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Title: Exploring Older Adult Mental Health Considerations in the Context of the COVID-19 Pandemic: A Framework Approach

Keywords: older adult, aging, mental health, mental well-being, COVID-19, framework approach

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<u>Abstract</u>

Older adult mental health is a priority in Canada, especially with the deleterious effects of COVID-19. However, there is a gap in knowledge about the mental health-related considerations and concerns that are important for supporting aging Canadians.

Secondary framework analysis used deductive codes constructed from a critical mental health literature review, and inductive codes generated from n=268 previously gathered free-form survey responses from older adults, caregivers, and health/social care providers in Canada. Key considerations included 1) core principles that influence the experiences and outcomes of older adults; 2) societal and system-level factors affecting older adult mental health; 3) services, supports, and programs that were identified as valuable; and 4) mental health experiences and outcomes mapped to a mental health dual continuum model.

The expert-by-experience identified considerations are key elements that can be used when developing/adapting resources to ensure they are appropriate, relevant, and effective for aging Canadians' mental health needs.

1. Introduction

The emergence of the SARS-CoV-2 coronavirus global pandemic had a profound effect on the everyday lives of people across the world and the associated mental health consequences are wideranging. There is a need in Canada for mental health support, care, and treatment that are responsive to the diverse impacts of the COVID-19 pandemic on older adults. Understanding the mental health concerns of older adults is essential to developing or modifying services and supports to meet their needs (Beresford, 2013). Given the existing strain on the Canadian health and social care system, there is an urgency to identifying these needs in order to help program developers and policymakers most effectively allocate the limited resources available. Research is needed to fill the knowledge gap on the mental health concerns of aging Canadians while being sensitive to the changed context in Canada from the COVID-19 pandemic.

Over the past two decades within Canada, mental health in general, and older adult mental health specifically, has increasingly been identified as an area of concern. Advocacy, service, and public policy organizations including the Canadian Coalition for Seniors' Mental Health (Conn et al., 2014) and the National Institute on Aging (2020) have called attention to the importance of meeting older adults' mental health needs. In parallel, research-affiliated organizations like the Canadian Institutes for Health Research – Institute of Aging and the Canadian Association on Gerontology have advocated for more knowledge regarding the mental health experiences of older adults, most especially through their own voices (Canadian Institutes of Health Research - Institute of Aging, 2023; Meisner et al., 2020).

Spurred by public concerns, a significant body of research has amassed demonstrating the negative impact the COVID-19 pandemic on older adult mental health globally and in Canada. Expansive reviews like those from de Maio Nascimento et al. (2022) and Tyler et al. (2021) indicate declines in older adults' mental health including through experiences of increased depression, anxiety, social isolation, and loneliness. Greig et al. (2022) examined older adult mental health referrals in the United Kingdom and observed a significant positive association between feelings of loneliness and rates of non-accidental self-injury, psychotic symptoms, and problems with occupational/recreational activities (among other factors). Krendl and Perry (2021) reported that feelings of loneliness moderated an increase in depression among older adults with a close relationship network, and older adults without a close network reported greater depression during the onset of the pandemic irrespective of their loneliness. Over 70% of rural older adults in Manitoba reported feeling lonely at least 1-2 times a week and most reported feeling more isolated because of pandemic-related physical distancing measures (Herron et al., 2021). Similarly, more than one-third of the participants in a large sample of Canadian retired educators reported feeling lonely following the onset of COVID-19 (Savage et al., 2021).

The negative effects of the pandemic have established a need for resources supporting mental health, but further insight is needed to understand what is important for addressing it. Historically, older adults are under-engaged in research and service design conducted on their behalf (Beresford, 2013). This lack of engagement continues to be true in the wake of the global pandemic, when 'service user' engagement demonstrably decreased (Duffy et al., 2022). Involving older adults in mental health research and better understanding their needs helps produce knowledge that is relevant, appropriate, and useful (Kara, 2013).

It is also valuable to gather the perspectives of the caregivers and care providers supporting older adult mental health. Explicitly incorporating multiple perspectives in research more accurately

reflects the Canadian context, where many aging individuals occupy more than one social role (Federal/Provincial/Territorial Committee of Officials, 2006). This allows researchers to better account for the relationships that affect older adults, including the caregiver-care recipient dyadic relationship (Sebern & Whitlatch, 2007). It also provides additional health and social system context that might otherwise be lacking (Colgate & Jones, 2018).

With an established need for mental health services, but a lack of older adult perspectives involved in development efforts, there is an opportunity to bridge the gap by identifying the considerations and concerns that are important to these experts-by-experience while incorporating the changed context of the COVID-19 pandemic. Therefore, the research question investigated in this study was:

What are the considerations older adults, their caregivers, and health or social care providers have regarding aging and mental health support, care, and treatment, as identified during the beginning of the COVID-19 pandemic?

For the purposes of this research, 'considerations' were defined as: "the uncertainties, interests, and important factors that older adults, caregivers, and health or social care providers connect with mental health" (Kalles, 2022, p. 11). The term 'experts-by-experience' used in this paper is defined as individuals who have: lived or living experience with mental health; past or present interactions with mental health services/resources; or experience providing care (unpaid or paid) for an individual experiencing some mental health challenge or concern. Experts-by-experience may include (but are not limited to): aging individuals, unpaid family or friend caregivers, and paid health or social care providers who work with aging clients. This definition is purposely broadly and intended to be inclusive of many types of 'experience', as mental health is a pervasive and multi-faceted phenomenon.

The qualitative findings reported in this paper are drawn from a larger mixed methods study completed as part of EK's master's thesis that intended to identify, categorize, and interpret the mental health considerations of experts-by-experience before using the considerations to inform a secondary analysis into quantified differences in older adults' mental health since the onset of the pandemic (Kalles, 2022). The qualitative findings in this paper are reported with consideration for the COREQ checklist (Tong et al., 2007).

2. Methods

2.1. Theoretical orientation & Definition of 'mental health'

In line with the focus on producing relevant and rigorous results oriented towards action and decision-making, a pragmatic theoretical orientation was employed (Glasgow, 2013). Pragmatism explicitly operates within the realm of a socially situated challenge or problem, with a goal towards producing appropriate action to address said challenge or problem. A pragmatic theoretical orientation matches the goal of this research to not only identify the mental health considerations of experts-by-experience, but to do so in a way can be used in future service design and delivery to better meet the needs of aging Canadians.

As part of generating pragmatic knowledge, the dual continuum model of mental health from Keyes (2002) was used, which conceptualizes a complete state of mental health as two separate but inter-related spectrums of mental health/well-being and mental illness. The mental health continuum is comprised of three domains — emotional well-being (commonly referred to as hedonic well-being),

psychological well-being (i.e., eudaimonic well-being), and social well-being (Keyes, 2002). Psychological disorders like Generalized Anxiety Disorder, Major Depressive Disorder, or Post-Traumatic Stress Disorder fall along the mental illness continuum. In this dual model, someone with a mental illness or disorder can still have positive mental well-being by experiencing connectedness and belonging with others as well as by building and maintaining resources for coping and support. Alternatively, someone could experience poor mental well-being without necessarily having a mental illness diagnosis. Research has shown this conceptualization of 'complete' mental health better represents the experiences of older adults than a single bidirectional continuum of healthy vs. ill (Westerhof & Keyes, 2010).

2.2. Research design

The qualitative design of this research combined deductive and inductive components, to identify, categorize, and interpret the mental health-related considerations that older adults, and their caregivers and health/social care providers identified during the early phases of the COVID-19 pandemic. This consisted of two stages: 1) a critical literature review that generated deductive themes based on anticipated and previously observed mental health outcomes of pandemics and epidemics and 2) secondary framework analysis (Ritchie et al., 2013) of previously gathered qualitative survey data. The purpose of the critical literature review was to identify and review the *most relevant* research and develop a deductive starting point that was incorporated into the first stage of the secondary framework analysis described below. The analysis was conducted using NVivo 12 Pro.

2.3. Critical Literature Review

Data Collection

The critical literature review involved a series of 7 steps (see Table 1) drawn from Carnwell and Dally (2001) and Jesson and Lacey (2006). A systematic search strategy was developed with input from a research librarian and a combination of 3 databases were used in the review: PubMed, CINAHL (via Embase), and Scopus.

Table 1.

The critical literature review preparation, process, and analysis; drawn from Carnwell and Dally (2001) and Jesson and Lacey (2006)

Step Activity and Purpose

- 1. Defining the question and scope (preparation),
- 2. Identifying appropriate literature databases and keywords (preparation),
- 3. Completing the search (process),
- 4. Assessing results for inclusion (process),
- 5. Reading a selection and refining the assessment framework (process),
- 6. Reviewing the literature and coding content (analysis), and
- 7. Mapping codes to the dual-continuum mental health model (analysis).

The critical literature review was used to contextualize early mental health concerns being raised in the extant literature, and to provide guidance for potential areas of long-term importance based on historical precedent. The focus was on all respiratory virus pandemics and epidemics occurring since 2000, which included: Severe Acute Respiratory Syndrome Coronavirus (SARS; 2002/2003), Influenza A subtype H1N1 (H1N1; 2009), Middle East Respiratory Syndrome Coronavirus (MERS; 2012/2013), and Severe Acute Respiratory Syndrome Coronavirus-2 (COVID-19; 2019-2023).

To identify deductive themes for the subsequent framework analysis, review papers were selected for inclusion and all other article types were excluded. Reviews were required to be written in English and published in a peer-reviewed journal. Papers needed to include a primary review component, rather than predominantly functioning as a commentary, editorial, letter to the editor, or protocol paper. The inclusion criteria requiring papers to focus on 'older adults' was purposely broadly defined, and no minimum cut-off age was set.

The overall question for the critical literature review was: What respiratory virus pandemic- or epidemic-related mental health changes for older adults have been identified, or are anticipated, as identified in reviews published since 2000 in the international peer-reviewed literature? The objectives were to: 1) identify key areas of mental health-related concerns; 2) codify areas into deductive themes with established definitions; and 3) to map themes to the 2-continuum model of mental health.

Papers were first screened by their title and abstract for fit with the inclusion and exclusion criteria, and ones that passed the first stage then proceeded to a full text review.

Literature Analysis

Papers that passed the full-text review were examined to extract information regarding the observed and anticipated mental health outcomes of older adults during pandemics and epidemics. This included a list of outcomes identified in each paper, as well as any definitions provided for a given outcome and the scales/tools used to assess it. In turn, these outcomes were sub-divided into experiences (e.g., social isolation) and feelings (e.g., apathy).

Following the examination of each paper individually, an overall list of experiences and outcomes was compiled and mapped to the dual-continuum model of mental health. The mapped model was reviewed in a peer debriefing session with one of the co-authors (JG), before being advanced to the framework analysis. The experiences and outcomes were used as a preliminary deductive coding framework in Stage 1 of the secondary framework analysis described below. The codes were absorbed into the coding framework in subsequent stages (Stages 2-5).

2.4. Secondary Framework Analysis

Original Survey Data Collection

The qualitative data used in the secondary framework analysis was drawn from a previously completed open-ended free-form survey where Canadian older adults, family and friend caregivers of older adults, and health and social care providers who work with older adults, were invited to share their aging and mental health related questions and priorities (citation omitted for blinding). This data was gathered between February 2020 and June 2020 by the [blinded] as part of a collaborative initiative with the [blinded] to identify a priority list of unanswered research questions on aging and mental health according to Canadians utilizing a modified James Lind Alliance approach (https://www.jla.nihr.ac.uk/). As part of the initiative, a series of two national surveys and four virtual workshops were completed between September 2019 and June 2021. The data used in this study came from the first national survey (see Appendix A in [blinded] for a copy of the original survey questions). Responses were gathered in both English and French. French responses were professionally translated before being included in the dataset. More detail about the original data collection procedures can be read in (citation omitted for blinding).

Secondary Data Selection for Analysis

A total of n = 305 survey responses were gathered as part of the [blinded] and [blinded]'s priority-setting initiative. In the current secondary analysis study, participant responses from the original dataset were excluded if free-text responses regarding mental health support, care, and treatment or respondent type (i.e., older adult, caregiver, health/social care provider) were missing. In total, n = 268 responses were eligible for inclusion in the secondary analysis.

Secondary Data Analysis

The secondary framework data analysis (Ritchie et al., 2013) began with familiarizing by reviewing and coding all of the free-form survey data as non-hierarchical nodes in NVivo. Next, the previously flat structure of the codes was transformed into a layered hierarchical tree node structure to identify a framework. At this time, labels assigned to components of the framework were largely descriptive and served primarily to capture the essence of the coded content, rather than to make interpretations about its purpose or meaning. The thematic framework was iteratively developed through discussion and consensus-driven decision-making between EK, JG, and CP, and then EK and CM. Indexing was accomplished by way of constructing the thematic framework in NVivo and the charting process involved consolidating the framework codes into 'summary' cells that captured the essence of the content, without reproducing it in unmanageable depth. Responses were sorted by age groups under 55, aged 56-65, aged 66-75, age 76+, and 'not identified'. The final stage of mapping and interpretation involved reviewing the data across cases (i.e., age groups) and across themes (i.e., framework concepts) to draw conclusions. Conclusions were generated by comparing responses, themes, and priorities a) across age groups to explore whether considerations and foci vary at different stages in the life course, and b) between sub-themes to draw higher-level conclusions about overall considerations and priorities.

2.5. Methodological rigour

Three techniques to improve rigour were applied in this research, with additional considerations addressing challenges unique to secondary qualitative data analysis. The techniques were: 1) producing a data audit trail including both intellectual and physical components which was maintained over the duration of the project (Carcary, 2020); 2) completing extensive memoing to support reflexivity and justify the analytical decision-making (Birks et al., 2008); and 3) holding a series of peer debriefing meetings between October 2021 – May 2022 to identify areas of potential bias, challenge implicit assumptions made during the analysis, and draw broader conclusions about the meanings gleaned from the data (Spall, 1998).

Qualitative secondary data analysis (QSDA) in this study was used to "reanalyze all or part of a data set by focusing on a concept that seemed to be present but was not specifically addressed in the primary analysis" (Hinds et al., 1997, p. 3). Two of the authors (EK, JG) were part of the research team that collected the survey data for the [blinded], which is generally considered to be a benefit to QSDA since it helps preserve the context in which the data was originally obtained (Ruggiano & Perry, 2019). Both authors are currently employed by the [blinded], with unrestricted access to the dataset for analysis. To address potential ethical and methodological concerns (Ruggiano & Perry, 2019), 3 steps were taken: 1) the study was delineated explicitly as a separate QSDA project; 2) ethics approval from the University of [blinded] was obtained prior to analysis initiation; and 3) peer debriefing was used as

an opportunity to bolster trustworthiness and credibility in the secondary analysis and minimize any interpretational biases (Spall, 1998).

2.6. Ethics Approval

Ethics approval was obtained from the University of [blinded] on November 12, 2021 [ORE# Blinded].

3. Findings

3.1. Critical literature review findings

A total of 238 articles were found during a systematic search of the literature on December 10, 2021, and 55 were omitted as duplicates (see Figure 1). A title and abstract review were conducted on 183 articles and 165 were deemed irrelevant, before 18 full-text papers were assessed for eligibility. Of those 18 articles, 16 were omitted for a primary focus on knowledge outputs other than a review (n = 8), a primary focus other than mental health changes (n = 4), a focus on the wrong population (n = 2), being unavailable in English (n = 1), or comparing results across cross-sectional age groups (n = 1). The final review included 2 articles, both of which were published in 2021ⁱ (Parlapani et al., 2021; Rodrigues et al., 2022).

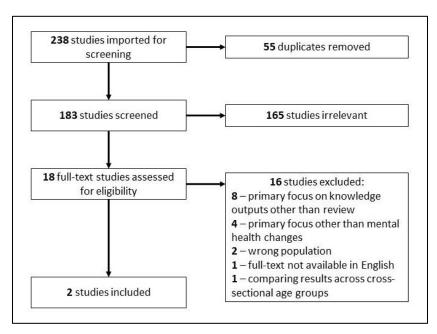


Figure 1. PRISMA-style diagram of the critical literature review results; originally from Kalles (2022)

The purpose of Parlapani and colleagues' (2021) paper was to explore the mental health impact of the COVID-19 pandemic on older adults using studies that employed validated psychometric tools. Rodrigues et al. (2022) looked at the impact of social isolation due to the COVID-19 pandemic on older adults as a single group of individuals aged 55+. Papers identified by Rodrigues et al. (2022) that were only focused on mental health interventions (n = 4) were disregarded during the review.

A total of 29 non-hierarchical mental health experience and outcome codes were constructed from the critical literature review papers. These related to mental health experiences (e.g., anxiousness,

low mood, sleep disruptions) and feelings/emotions (e.g., grief, gratitude for having lived a good life) (n = 21); mental illnesses (n = 7) like stress disorders or anxiety disorders; and n = 1 experience unrelated to mental health or mental illness – negative financial impacts. Neither of the published papers included definitions for the phenomena observed, and both papers reported on findings without differentiating between mental health and mental illness outcomes/measures. Where appropriate, given the outcomes and measures reported, phenomena in Parlapani et al. (2021) and Rodrigues et al. (2022) were separated into either mental health, mental illness or both mental health and mental illness related codes. Given the supplementary nature these codes played in the secondary framework analysis, they are not reported in full depth in this paper, but are available in Kalles (2022). The 29 codes were carried forward into the framework analysis coding process, although only codes that were mentioned in the free-form survey responses were retained in the final framework.

3.2. Framework approach findings

Abbreviated respondent characteristics are reported below; see (citation omitted for blinding) for a full description. Respondents to the qualitative survey were asked to select all perspectives that applied to them. They predominantly identified as older adults, aged 55+ (69.4%), although slightly over 40% of the respondents self-identified as a family or friend caregiver (43.3%), and almost one-third (29.9%) were health or social care providers providing paid care to older adults. Almost half (48.1%) of respondents identified more than one perspective and of those individuals, 62.0% were caregivers who were themselves older adults. In comparison to the total sample, 29.9% of respondents identified as caregiving older adults.

Just over half of respondents lived in Ontario (53.7%) and they were primarily between 56 and 65 years in age (40.3%), and female (79.5%). Respondents were overwhelmingly Caucasian (89.9%). See Table 2 for a detailed breakdown of the survey respondent demographics.

| Table 2. | | |
|--|----------|----------|
| Sample Characteristics for Qualitative Survey Responses | | |
| | <u>n</u> | <u>%</u> |
| Total number of eligible respondents | 268 | |
| Perspective (check all that apply) ¹ | | |
| Older adult (age 55+) | 186 | 69.4% |
| Caregiver (family, friend, neighbor etc. who provides support to an older adult) | 116 | 43.3% |
| Health and social care provider (paid to provide care to older adults) | 80 | 29.9% |
| Province/Territory of Residence | | |
| Alberta | 17 | 6.3% |
| British Columbia | 12 | 4.5% |
| Manitoba | 37 | 13.8% |
| New Brunswick | 9 | 3.4% |
| Newfoundland and Labrador | 23 | 8.6% |
| Nova Scotia | 5 | 1.9% |
| Northwest Territories | 0 | 0.00% |
| Nunavut | 1 | 0.4% |
| Ontario | 144 | 53.7% |
| Prince Edward Island | 1 | 0.4% |
| Quebec | 12 | 4.5% |

| Saskatchewan | 7 | 2.6% |
|---|-----|-------|
| Yukon | 0 | 0.00% |
| Age Group | | |
| Under 55 | 73 | 27.2% |
| Age 56-65 | 108 | 40.3% |
| Age 66-75 | 53 | 19.8% |
| Age 76 and older | 30 | 11.2% |
| Not identified | 4 | 1.5% |
| Gender | | |
| Female | 213 | 79.5% |
| Male | 52 | 19.4% |
| Not identified | 3 | 1.1% |
| Ethnicity | | |
| Asian – East (e.g., Chinese, Japanese, Korean) | 6 | 2.2% |
| Asian – South (e.g., Indian, Pakistani, Sri Lankan) | 3 | 1.1% |
| Asian – South East (e.g., Malaysian, Filipino, Vietnamese) | 2 | 0.8% |
| Black – North American (e.g., Canadian, American) | 1 | 0.4% |
| First Nations | 1 | 0.4% |
| Indian – Caribbean (e.g., Guyanese with origins in India) | 1 | 0.4% |
| Indigenous/First Nations – not included elsewhere | 1 | 0.4% |
| Métis | 1 | 0.4% |
| Middle Eastern (e.g., Egyptian, Iranian, Lebanese) | 1 | 0.4% |
| Mixed heritage (e.g., Black - African & White - North American) | 3 | 1.1% |
| Other (please specify) | | 1.5% |
| Prefer not to answer | 3 | 1.1% |
| White - European (e.g., English, Italian, Portuguese, Russian) | 43 | 16.0% |
| White - North American (e.g., Canadian, American) | 198 | 73.9% |
| ¹ Select all that apply options mean percentages will not add up to 100.0% | | |

Results from the secondary qualitative analysis indicate 4 key areas of consideration regarding aging and mental health support, care, and treatment. These are: 1) internally held principles influencing older adults' experiences and outcomes; 2) societal- and system-level factors affecting older adult mental health; 3) services, supports, and programs that could be valuable; and 4) mental health experiences and outcomes mapped to the mental health dual continuum model (see Figure 2).



Figure 2. Four key areas of consideration identified from the secondary framework analysis

Consistent throughout the areas of consideration discussed below is an implicit (and sometimes explicit) conceptualization of 'mental health' that extends beyond just mental well-being and mental illness. For respondents, mental health was part of an older adults' overall holistic well-being, which meant those concerns and considerations could not be and should not be separated out from the concerns and considerations that are related to an older adults' physical, cognitive, and emotional health. As one respondent phrased it,

Physical and mental health are intertwined and codependent. This is where the disconnect is. This is where our medical system and services fail to meet the needs of anyone who is struggling emotionally. This is where the foundation for improvement begins. Physical health and mental health go hand in hand. (P268)

Key Consideration 1 – Core Principles

When talking about aging and mental health, respondents implicitly built their perspective on a set of core principles (see Table 3 for a list of each sub-principle and exemplar quotes). If a principle is defined as "a moral rule or belief that helps you know what is right and wrong and that influences your actions" (Encyclopædia Britannica, 2023), then the data revealed principles of information, autonomy, and access are a set of moral rules or beliefs that respondents held about what older adults' mental health is, and how it should be. The principles served as a connection point between the internal/intrinsic environment of an older adult's mind and the external/extrinsic environment that an older adult inhabits (aka 'the system'). They were expressed as a set of requirements or demands that needed to be met for an older adult to experience positive mental health. This tied into both proactive and reactive situations – for example, by cueing an older adult to ponder "Who do I turn to? Who can

help me?" (P006) (i.e., proactive) or to state that they "would want someone [they] can talk [to], who will listen to me, not directions to a website for self help" (P006) (i.e., reactive).

Although the three principles are introduced separately below for clarity, they were discussed by respondents in a co-mingled way. For example, while respondents spoke about *information* that could be used to reinforce decision-making *autonomy* which would be actioned through *access* to resources, this was not a strictly linear process and all the principles were subject to each other in one way or another (e.g., *autonomy* also dictated the *information* an older adult could obtain). This comingling was so prevalent that disentangling a single experience, thought, or outcome into only *information*, *autonomy*, or *access*-relevant content was not possible.

| Table 3. | |
|---|--|
| Core principles identified during t | |
| | <u>Exemplar Quotes</u> |
| Core Principle 1. Information | |
| Defining mental health and mental illness across the life | "[What is the difference] between mental health and mental illness, [as] the terminology is confusing." (P120) |
| course | "What is considered a 'mental health' issue as opposed to a health issue? What is 'normal' aging and what is a mental health issue?" (P198) |
| What is dementia | "[how to recognize] aging and forgetfulness vs alzheimers or dementia" (P029) |
| | "What does wellness (in terms of mental health) look like for individuals with dementia or who have trouble with their memory?" (P002) |
| Signs to recognize and watch out for | "How can people in need of mental health support (and perhaps reluctant to seek it out) be identified?" (P105) |
| | "Danger signs that someone is not coping or perhaps at risk?" (P007) |
| Life course changes | "Preparing yourself mentally for retirement I struggle to find the new me. I have no idea who can help me with that. At my age, there are aging and ailing parents that put added pressure on your time, creating obligatory commitments." (P166) |
| | "I think about life changes – losing your license, having your spouse go to LTC/RH, changes in health" (P014) |
| Beneficial lifestyle behaviours | "What types of care contribute to PREVENTion of mental health problems in the elderly? Are services equally available to Canadians regardless of age? Should they be? I would like to know more about availability of services for seniors focused on mental health promotion, especially for minority language populations in rural areas." (P146, capitalization original) |
| How to support and help others who may be in need | "What services are available if I am alone and start to failhow will I manage my finances if I am all of a sudden alone and have never done so" (P232) |
| | "If I die before my husband, who will give my middle aged son with the mental illness the same kind of support that I am giving him now." (P197) |
| How to be a caregiver | "How do caregivers help?" (P145) |

| | "How to help and support a family member of a different generation and culture in a way that does not demean the elder and does not exhaust the caregiver." (P073) |
|---|--|
| Where to get help | "How and when can I and should I access services" (P220) |
| | "How do you know where to go for help about mental health?" (P238) |
| Assessment, treatment, and | "How does the referral to mental health work?" (P003) |
| care information | "What kind of assessment tools are currently being used" (P239) |
| | "[what type of] Treatment? The most appropriate, obviously." (P242) |
| Core Principle 2. Autonomy | |
| To live and age where one wants | "Support for me means that I am able to stay in my home (apartment or house) with the support of the community with cleaning (etc)" (P083) |
| | "I want care where my family and friends are very much involved in my daily life. I don't want to be locked away somewhere out of sight, out of mind." (P058) |
| To participate in the decision- making process | "I think treatment of elderly patients needs to include patient wants. Too often, elderly are assume "feeble" and not able to make decisions. Unless [there is] mental impairment, utilize what the elderly patient wants." (P078) |
| To receive care for the whole self rather than individual | "the distinction between support, care and treatment is semantic! The three are lumped together and required for optimal outcomes." (P206) |
| pieces | "Are doctors and psychiatrists considering the WHOLE person when they are developing treatment/medication plans? Are they being holistic in understanding the older adults rich, rich history and knowledge about themselves and their body's needs?" (P219) |
| To preserve the ability to decide for as long as possible | " [support] a capable person's right to choose (even if the provider does not agree with the choice" (P018) |
| | "If there is a problem with competence, it would be helpful [if] the supporter knows or is given information about how to support the person and set up decision-making supports and power of attorney." (P252) |
| To be seen and treated as a | "How can I focus on the person and not on the results?" (P174) |
| person | "What is important to me isbeing treated with respect, not being neglected or mistreated" (P055) |
| Core Principle 3. Access | |
| | |

| Resources that exist and are discoverable | "I think about how difficult it can be to access the support I find that there is a wealth of resources but finding what I need when I need it, whether for myself, family or clients is very challenging. Even knowing where to look, who to call, what are the appropriate questions to ask to get the answers is very difficult." (P188) |
|---|--|
| | "Why is it so hard to FIND mental health supports in the community or even through your family MD?" (P201) |
| Resources that are accessible from an older adult's place of residence | "When my mother was finally convinced to seek help, the only community service available was in an inaccessible building." (P157) |
| | "Having care from trained individuals locally if not in my home is really important as is equal access to services and supports." (P217) |
| Resources that are financially feasible | "Affordable supports and services in the community to keep older people active and in touch. Especially those at home alone." (P152) |
| Resources that are available in a | "Mental health care options should not be such long waits for professional help." (P124) |
| timely manner | "What efforts are being made to make psychological care more available. How should seniors access such care? A waiting time of over a year is far too long." (P146) |
| Resources that are appropriate for personal needs, beliefs, and circumstances | "I believe there are significant differences between the different ethnic groups living in Canada in terms of the support they deem most effective and appropriate. Emotional support must be provided in the person's primary language (French, English, First Nations languages, etc.) but also in a culturally appropriate manner Can you identify these differences and the elements that are "universal" by making sure to include the First Nations, Quebecers, Acadians, and other cultural groups who remain in Canada?" (P075, translated from French). |

Core Principle: Information

The first core principle was *information*, and across the lifespan, respondents spoke about 9 different needed areas of information: 1) defining mental health and mental illness across the life course; 2) what is dementia; 3) signs to recognize and watch out for; 4) life course changes; 5) beneficial lifestyle behaviours; 6) how to support and help others who may be in need; 7) how to be a caregiver; 8) where to get help; and 9) assessment, treatment, and care information (see Table 3). The topics were generally consistent across age groups, except for *life course changes*, where the types of changes discussed were congruent with the changes people might typically encounter in that stage of life (e.g., transitions into retirement for young-older adults, coping with a loss in social support when your peer group have died for oldest-older adults).

Across all the *information* topics was a recurring pattern of individuals identifying a lack of core/foundational information about mental health, either in what that was (areas 1-2), how it manifests under various contexts (areas 3-4), or how it could be facilitated in oneself or others (areas 5-9). For many respondents, this lack of foundational information impeded their ability to make and/or understand the 'best' mental health-related support, care, or treatment decisions. For example, one respondent wondered,

"I want to know who will take care of me, and where. Will home care actually be sufficient, or will I need more supervision? Will I be stashed in a crowded room in a nursing home? Will I have some semblance of privacy and homey atmosphere?" (P062)

Even care providers identified knowledge gaps, with one provider stating, "I don't know a lot about [mental health] other than prescribing antidepressants. Are there any actual therapists focused on the elderly? I work in health care and am unaware." (P017).

The need for information to make decisions was most explicit with the topics around where to get help and assessment, treatment, and care information. In the context of where to get help respondents spoke about a lack of information around what help is available, when someone should seek it out, and who to contact to access it. When discussing assessment, treatment, and care information there was an identified lack of knowledge about almost all aspects of the care journey, including the referral process, assessment practices, and treatment availability (plus treatment appropriateness for older adults).

Core Principle: Autonomy

The second core principle influencing older adults' mental health was *autonomy*, which represented a desire for older adults' decisions to be respected and acted upon. In the context of aging and mental health, respondents (whether an older themselves or not) wanted older adults to have the ability 1) to live and age where one wants; 2) to participate in the decision-making process; 3) to receive care for the whole self rather than individual pieces; 4) to preserve the ability to decide for as long as possible; and 5) to be seen and treated as a person. The principle *of autonomy* and the 5 areas discussed by respondents underscored a recurring struggle regarding older adults' efforts to be seen as independent individuals with "...rich, rich history and knowledge about themselves and their body's needs" (P219), who are capable of making their own choices not only in mental health, but in their own bodily autonomy and livelihood.

Elements of ageist and negative mental health stigmas were implicitly discussed as a foil for the need for *autonomy*, with one respondent phrasing the negative impact of these stigmas on decisional opportunities as circumstances where "too often, [the] elderly are assumed 'feeble' and not able to make decisions." (P078).

Core Principle: Access

The third principle is a need for *access* to resources to realize a given decision. This may include tangible resources (e.g., home care services), or intangible resources (e.g., respectful clinicians who recognize the need for care in line with personal beliefs). There were six components of access identified, which focused on supports that 1) exist and are discoverable; as well as ones that are 2) accessible from an older adult's place of residence; 3) financially feasible; 4) available in a timely manner; 5) obtainable without jumping through hoops, and 6) appropriate for personal needs, beliefs, and circumstances. The crux of the *access* principle was that even if an older adult's *information* and *autonomy* needs are met and they can make a mental health-related decision, there remains a final step needed to actualize it.

To respondents, this was a particularly challenging principle to meet, as it often depended on inadequate structural supports that were beyond a single individual to address. This meant that many respondents talked about how "more available and dedicated services" (P142) were needed and even if they did exist that "the biggest obstacles are connecting the dots in program & service availability" (P243). This was especially true for locating resources that meet an older adult's unique cultural, linguistic, communicative, spiritual, geographic, etc. needs.

Key Consideration 2 – Societal- and System-Level Factors

Four types of societal- and system-level factors were identified from the responses (see Table 4). These are: 1) societal structures; 2) social stigmas; 3) health system structures and practices; and 4) service-related structures. Respondents identified these societal- and system-level factors as ones that either a) exerted a direct influence on older adults' well-being, for example, through experiences of social stigma, or b) had an indirect influence on older adults' well-being by affecting the availability, accessibility, efficacy, and appropriateness of options that an older adult might engage with in order to manage their mental health (e.g., by seeking referral to a social wellness program). The societal- and system-level factors were often brought up in the context of the core principles, as elements that typically had a negative impact on an older adult, although there was some mention of the positive and neutral influences they can exert.

Importantly, although the factors are highlighted below in the context of mental health specifically, in many cases, respondents referred more broadly to an individual's holistic well-being, which included physical, emotional, and mental components. There was little differentiation made between when a factor might affect mental health but not physical, cognitive, or other types of health.

| Table 4. | |
|--|--|
| Societal- and system-level factors | s that affect older adult mental health |
| Societal Structures | |
| Lack of recognition for paid and unpaid caregiving | "We need support people to care for our elders with intelligence, skill and compassion. This will never happen if the people in these positions are grossly underpaid and regarded as one of the lowest rungs on the employment ladder. Caring for the most vulnerable in our society is and should be regarded as something sacred. When the care of the most vulnerable becomes overly driven by profit margins it is sickening. Currently I tend to regard many of the LTC facilities I am aware of as death warehouses. I dread ever placing my loved one in such a place and not much is currently occurring in our present circumstances to dissuade me of that perception." (P055) |
| Housing and structural barriers | "I think of visiting a local shelter at 2100 and in their 20 beds for women, on that night, 19 were full, 4 had walkers beside them, and at least 10 occupants had grey hair." (P188) |
| | "Housing and income are frequently issues for older adults." (P212) |
| Pandemic-related changes | One clinician noted as a positive influence that when family and friend visits were eliminated, "residents with dementia/Alzheimers settled and [were] not as tormented. They seem to forget family and home therefore they do not grieve, cry, [or experience] anxiety about not seeing family or home. It's like they forget they are not with family at home and settle into a 'new normal'." (P010). On the other hand, one older adult shared, "I live at home, alone since my wife developed dementia and I had to find a long term residence for her 3 years ago. She does not speak, write or read, otherwise she is healthy. It's a very trying time with COVID-19 all around us. How do I cope?" (P088). |
| Social Stigmas | |
| Ageism | "Now, as a person with mental illness gets older they are less important. We are worried about those new cases coming into the system and we put on hold those that have been battling mental illness for many years." (P192) |
| Mental health stigma | I think that in order to best support one another we must all be open to having discussions with our peers to normalize certain aspects of mental health while also to empower others to seek the proper care when necessary. (P108) |
| Health System Structures & Pract | <u>ices</u> |
| Healthcare system action and inaction | "Our current payment structure of family health centres, provide good care of preventive and minor issues. But the medical care for patient and caregiver in a chronic, complex situation is laughable." (P055) |

| | "I work in the health care system and the biggest barrier to supporting mental health and aging is the time that is offered to individuals and their families to assist, support and offer resources." (P112) |
|--|---|
| | "Why is mental health not baked into our healthcare system? We are navigating too many disconnected silos and NONE take responsibility for the part they play in dehumanization and social isolation." (P223) |
| Default reliance on medication for care | "It seems a common way to treat mental health in aged is to medicate rather than provide more normalized environment and holistic approaches. I understand medication to be important but wonder why it seems to be a challenge to approach things non institutionally." (P048) |
| | "Is medication needed? Or is it being used to try to sweep the issue under the carpet? Is the senior depressed or is it a side affect from medication that is causing the person to struggle?" (P268) |
| Waitlists and service delays | "Various mental health care options should not be such long wait lists for professional help" (P124) |
| | "For severe issues it can take years for help. How many people are hanging on by a thread? Does our society really care about this?" (P238) |
| Health and social care providers as barriers or facilitators of care | "Care from my GP is most important although she is very inaccessible and limited in time. Moving forward I don't see her as a support to mental health so who??" (P008) |
| | "What tools or resources are available to my family physician for mental health assessment? Our doctor keeps a good watch on our physical health on routine visits, but mental health assessment might be equally important." (P061) |
| | "I think of how care providers offer fragments of what is needed, doctors that will only hear one problem per visit, care that blames people for a lifetime of systemic abuse like poverty." (P188) |
| Service-related Structures | |
| Geographic accessibility & availability | "How can the mental health of older adults in rural and isolated areas with limited access to resources and services be best supported." (P001) |
| | "What resources and services are available to those with limited internet connection?" (P039) |
| Transportation | "Accommodation for seniors that aren't mobile/don't have transportation/can't afford transportation costs." (P189) |
| Finances and costs of services | "Mental health supports are so scarce and so expensive. How can any support be obtained by those with limited income or no health insurance?" (P007) |
| | "Care should be accessible to all regardless of income." (P132) |
| | |

| Technology that doesn't support aging needs | "These days, internet seems essential. So how can i maintain skills, access, etc.? I currently cannot text on a phone for example." (P251) |
|---|---|
| | "with increasing phone technologies and complexity, it gets harder to reach those with memory or vision problems (especially both)." (P119) |

Societal- and System-Level Factors: Societal Structures

Three societal structures were identified by respondents. These were a lack of recognition for paid and unpaid caregiving; housing and structural barriers; and pandemic-related changes. Although it was only explicitly raised by a small number of respondents, no one who discussed it felt that caregivers (either paid or unpaid) received adequate recognition and compensation for their work. For some this was an especially charged topic, with one respondent demanding that,

We need support people to care for our elders with intelligence, skill and compassion. This will never happen if the people in these positions are grossly underpaid and regarded as one of the lowest rungs on the employment ladder. Caring for the most vulnerable in our society is and should be regarded as something sacred. (P055).

In the case of housing and structural barriers, some respondents noted the negative impact that a lack of "safe affordable supportive housing" (P264) can have. A small number of individuals talked about the (positive and negative) influences of the COVID-19 pandemic, including that with fewer/no visits from family or friends that long-term care residents with dementia seemingly forgot they weren't at home and settled into a 'new normal'. One respondent shared,

I live at home, alone since my wife developed dementia and I had to find a long term residence for her 3 years ago. She does not speak, write or read, otherwise she is healthy. It's a very trying time... with COVID-19 all around us. How do I cope? (P088).

Societal- and System-Level Factors: Social Stigmas

The two social stigmas identified were ageism and mental health stigma. Respondents discussed the impact of ageism generally, and in conjunction with mental health. One respondent wondered, "does our society really care about [how many people are hanging on by a thread]?" (P238) and asked, "if people who are articulate and know the ropes have troubles what about the less able?" (P238). In the context of mental health "...there is a stigma attached, people associate anxiety, depression, suicide risk etc. with younger people and do not consider elderly at high risk for these concerns." (P128). Many respondents identified the implicit barriers ageism raises around willingness to seek out help, awareness of resources, and the attitudes of care providers towards those needing assistance.

The experiences of mental health stigma that respondents spoke about were varied. In some cases, they related to the differing treatment 'mental health issues' get when compared to physical health – "Unlike many physical conditions, mental health conditions are viewed as relevant even decades later than any episode and treatment/therapy has ended." (P012). Others took a solutions-based approach, saying,

I think that in order to best support one another we must all be open to having discussions with our peers to normalize certain aspects of mental health while also to empower others to seek the proper care when necessary. (P108)

Societal- and System-Level Factors: Health System Structures & Practices

Several wide-ranging factors related to health system structures and practices were discussed. These included the healthcare system action and inaction; a default reliance on medication for care; waitlists and services delays; and the function of health and social care providers as barriers or

facilitators of care. Healthcare system action and inaction was viewed by many as a negative force in the mental health of older adults. A lack of sufficient funding, inadequate support for person-centred over task-focused care, and fragmented systems were some of the elements that contributed to this belief. Across all ages, there was a sense that the system as it currently exists is failing to meet the needs, demands, and desires of the people it is meant to help. This was exacerbated by other health system structures and practices, including when respondents across all age groups felt "a common way to treat mental health in [the] aged is to medicate" (P048), and when referrals are provided, their efficacy is affected by "long wait times for medical care" (P262).

Respondents believed that the "most important support would probably [be] a point of entry person who could help with system access [and] knowledge of what's available" (P232). Although there was acknowledgement for the large knowledge gap among non-mental health specialist care professionals when it comes to mental health, the family doctor was seen as a convenient and accessible ally for those needing care. Respondents did feel that this access route would only be truly successful if the health system supported it through training and compensation that ensured "...doctors are willing and able to deal with the chronic and complex..." (P055).

Societal- and System-Level Factors: Service-related Structures

Four types of service-related structures were identified, which were related to geographic accessibility and availability; transportation; finances and costs of services; and technology that doesn't support aging needs. Geographic accessibility and availability for those living in rural communities was a concern, but at least one respondent expressed the view that there are "far too few professionals available -- even in cities." (P242). This tied into the availability of transportation and the belief of several respondents that more resources are needed "...for transportation for elders to get to appointments or centre[s] to enjoy company." (P246). Across all age groups there was a concern for the cost of services and that "[mental health supports] are often out of the financial reach for many." (P167). In some cases, technology that does not support aging needs was seen as an important barrier to care, since "with increasing phone technologies and complexity, it gets harder to reach those with memory or vision problems (especially both)." (P119).

Key Consideration 3 – Services, Supports, and Programs

When talking about aging and mental health, respondents mentioned several categories of services, supports, and programs which they felt could positively benefit older adults. There was no differentiation between resources (i.e., services, supports, programs) that already exist and ones that would simply be beneficial to develop. Four areas of services, supports, and programs were discussed, which related to 1) social needs, 2) physical needs, 3) facilitators of access, and 4) persons needing assistance.

| Table 5. | |
|---|--|
| | that could benefit older adult mental health |
| Social Needs Resources | |
| Therapy, counselling, and peer support | "I believe from personal experience a therapist is key to help provide you with tools to cope." (P167) |
| | "Ongoing contact with a person or group who would provide support. This could be telephone, email contact, visitor or a wraparound group made up of volunteers who would get to know the individual and listen deeply to the person as they live their life." (P059) |
| Programs and opportunities to build connections with others | "For someone with an active mind, are there programs that will allow for self-expression? ie-hobbys, such as workshops, craft rooms, or writing, etc." (P050) |
| and foster meaning and purpose | "Having meaningful activities and social connections in life, so older adults feel supported and valued and that life is still interesting." (P094) |
| Community-based or social support programs | "Not enough free in home or community group supports for people living alone to stay connected. Day programs have a cost. Limited and restrictive home care services, lack of 'friendly visitor' programs for isolated seniors." (P095) |
| Physical Needs Resources | |
| Homecare services | "[My mother] also has a support worker come two mornings a week. These have made it possible to stay in her home for a while longer. These programs are vital to her staying in her home." (P134) |
| | "What kind of mental health services are available to seniors living in rural communities with little or no access to transportation. Enhanced home care and home support services in rural communities are most important to me." (P239) |
| Medical care (i.e., primary care) | "Access to doctors and nurses who specialize in treatment of the elderly, both physical and cognitive." (P033) |
| Opportunities for medication reviews and de-prescribing | "Polypharmacy for sure. I know several past patients have had 10-12 pills first thing in the morning and are unable to have breakfast. SSRIs are very commonly prescribed but may not always be needed everyday." (P038) |
| | "I am concerned about over-medication of older people. I saw that my mother was taking about 20 different meds and vitamins each day, and wondered how alert her family doctor was to the problems that might have been caused by this. I do not think there are sufficient numbers of family doctors and other specialists who are focused on this potential problem." (P123) |
| Facilitators of Access | |

| Opportunities to incorporate technology for facilitating care delivery and/or social contact | "If one is separated from one's friends and/or close family because of having illness, physical or mental disability I see it as vital that a way to connect a person with others be facilitated perhaps there are tools and devices that would be simple enough for the elderly or effective enough that caregivers could help with that type of connection." (P057) |
|--|---|
| | "What does mental health care for older adults look like in the future given rise of technology? Can an app that provides cognitive behaviour therapy replace mental health professionals?" (P235) |
| Transportation and mobility assistance | "Support for active living and transportation. Support for other conditions which might limit active living and transportation." (P165) |
| | "Another issue is grocery shopping." (P222) |
| Persons Needing Assistance | |
| Assessment and support for persons living with dementia and their families and/or caregivers | "Support for families coping with a family member with dementia. Some templates for Health Care workers as they provide care for dementia/Alzheimer residents." (P010) |
| | "My 98 year old mother has moderate dementia and it is very difficult to know what is best for her - I always feel that whatever I am doing is not good enough, but I don't know if better care is possible. She is currently in assisted living and seems pretty good but I would like to have more information about what would be best for her." (P247) |
| Resources and supports targeted towards unpaid and | "What about the person who, at 60, is now retired and providing support to parents? How do we support the 60 year old's mental health?" (P073) |
| family caregivers | "I am a caregiver and over 70. Issues to me are anxiety of how to cope, burnout, what will happen to my husband if I take sick, then the larger issue of grief when the inevitable happens." (P167) |
| Resources and supports targeted towards health and social care providers | "A treatment option I would consider is workshops about mental health and aging within the workplace, ensure that health care workers understand what to look for and where to get help. Differentiate between panic attacks vs anxiety, sadness vs depression. As a nurse we know the signs and symptoms but when it comes to our own help sometimes we are oblivious to it." (P100) |
| Resources and supports | "What supports are available for the older adult pertaining to substance use and/addictions?" (P021) |
| targeted towards older adults | "Spiritual care or accompaniment for the elderly in long-term care." (P032) |
| | "Why are there so few programs for aging people with MH issues?" (P238) |

Services, Supports, and Programs: Social Needs Resources

Social needs resources included therapy, counselling, and peer support; programs and opportunities to build connections with others, and foster meaning and purpose; and community-based or social support programs. Therapy, counselling, and peer support were some of the most frequently identified resources and were meant to give "...ongoing contact with a person or group who would provide support.... [and] who would get to know the individual and listen deeply to the person as they live their life." (P059). They were the person-to-person complement of programs and opportunities to build connections with others, and foster meaning and purpose (which were also some of the most commonly desired resources). The goal of these resources is to enable meaningful engagement, social interaction, and active (both physical and social) living. Their specific form was flexible but should include elements allowing for self-expression or opportunities to share learnings, and ultimately foster "meaningful activities and social connections in life, so older adults feel supported and valued and that life is still interesting." (P094).

Community-based or social support programs took many forms in participant commetns, but largely were discussed as serving as a middle ground between in-home services and institutional/primary care services. Although some individuals provided specific examples such as "respite for seniors, day programs, income support..." (P093), many simply identified "community programs" (P160), "community based supports..." (P180) or "social supports" (P008).

Services, Supports, and Programs: Physical Needs Resources

Physical needs consisted of 1) home care services; 2) medical care (i.e., primary care); and 3) opportunities for medication reviews and de-prescribing. Home care services were seen as an important resource and one that can make it possible for older adults to live at home longer. Access to medical and physical help was important, which included clinical supports like stroke recovery resources, as well as paramedical services like physiotherapy and physical training. They were to be "care that helps minimize the impacts of the disease progression.... by which patients can hold ground as long as possible and maintain quality of life." (P055).

The overprescribing and use of medication with older adults was seen as an important issue across all age groups, and respondents wanted opportunities for medication reviews and de-prescribing. Many shared opinions that overprescribing not only cost precious money but could also lead to complications with other medications. De-prescribing and opportunities for medication review were seen to help address this issue.

Services, Supports, and Programs: Facilitators of Access

Two factors were identified as facilitators of access: 1) opportunities to incorporate technology for facilitating care delivery and/or social contact; and 2) transportation and mobility assistance. It was not the majority opinion (especially considering concerns raised around technology that does not incorporate aging needs), but some respondents spoke about incorporating technology as a facilitator for either care delivery or social contact. For example, "virtual friendly visiting visits by phone or online would be nice to decrease loneliness and to increase socialization" (P018). It was important though, that "...technological advancements that are being implemented or being developed right now...[are] made

with [the] aging population as their target audience" (P034) as a way to offset issues unique to older adults.

According to respondents, transportation and mobility assistance were important to facilitate engagement with essential services and supports like day programs, appointments, meetups, and grocery shopping.

Services, Supports, and Programs: Persons Needing Assistance

In addition to the types of resources needed, respondents also spoke about resources that could help specific groups/persons who needed assistance. These were: 1) assessment and support for persons living with dementia and their families and/or caregivers; and resources and supports targeted towards 2) unpaid and family caregivers; 3) health and social care providers; and 4) older adults. In terms of assessment and support for persons living with dementia, many of the comments were focused on early detection, diagnosis and "…resources designed for those who have Alzheimers or other forms of dementia" (P002) in addition to supporting care partners and family members.

Like the community-based and social support programs discussed above, respondents broadly identified the need for "caregiver support" (P027; P140) or "support for PSW's, nurses" (P035), or "health care professionals" (P160) without necessarily specifying what form this support might take. In terms of resources and supports targeted towards older adults, this primarily involved marginalized or potentially disadvantaged groups like individuals dealing with addictions or substance use issues, and those living in long term care.

Key Consideration 4 – Mental Health Outcomes and Experiences

The final area of consideration was that of mental health experiences and outcomes. In total 11 experiences and outcomes were discussed (see Table 6) on the continuum of mental health (n = 8): anxiousness; apathy; emotional loneliness; social loneliness; grief and grieving; low mood; sleep disruptions; and social isolation. The continuum of mental illness (n = 3) included: anxiety disorder (i.e., Generalized Anxiety Disorder; GAD); depressive disorder (i.e., Major Depressive Disorder; MDD); and suicidal ideation. These were not necessarily considerations that respondents were experiencing themselves but were ones they believed were important in the context of older adult mental health.

| Table 6. | |
|--|--|
| Mental health & mental illness continuum outcomes and experiences Mental Health Continuum | |
| Anxiousness | "Anxiety in people 60+" (P076, translated from French) |
| Apathy | "My wife has no interest in going for a walk in the sunshine and fresh air, no interest in making conversation with friends, new or old, no interest in self improvement through voice exercises, stability strengthening or mental stimulation like puzzles or games, even though she was a secondary school teacher." (P070) |
| Emotional loneliness | "Loneliness is a huge factor in aging and mental health." (P179) |
| Social Ioneliness | "It can be a time when it is very difficult to even be motivated to make new friends in new environments, creating more reasons for loneliness. I would really like to see more research on the link between loneliness translating into poorer physical health, so that appropriate attention is paid to this aspect of mental health. This is a key aspect of support." (P071) |
| Grief and grieving | "How do you cope with loss? How to cope with loss of loved ones? Death and Dying. Connections." (P023) |
| | "My major concern is the state of depression both are experiencing The elder with concern for the younger, & the younger one with realizing it will get worse as time goes on, & feeling lost & hopeless As the only remaining sibling with all of my facilities still intact, I worry for both of them (P186) |
| Low mood | "We are supposed to be f^{***ed} (sic) up a bit because we are old so if you are experiencing depression that's normal as far as the young person telling you is concerned." (P175) |
| Sleep disruptions | "Supports for promoting sleep." (P111) |
| Social isolation | "Social isolation is clearly a problem for many seniors. It often intensifies as old friends die." (P222) |
| Mental Illness Continuum | |
| Anxiety disorder(s) | "What is normal anxiety and what is [an] anxiety disorder?" (P008) |
| Depressive disorder(s) | "I have had clinical depression all my life and now can live with it but it takes away a good deal of my life." (P127) |
| Suicidal ideation | "I knew a very depressed elderly person who wanted to be euthanized - fortunately, in that case, the psychiatrist spotted the illness, but mental problems are often dismissed in the elderly." (P157) |

Mental Health Outcomes and Experiences: Mental Health/Mental Well-being Continuum

Anxiousness was largely undefined by respondents, who just wanted to know about "anxiety in people 60+" (P076) without providing more details. Apathy in older adults was considered a "lack of motivation" (P041) and a "loss of interest" (P199), and was exemplified by one respondent who worried about their partner, stating,

My wife has no interest in going for a walk in the sunshine and fresh air, no interest in making conversation with friends, new or old, no interest in self improvement through voice exercises, stability strengthening or mental stimulation like puzzles or games, even though she was a secondary school teacher. (P070)

Experiences of emotional loneliness and social loneliness were discussed by many respondents. Respondents spoke about "coping with loneliness" (P056) as an example of emotional loneliness, and "[times] when it is very difficult to even be motivated to make new friends in new environments, creating more reasons for loneliness" (P071) as an example of social loneliness.

Responses around grief and grieving were described as not just about "bereavement supports" (P014) but also loss as a multi-dimensional construct incorporating the "impact of life limiting disease" (P007), loss of social roles due to retirement, and caregiving grief, among others. For example, one respondent spoke about their struggles from observing the decline of their siblings with dementia,

My major concern is the state of depression both are experiencing.... The elder with concern for the younger, & the younger one with <u>realizing it will get worse as time goes on, & feeling lost & hopeless.... As the only remaining sibling with all of my facilities still intact, I worry for both of them.... (P186; emphasis added)</u>

Low mood incorporated all experiences of low or depressed mood and non-clinical depression. For example, respondents talking about how "We are supported to be f^{***ed} up a bit because we are old so if you are experiencing depression that's normal as far as the young person telling you is concerned." (P175, formatting original).

Sleep disruption was only identified by one respondent in the context of "supports for promoting sleep" (P111).

Finally, social isolation was the most frequently identified mental health/well-being experience. The experiences and concerns of respondents are exemplified in the response of one individual,

I am 71, in good health, a woman, living on my own. I have no children and am a widow. Being self-isolated during the COVID-19 Pandemic has caused me to feel what it is like to be isolated and not be able to change the situation.... I can now imagine what it might be like to be isolated because of physical or mental incapacities when I am older. I can see the importance of having the emotional and social support of friends and family. (P057)

Mental Health Outcomes and Experiences: Mental Illness Continuum

One respondent asked about anxiety disorders and wanted to know, "what is normal anxiety and what is anxiety disorder" (P008). Depressive disorder was based on clinically diagnosable depression, as one respondent wondered, "how to identify clinical depression or situational depression"

(P008), and another spoke about how they "have had clinical depression all [their] life and now can live with it but it takes away a good deal of [their] life." (P127). Suicidal ideation was identified by 3 respondents around "suicide prevention and intervention" (P255) and "how to help someone thinking [of] suicide" (P159).

4. Discussion

This research intended to apply a pragmatic approach towards exploring the mental health considerations important to experts-by-experience in Canada at the onset of the COVID-19 pandemic. Four key considerations were identified from the secondary framework analysis conducted. These were: 1) core principles respondents felt influenced the experiences and outcomes of older adults; 2) societal-and system-level factors that affect older adult mental health; 3) services, supports, and programs that respondents felt would be valuable; and 4) mental health experiences and outcomes as mapped to the dual continuum model of mental health.

The core principles were a set of essential considerations that older adults, caregivers, and health and social care providers felt were strongly tied to the mental health of older adults. These principles were pervasive – they appeared in frustrations about resources not accommodating older adults' technological needs, they motived questions about appropriate treatment options, and most of all they encouraged a change in the status quo. Respondents felt, if an older adult has the necessary *information* about mental health across the life course, with the *autonomy* to decide what care was most appropriate for their whole self, and with *access* to the resources needed to action this – they would be much better off.

It is possible that these principles may function as an intermediary between the connections internal 'resources'/beliefs and external societal- and system-level factors have on mental health experiences and outcomes. Although our understanding of mental health is continuously evolving and necessarily incomplete, we do know that both intrinsic and extrinsic factors play a role in the outcomes and experiences observed. Internal phenomena such as self-compassion (Hwang et al., 2016) have evidence to support their influence on subjective mental health. Similarly, external influences such as service access (von Humboldt et al., 2022) also have a demonstrated impact on mental health.

The core principles important for older adult mental health fit within this existing knowledge and based on respondents' conceptualization, suggest internal and external factors may each have a direct action upon mental health experiences and outcomes, and, if they help older adults fulfill their needs of information, autonomy, and access, an indirect action through the principles (see Figure 3 for a visualization of this concept). In the opposite direction, internal or external factors that inhibit the fulfillment of these principles may negatively affect mental health experiences and outcomes – either by negating the positive effects of other factors, or by introducing additional 'stressors'.

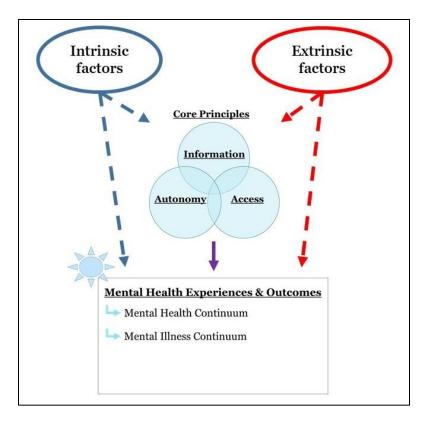


Figure 3. Tentative connection proposed between intrinsic and extrinsic factors on the core principles

The explicit, unprompted identification of these principles as important considerations regarding aging and mental health for older adults is a novel finding, as is the interplay between the three principles themselves. Prior literature has identified the principles in the context of mental health experiences and outcomes, but they are predominantly examined in isolation. For example, the movement towards shared decision-making and the participation of service users in their care could be considered a practical fulfillment of the *autonomy* principle. Mental health literacy, which has been defined as the "knowledge and beliefs about mental disorders which aid their recognition, management, or prevention" (Jorm et al., 1997, p. 182) could be considered a direct influence on the intrinsic fulfillment of the *information* principle whereby it affects one's ability to interpret information regarding mental health or illness. And health service accessibility, an almost linear example of the *access* principle, has been shown to relate to older adults' mental health and behaviours (von Humboldt et al., 2022).

When considering existing and potential resources for older adult mental health, the identification of these core principles indicates that it is important to not only assess the resource itself, but also the holistic interplay between the resource, an individual's unique circumstances and abilities, and the environment within which both the resource and the individual co-exist. This is in line with existing theories like the Strength and Vulnerability (SAVI) model, which recognize that both internal and external phenomena have a significant impact on an older adults' well-being (Charles & Luong, 2013).

A recurring challenge described by respondents was their lack of foundational mental health-related knowledge. To be clear, respondents were quite sophisticated in their awareness of societal- and system-level factors and services, supports, and programs which can influence mental health

experiences and outcomes. Many of those factors have been explored in healthcare contexts generally (van Gaans & Dent, 2018) and some (e.g., a lack of recognition for paid and unpaid caregiving) have established mental health niches. What respondents struggled for was a core understanding of what older adult mental health is, and knowledge of what can be done to foster it against those long-standing and largely negative extrinsic factors.

This awareness of external factors, but gap in core knowledge and actionable resources suggests several things. First, more accessible information is needed to educate older adults *and* the general populace on what older adult mental health is. Action-oriented initiatives combining research and participatory principles like the work being conducted by [blinded] to co-design an evidence-based way to start mental health-related conversations are an important step forward, but more work is needed. Second, there needs to be some bridge between understanding mental health, awareness of what is affecting one's well-being, and being able to address it. As Canada moves forward from the COVID-19 pandemic, more resources including older adult-focused services, supports, and programs are needed. To facilitate this, funding and policy changes must not only focus on mental health promotion from a direct service or funding perspective, but also from the perspective of understanding and addressing the role systemic social barriers and inequities play in overall mental well-being.

A final consideration is that although prompted to think specifically about aging and *mental health*, respondents discussed a broad and encompassing 'well-being' which incorporated elements of not just mental health, but also those of physical, social, and cognitive health. It is entirely plausible that for respondents, mental health cannot be separated from overall health and well-being, which is a concept with some existing support (Schnittker, 2005).

4.1. Practical implications

These findings support that older adult mental health is a complex and multi-dimensional construct that is influenced a) by both the internal processes of an individual and the external processes of their circumstances, and b) by the interplay between these two factors. Existing and planned programs should take these considerations into account when determining how best to meet the needs of their older adult clientele. The core principles can be integrated at a foundational level by providing insight into how unique internal processes, strengths, and vulnerabilities can be leveraged in concert with a recognition of the specific circumstances that an older adult is living in.

The findings also have implications at a policy level as the need for continuing support of older adult mental health is evident. Although the specific dynamics between the core principles, internal processes, and external circumstances must be explored further in future research, these findings highlight the wide-ranging impact that broad system and social issues have on older adult mental health.

4.2. Limitations and opportunities

There are several strengths in this research. This study gives representation to the often-missing experiences and voices of aging individuals, providing a novel glimpse into the way that internal experiences/phenomenon and external societal- and system-level factors may influence older adults' mental health experiences and outcomes. The incorporation of multiple expert-by-experience perspectives provides a realistic view of the Canadian context and the mental health considerations relevant for older adults.

There are some limitations to account for. Given the non-representative demographics of the survey respondents, caution should be used when drawing conclusions for the overall Canadian population. The findings from this work suggest important directions that should be considered when designing or adapting services/programs for older adults, however they should be validated with the specific population(s) of interest, to ensure they represent their needs, questions, and concerns.

4.3. Conclusion

Understanding the mental health considerations for Canadian older adults is an essential step in ensuring that the services, supports, and programs available meet the needs of aging individuals and their support network of caregivers and care providers. With this knowledge program developers and funders can more effectively direct precious resources to address the effects of the COVID-19 pandemic.

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