validate its content and scope. The same bilingual researchers facilitated all data collection and kept reflexive notes. Transcripts were checked carefully for accuracy. Several researchers independently coded transcripts and collaboratively developed and refined themes. Data from all relevant stakeholders were collected, providing a comprehensive understanding of the topic. Finally, we used a minimally interpretive data analysis method, ensuring greater fidelity to participants' accounts (Sandelowski, 2000, 2010; Sullivan-Bolyai et al., 2005).

Results

Demographic characteristics of participants are reported in Supplemental Table 1. Our analysis yielded three main themes: spheres of responsibility and influence; relative and nuanced roles and responsibilities; and perceived failings of the healthcare system.

Spheres of Responsibility and Influence

Participants identified individuals with mental health problems; stakeholders in these individuals' immediate and extended social networks; macro-level stakeholders with influence; and society as a whole as having important responsibilities (Table 1). These groups correspond to different spheres of an individual's social world. Stakeholders in these spheres vary in their proximity to the individual, the degree of formality of the supports they provide, and the extent of their influence.

Individuals with mental health problems. There was consensus across stakeholder groups that individuals with mental health problems are ultimately responsible for, and are the "conductors" of, their own lives.

CMⁱ: [...] 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 from French)*

Taking responsibility for one's own life was seen by some to include recognizing and accepting one's illness. Several participants (including service users) agreed that while others can offer support, persons with mental illnesses must first be willing to help themselves. This was seen as a basic precondition for recovery. More than simply complying with doctors' orders, this was seen to mean actively participating in treatment and doing what they can to get better.

SU: 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.

SU: Oh, yeah, absolutely.

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

SU: Yeah.

SU: Yeah, you can't help somebody that doesn't want to be helped.

Individuals were thus seen not only as recipients of care, but also as active agents who can satisfy many of their own needs. In fact, taking responsibility for one's own life and recovery was seen by some to be itself indicative of recovery.

PM: Well, to the extent that someone [with] mental health problems is able to be autonomous and to assume responsibility, I think that's a sign already of health.

Several participants felt that individuals with mental illnesses also have a key role in advocating for their needs and those of others like them and should contribute to mental health policy- and decision-making. Importantly, however, some family members hesitated to assign too much responsibility to service users, particularly when they were acutely ill.

FM: I don't know if I can – I mean, they should be responsible but I'm thinking of my son right now. [...] You can't really blame them because your perception is your reality, right? [...] So really, I can't say that they should be responsible for something because it's what your brain is telling you, this is why it's called mental illness. So, I don't know if I want to give him that much [responsibility].

Table 1. Summary of stakeholder roles and responsibilities

Stakeholder	Roles/Responsibilities
Individual with mental health problems	<p>Take responsibility for own life and treatment/recovery</p> <p>Advocate for own needs and those of others with mental illnesses and be involved in policy- and decision-making</p> <p>Responsibility depends on capacity and stage of illness</p>
Stakeholders in the immediate social network	
Families	<p>Provide emotional and instrumental support</p> <p>Be involved in treatment (e.g., assist in treatment plan, update treatment team)</p> <p>Learn about illness and “do no harm” (e.g., by criticizing/blaming)</p> <p>Advocate for ill loved one and be involved in policy- and decision-making</p> <p>No or limited role (small number of service users)</p>
Friends and communities	<p>Provide emotional support and encourage autonomy</p> <p>Facilitate recovery and promote good mental health in the community</p>
Stakeholders in the extended social network	
Healthcare providers and institutions	<p>Provide services (wide range of medical, psychosocial and legal responsibilities) and assist recovery</p>

	Act as “intermediary” between different actors (service users, families, government, etc.)
	Advocate on behalf of service users and engage service users and families in decision-making
	Produce and share research knowledge; reduce stigma by increasing awareness
	Institutional management (e.g., developing treatment guidelines)
Community, non-governmental, and non-profit organizations	Advocate for persons with mental illnesses, help reduce stigma, inform government mental health policies
	Provide support services to persons with mental health problems (e.g., help reintegrate into work/school)
	Help prevent mental health problems
Educational institutions, researchers, and employers/workplaces	Produce and share research knowledge; include key stakeholders (e.g., service users, families, clinicians) in research
	Increase public awareness of mental health problems and improve clinical mental health training
	Assist reintegration of persons with mental illnesses into school or work
	Reduce stigma at school and work

Macro-level stakeholders with influence

Government	Set up basic mental health infrastructure
	Fund programs/services, subsidize costs, provide financial assistance

Create mental health policies and set priorities informed by key stakeholders

Identify unmet needs and improve services

Increase visibility of mental health problems and reduce stigma

Prioritize mental health on the political agenda

Private sector

Subsidize costs of medications and services

Philanthropic organizations

Fund mental health programs/services through donations

Reduce stigma

The media

Increase visibility and public awareness of mental health issues

Reduce stigma

Society as a whole

Fund (directly and indirectly) mental health services and initiatives

Advocate for/support persons with mental illnesses, help influence government mental health policies, reduce stigma, care about mental health

Many participants qualified that an ill individual can only assume responsibility to the extent that they are capable of doing so, and that this capacity may fluctuate over time.

Stakeholders in the individual's immediate social network.

Families. Families were perceived by all stakeholders (including families themselves) to play a pivotal role in supporting individuals with mental health problems and to be most responsible for providing emotional support, affection, and acceptance. They were also deemed responsible for providing various instrumental supports (e.g., financial assistance, housing).

PM: People's social fabric has to be very strong to help them recover. [...] To me that's clear. It's family and loved ones who are most important for the patient. *(Translated from French)*

Participants also felt that families should be aware of and assist in their ill relative's treatment (e.g., by issuing medication reminders, encouraging social outings, etc.) and should be attentive to and provide the treatment team with updates about changes in their clinical state.

PM: I think families are uniquely positioned to understand what the strengths of that individual are and were before the individual got sick. [...] 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.

Two policymakers and one treatment provider cautioned that families can sometimes cause harm (e.g., by blaming their loved one because of limited awareness of mental illness). Families or service users did not voice this caveat. These participants expected families to learn about their loved one's illness and attend psychoeducation sessions.

P: I think the role of family is fundamental [...] 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.

A few participants identified families as having a role in fostering mental health within the family and directing or accompanying a loved one to care. Policymakers also expressed that families should advocate for their ill relative, promote the cause of mental health, help reduce stigma, and be involved in mental health policy- and decision-making.

Notably, a few service users were reluctant to assign too much responsibility to families for fear of overburdening them, and voiced appreciation for all their families did.

Friends and communities. A few participants across stakeholder groups assigned responsibilities to ill individuals' friends and communities. They saw friends and peers as providing emotional and moral support, encouraging growth, and fostering autonomy.

PM: Me, my daughter, who was schizophrenic [...], 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 from French)*

Participants felt that communities could promote mental health and facilitate recovery; for instance, by providing opportunities for ill individuals to meet with peers.

Stakeholders in the individual's extended social network.

Healthcare providers and institutions. Participants across stakeholder groups assigned a wide range of medical, psychosocial, and legal roles to healthcare providers and institutions.

Case managers, in particular, gave specific examples of their responsibilities:

CM: Our role is a good long list. It's 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 a lot of substance abuse stuff comes up, then helping them navigate around that. These are all more 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.

Although treatment providers largely agreed that they have a responsibility to mandate treatment when necessary (i.e., by seeking court orders), case managers' opinions about their role in managing crises varied. Some felt that they should be available outside regular work hours to prevent hospitalizations in crisis situations, but most expressed the need to maintain work/life boundaries and rejected the idea of being “on call” or replacing emergency services.

A few case managers described their role as that of a facilitator, negotiator, and intermediary between various actors; in a sense, as a fulcrum for service users and their families.

CM: The important role for us [case managers] in all that is, we are intermediaries between all kinds of things. [...] We sometimes, some days have the role of advocate or negotiator for [service users] vis-a-vis the

family, vis-a-vis the institution that pays us, vis-a-vis other government bodies, vis-a-vis employers, educators... you know, whatever. It's a lot, our role. *(Translated from French)*

Participants from all stakeholder groups felt that healthcare providers and institutions should be involved in advocacy; for instance, by communicating the needs and interests of persons with mental health problems to their families, employers, schools, and government and involving service users and families in decision-making.

PM: Institutions 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 service users; they often have answers to our questions. *(Translated from French)*

Related roles of healthcare providers and institutions included producing and sharing research knowledge with other institutions, increasing public awareness of mental illness, reducing stigma, and the prevention and early identification of mental health problems.

Policymakers also identified aspects of institutional management (e.g., developing treatment guidelines, fostering inter-professional collaboration) as responsibilities of healthcare providers and institutions.

Community, non-governmental, and non-profit organizations. Advocacy was one of the main roles attributed to community, non-governmental, and non-profit mental health organizations by treatment providers, service users, and one policymaker. These organizations were deemed responsible for reducing stigma and pushing for governmental policy-level change.

PM: 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, etc. And there, families and patients and other organizations, community organizations, need to continually push that mental health becomes a priority like other healthcare issues in our society.

Several policymakers expressed that community organizations play an important role in providing supports and resources to individuals with mental health problems, such as helping them reintegrate into work, school, and leisure activities. One policymaker also highlighted their role in helping prevent mental illness:

PM: The community groups also have a role to play because 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 problems and being there before things get out of hand.

Educational institutions, researchers, and employers/workplaces. A few participants, mostly policymakers, felt that educational institutions and researchers are responsible for producing and sharing research to improve mental health services. Researchers were seen as responsible for including key stakeholders like service users, families, and clinicians in research in order to produce more relevant and politically influential findings.

PM: I think we'll succeed in influencing politically even more once research projects involve families more. [...] The more we'll be able to have that collaboration - patient, family, clinician and researcher - the more we'll be able to influence governments politically. *(Translated from French)*

In addition to educating people about mental health problems and improving mental health training for clinicians (e.g., via mental health internships and teaching more holistic approaches), one policymaker felt that educational institutions and workplaces should make it easier for students and employees to talk about and seek help for mental health problems. Some also felt that schools and employers can help individuals resume role functions disrupted by their illness; for example, by making accommodations to ease their reintegration into school or work:

FM: [...] [my son] got a warning because he was missing too much [work]. I called [case manager] and asked him if he could arrange something. So they wrote a letter to the effect that [he] 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 [...]. That helped him. That's good. *(Translated from French)*

Macro-level stakeholders with influence.

The government. Participants across stakeholder groups frequently mentioned government as an important player. They varyingly referred to the government as a singular entity, a level of government (federal, provincial, or regional/municipal), or all publicly funded institutions. Most regarded governments as fundamentally responsible for setting up and funding mental health programs and services, paying healthcare providers' salaries, and creating policies.

One policymaker highlighted that government policies should be informed by relevant stakeholders, such as persons with mental illnesses and their families:

PM: 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.

Several participants (a family member, a service user, and some policymakers) expressed a desire for greater government subsidization of psychiatric medications, psychotherapy, and addiction services. Providing financial assistance (e.g., disability benefits) to individuals with mental illnesses was also seen as a government responsibility. One service user, however, opined that such governmental assistance discourages people from helping themselves.

The government was also deemed responsible for identifying unmet mental health needs and improving services. Treatment providers and policymakers felt that governments should make services more accessible and change welfare and disability benefits regimes so as to not disincentivize individuals from returning to work or school.

Participants from all stakeholder groups expressed that the government should increase the visibility of mental health problems and reduce stigma:

CM: And [the government] can also indirectly advertise through campaigns, demystify mental health a little bit, [launch] publicity campaigns. They can also indirectly help to advance the cause of mental health. *(Translated from French)*

Some noted that awareness campaigns tend to focus on common mental disorders (e.g., depression) and not on more serious and lesser-known illnesses like psychosis. Participants also expected the government to maintain the priority of mental health issues on the political agenda.

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 needs of individuals with mental health problems. Some felt that

pharmaceutical companies could help by subsidizing the costs of psychiatric medications or by offering free samples. Others highlighted the important role played by insurance companies in covering (at least partially) the costs of medications and psychologist services.

FM: 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.

Philanthropic organizations. A few policymakers and one treatment provider described philanthropic organizations as supporting individuals with mental health problems by funding projects, programs and services that mental health institutions may not otherwise be able to provide.

PM: I think philanthropic organizations get involved in projects and contribute to make certain ideas, certain projects happen, that would not happen if they had not given the financial part. [...] 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.

Philanthropic organizations were also understood to play a role in reducing mental illness stigma by leveraging their power and influence.

The media. A service user and a treatment provider identified the media as playing an important role in increasing the visibility of mental health issues, educating and informing the public, and reducing stigma.

SU: [...] 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.

Society as a whole. A few participants across most stakeholder groups went beyond specific individuals or groups to name society as a whole as having a responsibility to support individuals with mental health problems. Treatment providers and one policymaker noted that in Canada's public healthcare system, tax-paying citizens fund most mental health services. Members of society also directly support specific mental health initiatives (e.g., by donating to

causes). A service user and a policymaker also felt that all citizens should advocate for persons with mental illnesses by representing their interests to the government, by helping influence policies, and by destigmatizing mental illness. More fundamentally, policymakers expressed that all citizens should care about mental health and support people with mental health problems.

PM: 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.

Relative and Nuanced Roles and Responsibilities

Participants' narratives revealed nuanced, relative views of roles and responsibilities. Across stakeholder groups, many participants considered individuals with mental health problems and their families/caregivers, followed by healthcare providers/institutions and the government, to have the most important roles to play. Notably, though, they viewed roles and responsibilities as dynamic and context-sensitive, varying case by case and even within an individual case depending on the individual's needs, phase of illness or recovery, age or stage of personal development, capacity to support themselves, and their family's capacity to support them. Thus, participants felt that different stakeholders can play more or less important roles depending on these factors.

PM: 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 [...] 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.

Several participants disagreed that some stakeholders' roles are more or less important than others'. Indeed, most endorsed a partnership or sharing of roles, with each stakeholder playing a different but equally valuable role and having different strengths and competencies.

CM: [...] I think that each role should overlap [...], because even if we maybe have a different way of

addressing a problem, the role of each is to support the individual, to help the individual accomplish their goal. [...] So ideally, all the different actors would be like – there would be overlap and everyone would help each other towards an ultimate goal. *(Translated from French)*

PM: What we [different stakeholders] have in common is the desire to help patients. What differentiates us is the competency that - the link that we each have with the patients, whether we're the father, the mother or the nurse or the doctor or whatever. And society too and institutions like universities, CEGEPs [colleges] and everything. [...] But each [stakeholder] has their specific role. *(Translated from French)*

Several participants spoke of role boundaries, or limits to how much responsibility certain stakeholders can or should assume. Several case managers reported having to assume what they felt should be parents' responsibilities, while other participants set limits to family responsibilities:

CM: I think the families should take an active role in connecting and helping communication with the schools also. I don't think that should just be our role. I think that's like "parenticizing" our role sometimes.

PM: 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.

Consistent with the idea of role boundaries, some stakeholders were seen to have distinct, exclusive responsibilities (families provide emotional support, governments create policies, etc.). However, participants also frequently attributed some responsibilities (e.g., advocacy, stigma reduction, etc.) to multiple stakeholder groups, suggesting that various stakeholders with different levels of influence should collectively assume certain responsibilities.

Perceived Failings of the Healthcare System

Several participants (predominantly policymakers) described numerous healthcare system failings, especially with respect to access to care. Participants decried reduced or delayed access and discontinuity of care, inequitable distribution of mental health services, lack of appropriate or inadequately publicized services and resources, and delayed transitions between services (e.g., between child/adolescent and adult services or primary and specialized services). Access to care was seen to be further impeded by the prohibitive costs of psychotherapy and many medications.

PM: Accessing psychotherapy sessions with a psychologist is expensive - it's \$100 or more per hour. The majority and the average person can't afford that, they have to wait 8, 9, 10 months before getting a consultation. I think there's work to be done for that at the level of policy makers. *(Translated from French)*

Some participants were concerned about the quality of mental healthcare, describing services as under-intensive, time-limited, generic, not holistic, or unresponsive to needs. Use of non-evidence-based practices, lack of program evaluation, and treatment providers having inadequate training and supervision were cited as detrimental to the quality of care.

PM: I think in general it's not popular to talk about quality. [...] ultimately what we say is that the problem is access, when people get access to services they're good. But I'm not sure about that.

Participants also noted insufficient collaboration between stakeholders (e.g., due to the siloed nature of mental health professions, practice, and research) as a failing. They called for more interdisciplinary mental health teams instead of different professionals delivering services independently. Researchers were also urged to step up the inclusion of clinicians, service users, and families in research.

PM: [...] I would say that there are two kinds of things in psychiatry. There are things that are treated by individual professionals. That doesn't work. There are things that are treated by multidisciplinary teams. [...] The psychiatrist who has their patient [...] [and] does not want to have nurses involved, does not want to have pharmacists involved - forget it, it doesn't work. What works is teams. *(Translated from French)*

Several participants raised concerns about perceived barriers to family and service user involvement in mental healthcare and decision-making at the individual and institutional levels. Family involvement was seen to be hindered by confidentiality laws or their misinterpretation, resulting in limited information sharing between families and clinicians.

PM: I also see a lot of harm being done under the rubric of confidentiality rules where families are not allowed to get information because the young individual is 18 years old [...]. I think that that's causing unnecessary harm to families and I think that we need to address that.

In addition, a few participants felt that service users and families are not given enough opportunities to participate meaningfully in policy- and decision-making.

A broader concern related to the government's priorities and vision for mental health. Many felt that the government prioritizes physical health over mental health, highlighting inequities between funding allocations and the absorption of psychiatric institutions into large general health networks under Quebec's health system reorganization.

PM: Psychiatry will now be entirely in the *CIUSSS*, the integrated health centre. My fear is that psychiatry, in the priorities of these institutions, will fall to the bottom of the pile of priorities, as has always been the case in traditional hospitals. *(Translated from French)*

The changing of government health priorities with successive elections; the government's lack of attention to the multifaceted, interconnected nature of mental health issues (e.g., homelessness, substance abuse, suicide, etc.); and the greater focus on treatment rather than prevention were also cited as healthcare system failings.

Discussion

Supporting Individuals with Mental Health Problems: An Individual and Societal Responsibility

We sought to explore, in the context of an early intervention service for FEP, key stakeholders' perceptions of who should be responsible for supporting individuals with mental health problems and what responsibilities they ascribe to these parties. We found that while participants widely perceived individuals with mental health problems to have ultimate responsibility for their own lives and recovery, they attributed important support roles and responsibilities to various other social actors. Satisfying one's needs for support and by extension, pursuing recovery can thus be seen as an individual responsibility facilitated or hindered by the larger social context. This conceptualization echoes the social determinants of health literature, which posits that while individuals should take responsibility for their own health to the extent possible, society has a responsibility to enable people to have control over their lives and health (Marmot, 2015). Similarly, qualitative research on recovery in mental

illness highlights the centrality of self-agency, accountability, and personal responsibility (Bjornestad et al., 2017; Hansen, Stige, Davidson, Moltu, & Veseth, 2018; Windell, Norman, Lal, & Malla, 2015); however, recovery must be facilitated by supportive mental health services and other social structures that offer personally meaningful, valued life opportunities (Davidson, 2016; Hopper, 2007). Recovery-oriented policy documents (e.g. MHCC, 2015; SAMHSA, 2012) also highlight personal responsibility as a core component of recovery but stress that mental health services, families, and communities have critical roles to play in supporting and promoting individuals' capacities for responsibility and agency. Further, as our study participants pointed out, families, treatment providers, and other parties should play a more active role when an individual is acutely ill or lacks awareness of their illness. This does, however, create a tension between the valuing of agency and self-determination and the need for other stakeholders to step in to address needs that persons with serious mental illnesses cannot meet themselves for various reasons. This tension is particularly salient in psychosis, an illness that can compromise insight and cognitive and functional capacities, and must be negotiated by all stakeholders.

It is noteworthy that service users were the most enthusiastic proponents of taking personal responsibility, while other stakeholders were occasionally reluctant to assign them too much responsibility. This discrepancy warrants exploration, as it may reflect the tension described above or reveal paternalistic or risk-averse attitudes (Farrelly et al., 2015).

Discrepancies between Stated Roles and Responsibilities and Actual Practices

Participants' discussion of healthcare system failings highlighted several discrepancies between their views of roles and responsibilities and current mental health policies and practices. Confidentiality laws (or misinterpretations of these) and mental health practices that often exclude families or neglect their concerns (Lavis et al., 2015) are incongruent with the view,

frequently expressed by participants, that families should be involved in their ill relative's treatment and be seen as integral members of the treatment team. The limited opportunities currently afforded to service users and their families to contribute meaningfully to institutional- and systems-level policy- and decision-making also contradict the expressed importance of this role among several participants, especially policymakers. Participants' widespread agreement that various stakeholders should share responsibilities and coordinate efforts echoes Canadian and international mental health policy documents (MHCC, 2012; National Treatment Strategy Working Group, 2008; WHO, 2013). However, this stands in contrast to the current silo-like organization of mental health services and professions (Hall, 2005; Kilbourne, Fullerton, Dausey, Pincus, & Hermann, 2010; Linden, 2015), wherein mental healthcare is delivered by multiple sectors and different service providers/professionals, often with a lack of communication or collaboration (National Treatment Strategy Working Group, 2008).

More than any other stakeholder group, policymakers were openly critical of the healthcare system and its failings. Paradoxically, they are also the stakeholders with the greatest responsibility and power to remedy these issues. Service users and families discussed systemic failings far less frequently, suggesting that they may not have enough power (real or perceived) to expect or effect improvements in the healthcare system.

Contextual Considerations

The study context may have resulted in particularities in participants' views. The setting of this study at an early psychosis service within a psychiatric institution may have framed participants' thinking about responsibilities to necessarily include healthcare providers and institutions, as opposed to peer mentors, for instance. Likewise, consensus on the importance of families may reflect the emphasis placed on family engagement by early psychosis services

(Bertolote & McGorry, 2005). The roles and responsibilities of health professionals also vary across healthcare contexts. In many early psychosis services, case managers, not psychiatrists, are central treatment providers who have the same core responsibilities (providing psychoeducation, helping find housing, dealing with substance use, etc.) regardless of their disciplinary background (nursing, social work, etc.). In contrast, in other settings, physicians have primary authority and allied professionals fulfil responsibilities more closely linked to their disciplines (e.g., social workers help find housing, nurses monitor metabolic indices, etc.).

Participants' frequent appeals to the fundamental responsibility of individuals with mental illnesses also reflect the historical and cultural context of this study. The mental health recovery model, which emphasizes service user empowerment and self-determination, is rapidly gaining traction (MHCC, 2015; WHO, 2013; WHO Regional Office for Europe, 2010). Moreover, autonomy and self-sufficiency are highly valued in individualistic societies like Canada (Miller, 1994). The roles of persons with mental illnesses may be minimized in cultural settings that endorse more communal values (Iyer, Loohuis, Pope, Rangaswamy, & Malla, 2014; Iyer et al., 2015).

The strong consensus on the role of the government may reflect the largely left-leaning political orientation of most participants (Supplemental Table 1) and the sociocultural context of this study. Canada has a publicly funded universal healthcare system and most Canadians strongly support the government's role in healthcare (Duckett & Kempton, 2012; Mendelsohn, 2002). 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 government is more divided (Doherty, Kiley, Tyson, & Jameson, 2015).

The study setting may also help explain why certain parties (e.g., friends, community organizations, the private sector, etc.) were less frequently cited as having responsibilities. Youth with FEP tend to have limited social networks and few close friends (Gayer-Anderson & Morgan, 2013), and the neighbourhoods served by our early psychosis program, being materially and socially deprived, may offer limited supports. The supports provided by these less frequently mentioned stakeholders may also be less direct and visible, or may have been seen as less relevant or appropriate. Had our study been conducted in a collectivist context, neighbours, employers, and the wider community may have been assigned more important roles. Likewise, in another milieu, religious or spiritual organizations might have been mentioned more frequently. Notably, these less frequently cited parties tended to be mentioned by policymakers and treatment providers. This suggests that power differentials may shape perceptions of responsibility, as policymakers and treatment providers are better positioned to know what resources are, or should be, available to people with mental health problems.

Strengths

This is the first study to explore key stakeholders' views of responsibility for supporting individuals with mental health problems. We have discovered multifaceted, nuanced views of roles and responsibilities and have uncovered important healthcare system failings and discrepancies between stakeholder views and actual practices. Our study was methodologically rigorous, with care taken to incorporate service user, family, clinician, and researcher perspectives into the interview guide and multiple researchers contributing to data collection, analysis, and the interpretation of findings.

Limitations

Policymakers were the only stakeholders interviewed individually. As such, they had more time to elaborate their responses. This may explain why they, more than other participants, identified a greater range of stakeholders as having responsibilities and provided more detailed descriptions. This may also however be due to their higher familiarity with the healthcare system. While we purposively sampled the most relevant stakeholders involved in shaping mental health practices and policies, including a group of members of the general public may have yielded additional insights, as average citizens also influence health agendas.

Implications and Conclusions

Our study has important implications for mental health policies and services and suggests ways to improve both the structure and functioning of care. By revealing who pertinent stakeholders feel should be responsible for supporting individuals with mental illnesses and the nature of these responsibilities, our study can help strengthen stakeholder accountability.

Given the broad consensus among participants on the stakeholders most responsible for supporting people with mental health problems, it is likely that the systemic failings mentioned by many, rather than discrepant views of responsibility, contribute to unmet or inadequately met needs. The various systemic issues identified can be seen as structural barriers that impede recovery and have a disabling, disempowering effect (Wallcraft & Hopper, 2015). It is critical that these issues are addressed and that individuals and their families be empowered to expect better from their healthcare system. For instance, to facilitate less siloed and more collaborative care, the greater sharing of responsibilities between stakeholders should be explicitly enacted by establishing integrated services wherein varied service providers/sectors are co-located or seamlessly linked (e.g., welfare, health, mental health, employment, etc.). In the treatment

context, service users, families/caregivers, and providers could explicitly discuss their views about who should be responsible for meeting which needs.

Individuals with mental health problems should be better supported to take responsibility for their recovery to the extent possible and should, along with their families, be given greater opportunities to partner in research, service design, and policy-making. Communities, schools, and workplaces should provide more and better publicized mental health supports and engage in advocacy and stigma reduction.

Future qualitative research should explore perceptions of responsibility in different settings (e.g., a community peer support organization) to further unpack the role of cultural and healthcare contexts in shaping stakeholders' views about responsibility for care.

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Supplemental Material

Supplemental Material for this article is at the end of the manuscript.

Note

CM = case manager; SU = service user; PM = policymaker; FM = family member; P = psychiatrist.

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Supplementary Table 1: Participant characteristics					
	Service users (n = 12*)	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 receiving services					
Parent	-	6 (50%)	-	-	-
Spouse/partner	-	3 (25%)	-	-	-
Sibling	-	2 (16.7%)	-	-	-
Other	-	1 (8.3%) ^a	-	-	-
Sex (male)	7 (58.3%)	3 (25%)	5 (41.7%)	4 (66.7%)	4 (66.7%)
Age	25.67 (6.02)	38.83 (15.11)	43.73 (10.16)	42.67 (7.60)	58.83 (9.10)
High school completed or more	6 (50%)	12 (100%)	12 (100%)	-	-
Yearly household income					
Less than \$20,000	3 (25%)	2 (16.7%)	-	-	-
\$20,000 to \$39,999	2 (16.7%)	5 (41.7%)	-	-	-
\$40,000 or more	2 (16.7%)	5 (42%)	-	-	-
Cannot answer	5 (41.7%)	0 (0%)	-	-	-
Baseline diagnosis of Schizophrenia Spectrum Disorder (vs. affective psychosis)	9 (75%)	-	-	-	-
Born in Canada		11 (91.7%)	8 (66.7%)	8 (66.7%)	4 (66.7%)
Ethnicity					
Arab	0 (0%)	0 (0%)	0 (0%)	1 (16.7%)	-
Black	3 (25%)	1 (8.3%)	0 (0%)	0 (0%)	-
Chinese	0 (0%)	0 (0%)	1 (8.3%)	0 (0%)	-
Latin American	2 (16.7%)	2 (16.7%)	1 (8.3%)	0 (0%)	-
South Asian	1 (8.3%)	2 (16.7%)	0 (0%)	0 (0%)	-
West Asian	0 (0%)	2 (16.7%)	0 (0%)	1 (16.7%)	-

White/Caucasian	5 (41.7%)	3 (25%)	10 (83.3%)	4 (66.7%)	-
Other	1 (8.3%) ^b	1 (8.3%) ^c	0 (0%)	0 (0%)	-
Not specified	0 (0%)	1 (8.3%)	0 (0%)	0 (0%)	-
Political orientation ^d	4.42 (2.07)	4.60 (1.77)	4.00 (1.15)	3.16 (1.16)	4.40 (1.81)
*Data only available for 12 of the 13 service users. ^a Nephew; ^b "A mix"; ^c African; ^d Rated on a scale from 1 (left-leaning) to 10 (right-leaning)					
