

Health Literacy and Serious or Persistent Mental Illness: A Mixed Methods Study

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ABSTRACT

Background: Health literacy is increasingly recognized as a major determinant of health; however, our insights into the health literacy strengths and needs of adults living with serious or persistent mental illness remain limited by a notable lack of research in this area. Improving our understanding is important because people in this group are especially vulnerable to numerous negative health outcomes, many preventable. **Objective:** To assess the health literacy strengths and needs of people living with serious or persistent mental illness in terms of their ability to acquire, understand, and use information about their illness and the health services they require. **Methods:** A cross-sectional convergent mixed methods design guided by the Ophelia Access and Equity Framework. People diagnosed with serious or persistent mental illness were offered participation. Quantitative and qualitative data was collected using questionnaires (Health Literacy Questionnaire [HLQ], World Health Organization [WHO-5]) and semi-structured interviews. Hierarchical cluster analysis identified and grouped participants with similar health literacy scores into mutually exclusive groups, for the development of clinical vignettes. **Key Results:** Participants struggled most with the appraisal of health information (HLQ mean 2.72, standard deviation [SD] .63 [scale 1-4]) and navigating what they often perceived to be a confusing health care system (HLQ mean 3.29, SD .79 [scale 1-5]). On the other hand, most participants reported positive experiences with their health care providers (HLQ mean 3.19, SD .62 [scale 1-4]) and generally felt understood and supported. The cluster analysis suggests we should not assume people living with serious or persistent mental illness have homogeneous HL strengths and needs, meaning a one-size-fits-all solution for improving health literacy in this diverse group will likely not be a successful strategy. It will be important to explore solutions that embrace patient-centered care approaches. **Conclusions:** This study is one of only a handful assessing the health literacy strengths and needs of people living with serious or persistent mental illness. By collecting both quantitative and qualitative data, then analyzing the results using sophisticated cluster analysis methods, the authors were able to develop clinical vignettes per the Ophelia Framework that offer results in a practical way that can be readily understood and acted upon by stakeholders. We found that the HLQ is a measure of HL that is acceptable to mental health clients, and our findings provide preliminary data on the use of this instrument in the mental health population. [HLRP: Health Literacy Research and Practice. 2023;7(1):e2–e13.]

Plain Language Summary: This study explored the health literacy strengths and needs of people living with serious or persistent mental illness. The results showed a mix of strengths and needs among our participants, though several consistent themes emerged. Most of our participants felt understood and supported by their health care providers, but many often struggle with judging the quality of health information and finding their way through the health care system.

People living with serious or persistent mental illness (SPMI) are often among humanity's most disadvantaged, and because of this vulnerability they frequently face additional barriers to achieving their optimal health state and health trajectory. One such barrier may be an inadequate level of health literacy (HL), with adequate HL defined by the authors as ei-

ther an adequate level of individual HL or adequate accommodation from health care providers or health care systems. As influential as many of the commonly accepted determinants predicting a person's health status (World Health Organization [WHO], 2013), HL is increasingly recognized by health care professionals and health-policy researchers as a major determinant

of a person's overall health and well-being (Fleary & Ettienné, 2019; Kutcher et al., 2016; Nutbeam & Lloyd, 2021). Important tasks such as providing informed consent, making healthier lifestyle choices, engaging in meaningful participation when planning care, and the ability to understand and follow guidance from health care providers all require an adequate level of HL or accommodation (Demian et al., 2016; Guntzviller et al., 2017; Jessup et al., 2018; O'Neill, 2021; Smith et al., 2013). Adequate levels of HL are now viewed as fundamental for increasing engagement, improving health outcomes, reducing health inequities, strengthening health systems, and developing effective health policy (Kutcher et al., 2016; Sørensen et al., 2012; WHO, 2013).

Interest in HL has seen explosive growth over the past 25 years (Nutbeam & Muscat, 2020; Pinheiro, 2021), with a sizeable and growing body of research exploring many aspects of HL across a diverse range of population groups and patient cohorts. Yet, while the richness, diversity, and depth of HL research is impressive, our insights into the HL strengths and needs of adults living with SPMI remain limited by a notable lack of research in this area (Clausen et al., 2016; Degan et al., 2019; Farrell et al., 2020; Krishan et al., 2012; Lincoln et al., 2021; Piatt et al., 2010). Improving our understanding of these strengths and needs is important because people in this often-marginalized group (Cleary et al., 2014) experiencing both inadequate HL and SPMI are especially vulnerable to numerous negative health outcomes, many preventable (De Hert et al., 2021; Olfson et al., 2015; Walker et al., 2015).

BACKGROUND

Health Literacy

The concept of HL continues to evolve (Kutcher et al., 2016; Rudd, 2015), as do the numerous definitions. HL is now un-

derstood as a broader construct (Batterham et al., 2016; Pinheiro, 2021), often referred to as multidimensional HL and influenced by the strengths and limitations of individuals and communities, and underpinned by the belief that environmental, political, and social factors influence an individual's ability to engage with health information and health services (Anwar et al., 2020; Batterham et al., 2014; Beauchamp et al., 2015; Degan et al., 2019). This work should not be confused with research exploring "mental health literacy," a term describing the knowledge, attitudes, and beliefs about mental health disorders held by people in general populations (Furnham & Swami, 2018).

A growing corpus of peer-reviewed literature exploring relationships between HL and health outcomes across a wide variety of patient populations and health care settings has reported inverse relationships (i.e., inadequate HL is often associated with a greater number of negative health outcomes) (WHO, 2013). Inadequate levels of HL have been consistently associated with a lower likelihood of participating in self-care activities, less use of preventative care services, difficulty interpreting labels and health messages, and a greater likelihood of making riskier health choices (e.g., tobacco use), experiencing a work-related accident, experiencing difficulties with managing chronic diseases, and adhering to a medication regimen (Berkman et al., 2011; WHO, 2013). Higher rates of health care utilization, including hospital admissions, readmissions, and expenditures among those with inadequate HL have been well-documented (Bailey et al., 2015; Cartwright et al., 2017; Dahl & Hosler, 2020; Krishan et al., 2012; Mitchell et al., 2012; Rasu et al., 2015; Son & Won, 2020).

Serious or Persistent Mental Illness

The National Institute of Mental Health ([NIMH], 2021) defines SPMI as "a mental, behavioral, or emotional disorder

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Grant: Funding for this study was provided by the Royal University Hospital Foundation.

Disclosure: The authors have no relevant financial relationships to disclose.

Acknowledgment: The authors thank the participants and staff at the Irene and Leslie Dubé Centre for Mental Health; Jodi Scott and the participants and staff at the McKerracher Community Health Centre; and a special thanks to our patient partner on this project, Marie Green.

Received: July 26, 2021; Accepted: June 21, 2022

doi:10.3928/24748307-20221215-01

resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.” Examples include schizophrenia, bipolar disorder, major depression, major anxiety (panic disorder), post-traumatic stress disorder, borderline personality disorder, obsessive compulsive disorder, and other mental health disorders with concurrent suicidal ideation (Clausen et al., 2016; Mental Illness Policy Org., 2017). The prevalence of mental health illness is significant, with mental health and addictive disorders estimated to have affected more than 1 billion people globally in 2016 (Rehm & Shield, 2019). In 2017, there were an estimated 11.2 million adults age 18 years or older in the United States living with SPMI (De Hert et al., 2021). By 2019, that estimate had increased to 13.1 million, roughly 5.2% of all adults (NIMH, 2021). In any given year, 1 in 5 people in Canada (about 6.6 million people) will personally experience a mental health problem or illness, and by age 40 years, an estimated 50% of the entire population will have experienced some type and severity of mental illness (Mental Health Commission of Canada, 2013).

Many people living with SPMI experience physical health comorbidities, often chronic and mostly preventable (De Hert et al., 2021; Olfson et al., 2015; Walker et al., 2015). Depending on the nature and number of co-morbidities, people living with SPMI will live shorter lives, primarily due to physical illness with estimates ranging between a loss of 10 to 20 years (De Hert et al., 2011; Laursen et al., 2016; Olfson et al., 2015). Preventable diseases of the cardiovascular system, respiratory tract, and nutritional and metabolic systems are more prevalent among people living with SPMI (De Hert et al., 2011; Ewart et al., 2017). Data from a nationally representative U.S. sample (Lee et al., 2016) found that 15.1% of people with SPMI reported a diagnosis of diabetes mellitus (vs. 6.6% among people without SPMI); 31.8% reported a diagnosis of hypertension (vs. 17.6%); and 28.4% reported a diagnosis of chronic obstructive pulmonary disease (vs. 9%).

OBJECTIVES

The purpose of this exploratory study was to assess the HL strengths and needs of people living with SPMI in terms of their ability to acquire, understand, and use information about their illness and the health services they require. The authors expect the knowledge generated from this assessment will be used by stakeholders (e.g., patients, clinicians, managers) for the co-design of HL interventions in areas of identified weakness.

Because this is an exploratory paper on a subject we know little about, we chose not to develop a priori hypotheses, although we did assume we would see differences between our

participants and the general population when reviewing levels of HL and between in- and out-patients.

METHODS

This study was approved by the Saskatchewan Health Authority, and the Behavioural Research Ethics Board (Human Ethics) at the University of Saskatchewan (Beh-1399). Funding was provided by the Royal University Hospital Foundation.

DESIGN

The cross-sectional convergent mixed methods (quantitative and qualitative) design of this study (Fetters et al., 2013; Moseholm & Fetters, 2017) was guided by the Ophelia Access and Equity Framework (Batterham et al., 2014) and informed by a participatory approach that included input from experienced health care providers and engaged patient family advisors. HL can be optimized using approaches tailored to patient strengths and circumstances. The Ophelia Access and Equity Framework (Batterham et al., 2014; Beauchamp et al., 2017) is a rigorous, evidence-based, and systematic approach for identifying, implementing, and evaluating multidimensional HL interventions. The Ophelia approach is by nature broad and definitely includes social support and interface with the health care system. This model does not view HL as an individual attribute but recognizes the importance of both social supports and the health care system.

Quantitative and qualitative data were collected in parallel. The two sets of data were analyzed separately and then merged, with the qualitative data providing context and detail to the quantitative findings. There are six steps in the Ophelia process, with this article reporting the results from step 1 (needs assessment). Similar HL studies have also followed this staggered approach (Jessup et al., 2017; Jessup et al., 2018). Step 1 involved a cross-sectional survey, interviews, cluster analysis for grouping participants with similar HL profiles.

Setting and Sample

Participants diagnosed with SPMI were recruited from a community health center and an inpatient acute-care hospital service both located in Saskatoon, Saskatchewan. Staff at both centers include registered nurses, social workers, counselors, and physicians. People living in and around Saskatoon have access to a full range of health care services delivered by a modern and comparatively well-resourced public health system. Because of the COVID-19 (coronavirus disease 2019) pandemic and restrictions on in-person research mandated by the provincial health authority in Saskatchewan, the project was suspended in March 2020 after 16 weeks of data collection. At that point, the researchers had collected 66 questionnaires (88% of

goal) and interviewed 14 participants (93% of goal). Post-hoc analysis revealed no significant differences between participants (e.g., age, sex, education, employment, mental health diagnoses) regardless of recruiting site, and data was analyzed as a single cohort. This was not unexpected because a significant number of participants routinely access mental health services from both sites.

There was no formal power calculation conducted. In keeping with other exploratory projects adopting the Ophelia approach (e.g., Batterham et al., 2014), we aimed to obtain a diverse cross-section of individuals with mental health needs. The suggestion from Osborne's group (creators of the Ophelia Framework) is to aim for a sample size of approximately 100 when conducting these projects in a new population.

DATA COLLECTION

Instruments

The Health Literacy Questionnaire (HLQ) is a patient-reported outcome measure (Osborne et al., 2013). The HLQ maps the HL strengths of individuals and groups of individuals across nine domains (**Table 1**). Summary scores for each of the nine domains provide insight into respondents' HL strengths and limitations, and together create a HL profile of a population (Batterham et al., 2016). The HLQ has been used to guide the development of interventions addressing multidimensional HL needs (Beauchamp et al., 2017), the psychometric properties of the nine scales have shown robust construct validity and reliability (Osborne et al., 2013), and the HLQ has been validated for use across numerous settings (Beauchamp et al., 2015; Elsworth et al., 2016; Hawkins et al., 2017; Morris et al., 2017).

The WHO-5 (Topp et al., 2015) is a validated measure assessing mood, vitality, and quality of life, and was administered in-person, along with bespoke questionnaires that collected sociodemographic, perceived health status, and internet usage data at the time the HLQ questionnaire was completed. Sociodemographic data included: age, sex, educational attainment, support at home, current employment status, perceived sufficiency of income, living alone, language spoken at home and postal code. Health status data included: self-reported medical diagnoses, and self-rated health. Internet usage data focused on frequency of use and content of information. Participants received a \$20 gift card in recognition of their contribution.

Interviews

To increase the richness of data gathered about HL and the specific challenges faced by our participants, a semi-structured interview guide based on each of the nine subscales of the

HLQ was devised (**Table A**). Participants who completed the HLQ and sociodemographic questionnaires were eligible to participate, and a subset of 15 participants were recruited consecutively for interviews. Individual one-to-one interviews were conducted by AM in a private office located at both sites; each interview took approximately 30 minutes to complete. Audio recordings were professionally transcribed for ease of analysis. Participants received a \$20 gift card in recognition of their additional contribution.

DATA ANALYSIS

Health Literacy Questionnaire

HLQ scores were calculated using the licensed scoring algorithm programs provided by Deakin University, Australia. The algorithms produce unweighted scores for the domains, with a final score for each domain being an average across all items in that domain. Descriptive analysis (e.g., means or percentages) and comparisons (e.g., *t*-tests or chi-square tests) were conducted.

Interviews

Transcripts were professionally transcribed and uploaded into NVivo v.12. Transcripts were independently coded line-by-line by DG and reviewed by AM. Themes were identified from the codes and reviewed, with emerging themes compared in relation to the codes and entire data set, using an abductive approach guided by the nine dimensions of the Ophelia framework.

Hierarchical Cluster Analysis

Hierarchical cluster analysis (HCA) is an exploratory tool designed to reveal natural groupings (clusters) within a data set that would otherwise not be apparent. It is most useful when you want to cluster a small number (less than a few hundred) of objects (IBM, 2014). HCA was used to identify and group participants with similar HL scores across the nine HLQ domains into mutually exclusive groups. The method for choosing the number of clusters for analysis has been previously described (Batterham et al., 2014; IBM, 2014).

RESULTS

Demographic and Health Data

The final sample included 66 participants. Self-reported demographic and health data are reported in **Table 2**. The ages of participants ranged between 19 and 76 years, with one-third of participants younger than age 30 years. A slight majority of participants (51.5%) rated their mental health as either poor or fair, while 48.5% reported their mental health

TABLE 1
Mean HLQ Domain Scores and Exemplar Quotes (N = 66)

| HLQ Domains | Mean (SD, Median) |
|---|-------------------------------|
| <p>1. Feeling understood and supported by health care providers</p> <p>“Every time I see my family doctor, I ask her question and she always has time to answer and she doesn’t rush me from her office and I don’t feel that she’s too busy for me and she always asking me if I need anything or have a question or if I’m doing okay and is always checking on me.”</p> <p>“As long as you try and find someone that understands what you’re going through or listens to you and takes you seriously, then that’s really all that matters to me.”</p> <p>“My psychiatrist, my family doctor and my nurse, they’re my team, I work with them to help me out and wherever I need they help me, and I know where to go now. I’m not as scared to ask for help.”</p> | 3.19 (.62, 3.25) ^a |
| <p>2. Having sufficient information to manage my health</p> <p>“I just kept asking around and I have a friend who runs a group home and so she put me in contact with someone who is able to answer my questions as far as process. But it’s about being consistent. Just digging until you get what you need.”</p> <p>“Resources for rural people: it’s been fairly hard to get ahold of medical information before moving to Saskatoon, because of a lack of internet access and transportation. So, I was relying primarily, like you could find in the local library. That wasn’t much.”</p> | 2.78 (.58, 2.75) |
| <p>3. Actively managing my health</p> <p>“Age-appropriate resources: I’m a 51-year-old man and finding a lot of mental health groups are geared towards people who are younger, people geared towards addictions—I do not fit in that ballpark. I literally fall between the cracks of that and that’s one of my biggest struggles is finding a healthy situation.”</p> <p>“I’d say I would like to learn how to look up lab results. My doctor use to send them to me in the mail and I really, really liked that, seeing my lab results cause it’s easy to understand. They show you the numbers and what’s normal and what’s not normal. But I hear now you can go online and have no idea how to do that. I’d really like to learn that.”</p> | 2.87 (.64, 2.8) |
| <p>4. Social support for health</p> <p>“Friends and family, I don’t really chat with my family about my issues. For my mental health, my friends and family pretty much just let me make my own decisions—educated decisions.”</p> <p>“Friends or family, not too much. A little bit. Maybe once I’ve got the information and ideas, maybe I’ll discuss what they think. Get some feedback.”</p> <p>“I was kind of in a toxic family situation that kind of tried to deny that that was going on because it kept them safer if I didn’t know what was happening.”</p> <p>“With my sister, we do talk a lot about our depression, and it helps when you are not going through it alone. And she gives me insight on what’s worked for her, and I give her insight, so it helps.”</p> | 2.8 (.64, 2.8) |
| <p>5. Appraisal of health information</p> <p>“Sometimes I fall into the trap of doctor Google. Google is not always your friend. So, I mostly turn to people I trust, people that can kind of, you know, give me what I need. And knowing I have to go to certain society websites because those are more validated too because they have the research to go along with them, so I can’t just google and expect everything to be true cause it’s not.”</p> <p>“I don’t trust much of the information on the internet because there are good articles, there are things describing it, but it’s different for every person and so you can’t apply that information to every case. So, I really trust the peer-reviewed articles. Simply because they have been reviewed by medical professionals.”</p> <p>“Most cases I can make—I can understand it and make use of it, but I still have to double check it just to be safe. Same with YouTube and that—depends on what level of medical words they’re using, if they’re really up there it’s harder to understand, but if it’s visual—sometimes they put the words visual and their meanings so then I can understand it and know what to do with it.”</p> | 2.72 (.63, 2.6) ^b |

as either *good*, *very good*, or *excellent*. Most participants (53%) reported no physical health concerns. All participants are active online.

Health Literacy Questionnaire

Table 1 presents the HL scores from the HLQ for each of the nine conceptually distinct domains, along with exemplar

TABLE 1 (CONTINUED)

Mean HLQ Domain Scores and Exemplar Quotes (N = 66)

| HLQ Domains | Mean (SD, Median) |
|--|-------------------------------------|
| <p>6. Ability to engage with healthcare providers</p> <p>“Staff. They need more people. If you are waiting months. Two weeks ago, I set up an appointment and I can’t get in until the end of January. Well at the time I set the appointment up, we were in a pretty big crisis, and I didn’t know where else to get the information or where to get support from. I think the services, I think the volume of people going through the system at McKerracher, both clients and family members, and they’re really strapped. There’s not enough of them to be able to meet the needs that are out there.”</p> <p>“More centers like this. I think the government needs to support these centers a lot more because there is a tremendous need for them. And I know health care dollars are scarce, but this is, to me, mental health is an epidemic. It has a big impact on being employed and being employable. Just saving lives. It has, I know, saved my life and I believe it has saved other lives and I think we need more, not less.”</p> | <p>3.48 (.78, 3.6)</p> |
| <p>7. Navigating the health care system</p> <p>“Navigating the psych world, I did have trouble navigating it but over the years I gradually learned how to do it. Part of that was just talking to other friends of mine who are also patients. So, I just gradually picked it up on my own.”</p> <p>“I find one of the challenges is that I didn’t know about the center and the only reason I found out about it was because of the poster on the board. It wasn’t explained to me all the services that are available and accessible in the city. I had asked to be referred to a dietician a few weeks ago and I was told that wasn’t possible, I would have to go to my family doctor and get a referral that way. I ended up getting the referral but I kind of had to jump through some hoops and nobody knew who could do what.”</p> <p>“When I went to Mental Health and Addictions, the addiction that I need to deal with, they don’t have an up-to-date list of all meetings in the city. So that would be helpful or even just a 12 step for AA (Alcoholics Anonymous) if they handed that out and just say these are the other options in the city. But yeah, having an updated list is very, very helpful if they would have that.”</p> | <p>3.29 (.79, 3.17)^c</p> |
| <p>8. Ability to find good health information</p> <p>“I go for information, usually first my doctor or a counsellor first. Or I go on to the internet. Usually places like Mayo Clinic I go to. So that’s where I tend to get my information. Having a system where you can figure out if a source is reliable easily right off the bat cause it sometimes it’s difficult to figure out if a source is reliable. And if the information you are getting is good. If it’s not from a top name brand like Mayo Clinic, you’re not gonna know necessarily if what you’re reading is true so I’d just say making reliable sources more readily accessible. And maybe journals and documents, that kind of stuff.”</p> <p>“So I use a lot of google and Med Web, WebMD website or the Saskatoon Health Region Website where I can find a lot of other resources also. When I access information on the internet, it’s usually on a level that I can understand. If not, I have a dictionary close by.”</p> <p>“Well, it depends sometimes how it’s written. If it’s written too technical then it’s a little bit tougher for me to understand it. But if it’s written more of an easier level, because sometimes medical things are written way up in medical literature that you don’t understand it, but most cases I can make – I can understand it and make use of it. Most times I’ll find like either YouTube videos that are fairly easy to understand or if I’m talking to a doctor, they’ll explain it in a way that’s easier to understand. But of course, there are always things out there that are maybe more complicated but there’s always a way to find something that you’ll understand.”</p> <p>“I’m not very technically literate. I know my basics on a computer, but sometimes getting onto a website and finding information is too hard. So having access to a phone on internet and a laptop with internet, getting into websites is okay, but navigating through them can become difficult when you don’t understand some of the language or it send you off to a different path.”</p> | <p>3.5 (.73, 3.5)</p> |

quotes from the interviews. Across domains 1-5, domain 1, feeling understood and supported by health care providers, received the highest mean HLQ score (3.19) while domain 5, appraisal of health information, received the lowest (2.72).

Across domains 6-9, domain 9, understand health information well enough to know what to do, received the highest mean HLQ score (3.63) while domain 7, navigating the health care system, received the lowest (3.29).

TABLE 1 (CONTINUED)

Mean HLQ Domain Scores and Exemplar Quotes (N = 66)

| HLQ Domains | Mean (SD, Median) |
|--|------------------------------------|
| <p>9. Understand health information well enough to know what to do</p> <p>“When somebody told me the information I can if it’s reading or writing I can’t because I don’t know how to read very well. But my family doctor, what she does is, she explains to me when somebody sends her a letter about me, she explains to me what it’s about and stuff like that. So, for me, reading I do have a bit of a reading disability where I don’t remember everything I read and I do find big words are really hard and I do get frustrated when it’s words you don’t know or words you have to constantly look up.”</p> <p>“The information I read if it’s on the internet, no most of it is above my head, over my head, that I don’t quite understand it. And on the internet a lot of times, there’s just far too much and I kind of get lost in it all and... but mostly it’s a little bit over my head, yeah for sure.”</p> <p>“When I get information about my meds especially or—especially about my meds, I really wish they would talk to me at my level instead of at a pharmaceutical level because there’s terms I don’t understand when it’s a simple question like what does this medication do for me compared to another medication? I get the pharmacology part of it where I completely don’t understand. It would be really helpful for me if I were to be talked to like a 10-year-old in the language I can understand instead of someone who has been trained in the medical field.”</p> | <p>3.63 (.86, 3.8)^d</p> |

Note. HLQ = Health Literacy Questionnaire. Domains 1-5, Likert scale 1-4: 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree. Domains 6-9, Likert scale 1-5: 1 = cannot do or usually difficult, 2 = very difficult, 3 = quite difficult, 4 = easy, 5 = very easy.

^aHighest (domains 1-5).

^bLowest (domains 1-5).

^cLowest (domains 6-9).

^dHighest (domains 6-9).

Cluster Solution

HCA of the survey data (specifically the nine HLQ conceptual domains) was performed using Ward’s method for linkage and squared Euclidean distance interval measurements using SPSS Version 26. Based on the resulting dendrogram, agglomeration schedule, and a best-practice guideline minimizing the standard deviation (Cheng et al., 2020) within clusters (ideally <0.60), 8 clusters were chosen to analyze (Table B).

Table 3 presents a summary of the key information from Table B and compares health and demographic contextual data against the nine HLQ conceptual domains by cluster. Specific contextual data was chosen because of the heterogeneity observed between clusters, meaning that an analysis comparing HLQ domain scores against this data might reveal interesting patterns and consistencies within the datasets. Mean age, gender, highest level of education attained, employment status, co-habitation, family support, and use of the internet did not vary significantly between clusters and was excluded.

DISCUSSION

Health Literacy Questionnaire

Our findings indicate that for this sample of people living with SPMI participants struggled most with the appraisal of

health information and navigating what they often perceive to be a confusing health care system lacking coordination of care. On the other hand, most participants reported positive experiences with their health care providers and generally feel understood and supported. Research on HL can be difficult to compare because of the heterogeneity of assessments used. Currently, there is no gold standard among HL assessment instruments, each having their own pros and cons. Instruments used to measure HL in the few previous studies conducted with SPMI populations include: the Single Item Literacy Screener (Clausen et al., 2016), the Rapid Assessment of Adult Literacy in Medicine (Krishnan et al., 2012; Farrell et al., 2020), the Rapid Assessment of Adult Literacy in Medicine – Short Form (Clausen et al., 2016), the Newest Vital Sign (Clausen et al., 2016), and the Lipkus Numeracy Scale and the Woodcock-Johnson-III (Tests 4 and 9) (Lincoln et al., 2021). As in this study, Degan et al. (2019) used the HLQ instrument (Osborne et al., 2013) for assessing HL.

Because of the heterogeneity in methodologies, instruments, and analysis across these studies it is difficult to directly compare results. Nevertheless, all studies (Clausen et al., 2016; Degan et al., 2019; Farrell et al., 2020; Krishan et al., 2012; Lincoln et al., 2021) reported lower levels of HL in people living with SPMI. Intriguingly, the only other similar

study to use the HLQ (Degan et al., 2019) reported identical findings for the highest and lowest HLQ scores. As in this study, feeling understood and supported by health care providers and understand health information well enough to know what to do reported the highest mean HLQ scores, while appraisal of health information and navigating the health care system both reported the lowest.

Hierarchical Cluster Analysis

Categorizing the HL of patients based only on a shared diagnosis may not be useful for identifying the HL strengths and needs of individuals within a group. The results of the cluster analysis strongly suggest that we should not view people living with SPMI as a homogeneous group in the context of a HL strengths and needs assessment, meaning a one-size-fits-all solution for improving HL in this group will likely not be a successful strategy. Degan et al. (2019) argued that the ability to identify and group participants by their unique HL strengths and weaknesses creates an opportunity to direct efforts toward those individuals who need the most help. They used Latent Profile Analysis, a technique similar to HCA, to create clusters of participants with varying levels of HL. The authors went on to argue that health care services should use this type of information to tailor programs and interventions that meet their service users' specific needs, and that HL scores alone can be of limited value to clinicians and decision makers (Degan et al., 2019).

Based on other similar research, we expected to see positive relationships between higher HLQ domain scores and: a lower number of psychiatric diagnoses, higher self-reported mental health, a higher WHO-5 score, and income sufficient to meet needs. For the most part this relationship was observed (Table 3). Participants in cluster 1 scored high across all nine HLQ domains and reported the lowest number of psychiatric diagnoses, high levels of self-reported mental health, the highest WHO-5 score among clusters, and household income sufficient to meet their needs. At the other end of the spectrum, participants in cluster 5 scored low or very low across all nine HLQ conceptual domains and reported a high number of psychiatric diagnoses, the lowest levels of self-reported mental health, below average WHO-5 scores, and household income insufficient to meet their needs. Patterns observed among the other clusters were mixed, but generally fit with our hypothesis (e.g., cluster 4), though not consistently in all cases (e.g., cluster 2).

Further research is needed, but taken together these results suggest that HLQ scores, number of psychiatric diagnoses, self-reported mental health, WHO-5 score, and sufficient income can provide important information useful for a holistic assessment of HL.

TABLE 2
Participant Demographic and Health Characteristics (N = 66)

| Characteristic | n (%) |
|---|-----------|
| Self-identified as female | 41 (62) |
| Completed high school or some postsecondary education | 46 (78) |
| Work for pay | 18 (27.3) |
| Living arrangements | |
| Alone | 32 (54.2) |
| With family/friends | 23 (39) |
| Group or care home | 4 (6.1) |
| Family they can count on to help with problems | 51 (77.3) |
| Sufficient income to meet their needs | 26 (39.4) |
| Internet usage | |
| At least once/week | 66 (100) |
| More than once/week | 47 (71.2) |
| Purpose | |
| Social media | 40 (60.6) |
| Health and wellness | 29 (43.9) |
| Sports and leisure | 14 (21.2) |
| General information | 45 (68.2) |
| Anxiety | 39 (59.1) |
| Depression | 38 (57.6) |
| Bipolar | 10 (15.2) |
| PTSD | 9 (13.6) |
| ADHD | 7 (10.6) |
| OCD | 6 (9.1) |
| Schizophrenia | 3 (4.5) |
| Substance misuse | 2 (3.0) |
| Asperger | 1 (1.5) |
| Other | 22 (33.3) |
| Arthritis | 8 (12.1) |
| Diabetes | 6 (9.1) |
| Cardiovascular | 3 (4.5) |
| Chronic pain | 3 (4.5) |
| Cancer | 2 (3.0) |
| Sleep apnea | 2 (3.0) |
| Fibromyalgia | 1 (1.5) |
| Parkinson's | 1 (1.5) |
| Osteoporosis | 0 (0) |
| Other | 17 (25.8) |
| None reported | 35 (53.0) |

Note. ADHD = attention-deficit/hyperactivity disorder; OCD = obsessive-compulsive disorder; PTSD = post-traumatic stress disorder.

INTERVIEWS

Themes emerged from the interview data: sufficient information is usually accessible, but is often only found with persistence; systemic barriers often limit a person's ability to

TABLE 3

Hierarchical Cluster Analysis /Demographic and Health Characteristics Analysis (N = 66)

| Cluster | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
|----------------------------------|---------|---------|---------------|---------------|---------------|---------------|---------|--------|
| Number of psychiatric diagnoses | Lowest | Highest | Average | Average | High | Low | Average | High |
| Self-reported mental health | High | Low | Highest | High | Lowest | Average | Lowest | Lowest |
| WHO-5 Score | Highest | Low | Above average | Above average | Below average | Above average | Average | Lowest |
| Income sufficient to meet needs | Yes | No | No | Yes | No | No | No | No |
| HLQ domains | | | | | | | | |
| Health provider support | High | Mod | Mod | High | Low | Mod | V. Low | Low |
| Having sufficient information | High | Low | Mod | Low | Low | Low | Low | Low |
| Actively managing health | High | Mod | Mod | Low | V. Low | Low | Mod | Low |
| Social support for health | High | Low | Mod | Mod | Low | Low | V. Low | Low |
| Appraisal of health information | High | Mod | Low | Low | V. Low | Low | Mod | Low |
| Active engagement | High | Mod | High | High | Low | Mod | Low | Mod |
| Navigating the health system | High | Low | Mod | High | V. Low | Mod | Low | Mod |
| Finding health information | High | High | High | High | Low | Low | High | Mod |
| Understanding health information | High | High | High | High | V. Low | Low | High | High |

Note. HLQ = Health Literacy Questionnaire; Mod = moderate; V. Low = Very Low; WHO = World Health Organization.

actively manage their health; levels of social support are often mixed, with some participants receiving very limited social support (especially from friends or family); most people generally trust their health care providers, they like to appraise information using a variety of sources, and participants were generally skeptical of online sources of health information (but usually know where to search for information they can trust); limited system resources limit engagement with providers; health information written for the lay-person is important; and less technical-medical jargon, more plain language will improve their understanding. Because this study is the only one in this area to use a mixed methods design and

collect qualitative data, we are unable to compare these findings with similar research.

STRENGTHS AND LIMITATIONS

This study is the first to use a mixed methods research design in this context, and the first to include HCA in the data analysis. This approach (Jessup et al., 2018) was well suited for achieving our research objective of assessing the HL strengths and needs of people living with SPMI and informing the next stage in the Ophelia model process, the co-design of targeted HL interventions. Using a mixed methods design meant we could bring together data from a variety of

sources, allowing us to uncover latent patterns and themes, and allowing for the use of novel analysis techniques.

However, this study was limited by a relatively small sample size and the nature of the HLQ as a participant self-reported measure could reflect inflated or deflated views of personal competency. People living with SPMI will experience times when they are more or less likely to participate in research studies. Some might never agree, and their perspectives could be under-represented. Participants in this study may have been especially engaged in their care, meaning that the results may be transferable, but not generalizable to others living with SPMI.

HCA is a technique that clusters individuals into different groups based on shared attributes. This could mean we are limiting opportunities for better understanding any similarities that might exist between those groups. In addition, there is some subjectivity inherent to HCA when choosing the number of clusters and choosing a greater or lesser number might influence the generalizability of the results. However, because this is an exploratory analysis, use of cluster analysis can provide some direction about the possible clusters in the sample. These potential clusters can then be used as a basis for subsequent projects.

CONCLUSION

This study is one of only a handful assessing the HL strengths and needs of people living with SPMI. This study has demonstrated both the feasibility and value of jointly collecting qualitative and quantitative data for assessing the HL strengths and needs of people living with SPMI.

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Table A

Participant Interview Guide

Thank you for agreeing to speak with me today. We are interested in finding out more about how people obtain, understand, and use information to make decisions about their health and healthcare. This is called health literacy. Understanding your journey as a patient will help us to better understand the things that help or hinder patients from obtaining, understanding, and using information about their health and healthcare.

Domain 1: Actively managing health

Q1. Could you please begin by telling me about your condition? What has led you to use the services provided in this clinic (unit)?

Probes: nature and duration of illness (mental health condition), symptoms, and other causes of distress, previous hospitalizations, previous interactions with healthcare providers, ability to self-manage condition, desire to actively manage own health.

Domain 2: Having sufficient information to manage health

Q2. As a patient who is making use of the services provided here, what are the types of information that you feel are most important to you right now? In what ways would this information be helpful to you? What are the questions or concerns that are still not answered to your satisfaction?

Probes: managing symptoms, medications, treatments.

Domain 3: Capacity to navigate the healthcare system

Q3. Have you experienced any difficulties in understanding where to go in the healthcare system to find the information you needed? If yes, what were the difficulties?

Domain 4: Ability to find good health information

Q4a. Do you feel that you have been able to access all of the important information you need to make decisions about your health and healthcare?

Q4b. What resources have you used to try to obtain the information you need?

Probes: healthcare providers, internet sources, written material, friends or family, others.

Domain 5: Ability to engage with healthcare providers

Q5. Sometimes patients find it difficult to talk to their healthcare providers. What has been your experience in communicating with the healthcare providers in this clinic (unit)?

Domain 6: Feeling understood and supported by healthcare providers

Q6. Patients don't always feel understood and supported by their healthcare providers when looking for information related to their health. What has been your own experience in this clinic (unit)? Outside of the clinic (unit)?

Domain 7: Appraisal of health information

Q7. Would you say that you trust the information you receive from (healthcare providers, the internet, written materials, friends or family, other sources)? Are there some sources of information that are more trust-worthy than others? What makes you say that?

Domain 8: Sufficient understanding of health information

Q8. When you access information, do you feel that you can easily understand and use this information to make decisions about your health and healthcare?

Domain 9: Social support for health

Q9. Patients and their friends and families are often partners when making decisions about their health and healthcare. What role does your family (or friends) play in searching for information related to your health condition? If family (or friends) do play a role, how does the healthcare team ensure that both you and your family (or friends) receive the information you need most?

Wrap-up

Q10. Finally, is there anything else that you would like to tell me about the ways in which you obtain, understand, and use health information to make the best health and healthcare decisions?

Q11. What recommendations do you have for the healthcare system that would make it easier to obtain, understand, and use health information related to your health condition?

| | | | | | | | | |
|--|------------------------|-----------------------|------------------------|------------------------|--------------------------|-----------------------|--------------------------|-----------------------|
| 1. Health Provider Support (Mean, SD) | 3.79 (0.28) High | 3.0 (0.25) Mod | 3.53 (0.29) Mod | 3.8 (0.22) High | 2.94 (0.67) Low | 3.01 (0.51) Mod | 1.92 (0.31) V. Low | 2.82 (0.4) Low |
| 2. Having Sufficient Information (Mean, SD) | 3.71 (0.28) High | 2.71 (0.37) Low | 3.09 (0.37) Mod | 2.95 (0.38) Low | 2.00 (0.53) Low | 2.75 (0.26) Low | 2.25 (0.35) Low | 2.32 (0.48) Low |
| 3. Actively Managing Health (Mean, SD) | 3.74 (0.28) High | 3.0 (0.2) Mod | 3.5 (0.39) Mod | 2.74 (0.55) Low | 1.7 (0.46) V. Low | 2.8 (0.25) Low | 3.13 (0.41) Mod | 2.38 (0.45) Low |
| 4. Social Support for Health (Mean, SD) | 3.89 (0.15) High | 2.67 (0.34) Low | 3.05 (0.3) Mod | 3.18 (0.42) Mod | 2.8 (0.51) Low | 2.55 (0.41) Low | 1.87 (0.19) V. Low | 2.24 (0.45) Low |
| 5. Appraisal of Health Information (Mean, SD) | 3.6 (0.47) High | 3.2 (0.2) Mod | 2.95 (0.26) Low | 2.64 (0.72) Low | 1.95 (0.3) V. Low | 2.52 (0.41) Low | 3.0 (0.16) Mod | 2.33 (0.48) Low |
| 6. Active Engagement (Mean, SD) | 4.69 (0.34) High | 3.07 (0.32) Mod | 3.65 (0.36) High | 4.04 (0.38) High | 2.50 (0.61) Low | 3.33 (0.61) Mod | 2.0 (0.34) Low | 3.27 (0.46) Mod |
| 7. Navigating the Health System (Mean, SD) | 4.69 (0.26) High | 2.72 (0.27) Low | 3.35 (0.39) Mod | 3.95 (0.37) High | 1.8 (0.22) V. Low | 3.05 (0.28) Mod | 2.39 (0.34) Low | 3.23 (0.5) Mod |
| 8. Finding Health Information (Mean, SD) | 4.31 (0.6) High | 3.9 (0.4) High | 3.95 (0.46) High | 3.96 (0.69) High | 2.4 (0.58) Low | 2.98 (0.24) Low | 3.67 (0.25) High | 3.33 (0.5) Mod |
| 9. Understanding Health Information (Mean, SD) | 4.6 (0.47) High | 4.2 (0.26) High | 3.85 (0.37) High | 4.06 (0.69) High | 1.65 (0.58) V. Low | 2.87 (0.24) Low | 3.87 (0.25) High | 3.98 (0.5) High |