

What Are the Personal Recovery Needs of Community-Dwelling Individuals with Mental Illness? Preliminary Findings from the Canadian Personal Recovery Outcome Measurement (C-PROM) Study

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ABSTRACT

Personal recovery is an overarching goal that underpins mental health community support and clinical services in Canada. Surprisingly, little information is available about the personal recovery needs of community-dwelling Canadians with mental illness. The purpose of this study is to describe these needs in a sample of adults living in a large urban centre. We performed a multi-site cross-sectional survey of adults who receive community-based mental health services in an urban setting. Participants were asked to complete six patient-reported outcome (PRO) measures about personal recovery, hope, mastery, and depression. We used descriptive and correlational analyses to summarize the data according to an established evidence-based theoretical conceptualization of recovery. Two hundred and twenty-eight individuals participated in the study. Participants indicated high levels of self-reported empowerment and hope and optimism about the future. In contrast, participants reported low levels of perceived connectedness, identity, and meaning in life. In conclusion, this study identified that recovery-oriented PRO measures can improve our understanding of the needs and goals of individuals with mental illness and highlight the ways in which individuals can achieve a sense of meaning in life. Understanding the recovery needs of Canadians with mental illness may help foster recovery-oriented healthcare by bringing person-centred approaches to the point of treatment, so as to ensure greater quality and accountability of mental health services.

Keywords: mental health, community health, recovery, patient-reported outcome

RÉSUMÉ

Le rétablissement personnel est un objectif prioritaire qui sous-tend les services communautaires de soutien en santé mentale et les services cliniques au Canada. Étonnamment, on dispose de peu d'information sur les besoins en matière de rétablissement personnel des Canadiens atteints de troubles mentaux qui vivent dans la collectivité. L'objectif de la présente étude est de décrire ces besoins à l'aide d'une enquête réalisée auprès d'un échantillon d'adultes vivant dans une grande agglomération urbaine. Nous avons réalisé une enquête transversale multisite auprès d'adultes recevant des services communautaires de santé mentale en milieu urbain. On a demandé aux participants de remplir six rapports d'état de santé évaluant le rétablissement personnel, l'espoir, la maîtrise de soi et la dépression. Nous avons eu recours à des analyses descriptives et corrélationnelles pour résumer les données recueillies, et ce, suivant une conceptualisation théorique fondée sur des données factuelles de rétablissement. Deux cent vingt-huit individus ont participé à l'étude. Les participants ont fait état de niveaux élevés d'autonomisation autodéclarée et exprimé de l'espoir et de l'optimisme pour l'avenir. À l'inverse, les participants ont fait état de faibles niveaux de perception d'affiliation, d'identité et du sens de la vie. En conclusion, la présente étude a permis de révéler que les rapports d'état de santé spécifiquement axés sur le rétablissement du patient peuvent améliorer notre compréhension des besoins et des aspirations des personnes atteintes de troubles mentaux et mettre en lumière les façons pour les individus de donner un sens à leur vie. La compréhension des besoins de rétablissement des Canadiens atteints de troubles mentaux peut contribuer à la mise en place de services en santé orientés vers le rétablissement du patient en favorisant l'adoption d'approches centrées sur la personne dans les lieux de traitement dans le but d'assurer une meilleure qualité et une plus grande responsabilité dans les services de santé mentale couramment prodigués.

Mots clés : santé mentale, santé communautaire, rétablissement du patient, résultat rapporté par le patient

BACKGROUND

Mental illness affects 450 million people and is the leading cause of mortality, ill-health and disability worldwide (Walker, McGee, & Druss, 2015; World Health Organization, 2013). Mental illness has been associated with a shortened lifespan, with estimates of individuals living 10 to 25 five years fewer than people without a mental health condition (Colton & Manderscheid, 2006). The profound disparity in life expectancy is striking and systemically costly. In the next 20 years, the global economic impact of mental illness is expected to reach US\$16.3 trillion (World Economic Forum: the Harvard School of Public Health, 2011; World Health Organization, 2013). In Canada alone, one in five individuals experiences mental illness and mental health problems each year, and the annual cost to taxpayers is approximately \$51 billion. Individuals with mental illness are more likely than people without to be unemployed (Poremski, Whitley, & Latimer, 2014), homeless (S. P. Barbic et al. 2018; Forchuk, Dickins, & Corring, 2016), experience poverty (Forchuk et al., 2016; Kulik, Gaetz, Crowe, & Ford-Jones, 2011), and report poor quality of life (J. Browne et al., 2017; Mechanic, McAlpine, Rosenfield, & Davis, 1994). The growing personal, social, and economic impacts of mental illness highlight that new approaches to mental healthcare are needed. One of the most promising new perspectives emphasizes a model of care that is based on *recovery* in addition to treatment.

In 2013, the World Health Organization (WHO) released its first global Mental Health Action Plan, stressing that:

People with mental disorders are able to exercise the full range of human rights and access high-quality, culturally appropriate health and social care in a timely way to promote recovery. (World Health Organization, 2013)

Recovery is defined as “a way of living a satisfying, hopeful, and contributing life, even with the limitations caused by illness” (Anthony, 1993). This outcome and philosophy of care has become an overarching goal for global mental health services and a primary objective of systems reform (Department of Health and Human Services, 2003; The Mental Health Commission of Canada, 2012). However, “recovery” as a social justice movement has been criticized for “unintentionally co-opting and mainstreaming the more radical goals of earlier activist consumer movements” (Hunt & Resnick, 2015). It has also been criticized for its subjectivity, difficulty to operationalize into an evidence-based model of service delivery (Kidd, McKenzie, & Virdee, 2014; MacMillan, 2014; Slade et al., 2014), and demonstrate outcomes beyond qualitative assessments to describe the construct (Davidson, Schmutte, Dinezeo, & Andres-Hyman, 2008; Davidson, Sells, Songster, & O’Connell, 2005; O’Connell, Tondora, Croog, Evans, & Davidson, 2005). Nevertheless, beyond the criticism, service organizations across the globe continue to face increasing pressure to articulate how the outcomes of their interventions/services align with a recovery-oriented framework (Kidd et al., 2010; Kidd et al., 2014; Slade et al., 2014). One of the main reasons for this persistence is the overall health movement towards patient-oriented care (S. P. Barbic, Cano, & Mathias, 2018; S. J. Cano, Pendrill, S. P., & Fisher Jr., 2018; Kirwan et al., 2017; Marshall, Haywood, & Fitzpatrick, 2006).

Patient-centred care has long been a core value of recovery. However, in most health fields it has not been a mainstream idea in research, clinical practice, or education (Browne, Cano, & Smith, 2017). At this time, there is increasing interest in understanding the needs and priorities of patients and transforming all healthcare into a more person-centred model (S. Cano, Vosk, Pendrill, & Stenner, 2016; S. J. Cano et al.,

2018; Pendrill, 2014). It can be argued that the recovery movement has been at the forefront of patient-centred care (Hunt & Resnick, 2015). One limitation to date is the lack of routine collection of recovery data to be used to improve health outcomes and quality of life of patients. But the outlook is promising. Efforts to advance the science of recovery measurement are underway (Keetharuth et al., 2018; Shanks et al., 2013; Slade et al., 2014; Thornicroft & Slade, 2014; Williams et al., 2012). For example, due to advances in the field of psychometrics, constructs that are not directly observable (such as recovery), can be robustly captured using patient reported outcome measures (PROs; S. Barbic, Kidd, & McKenzie, Under Review; Corrigan, Salzer, & Ralph, 2004; Salyers, Godfrey, Mueser, & Labriolo, 2007; Shanks et al., 2013; Williams et al., 2012). In psychiatry, as well as other areas of psychosocial rehabilitation, PROs play an increasingly important role in the assessment of subjective outcomes that cannot be directly observed. PROs can inform fundamental decisions in clinical practice, health policy, and treatment (S. P. Barbic & Cano, 2016; S. P. Barbic, Kidd, Davidson, McKenzie, & O'Connell, 2015; Brundage, Blazeby, & Revicki, 2012; S. J. Cano, Barrett, Zajicek, & Hobart, 2011; Gnanasakthy et al., 2012; Hobart, Cano, Zajicek, & Thompson, 2007). Yet, it has been highlighted recently that PROs are not being used to their full potential in modern healthcare policy decision-making and evidence-informed practice. For example, recently it has been estimated that only 11% of existing PROs have been developed based on patient-priorities (Wiering, de Boer, & Delnoij, 2017). In a recent editorial Coulter (2017) notes:

Multi-purpose applications of [PROs]—using them in individual clinical care and aggregating the data for performance assessment—remains largely aspirational at present... (Coulter, 2017)

Recovery PROs have the potential to provide valuable information about how a person is progressing in their journey. Most recovery PROs have been developed with significant investment from people with lived experience to develop and test the items. As Hunt and Resnick (2015) note:

If mental health professionals instead adopted the language and goals of patient-centered care as a first step toward joining the two movements [recovery and biomedical], the recovery movement could reclaim its social justice roots, and progress would be made toward reducing the duality between physical and mental health care systems. Professionals should return the recovery movement to those with lived experience, adopt the unified language of patient-centered care, and align professional transformation efforts under one holistic movement. (p.1235)

The information generated from recovery-oriented assessment can be used to develop and monitor care to ensure it aligns with the needs of patients. Understanding the recovery needs of Canadians is important to foster evidence-informed healthcare by bringing person-centred therapeutic approaches to the point of care (Canadian Institutes for Health Research, 2016). As a result, the purpose of this study is to describe the personal recovery needs of community-dwelling adults with mental illness using recovery-oriented PROs.

METHODS

Design

This paper reports on Phase 1 of the *Canadian Personal Recovery Outcome Measurement (C-PROM)* study wherein we performed a cross-sectional assessment of recovery in one Canadian urban centre. The overall objective of the C-PROM study is to develop a conceptual and measurement model for personal

recovery, as it is defined by Canadians. The other phases of the C-PROM study include (i) a cross-sectional recovery assessment of community-dwelling individuals with psychiatric disabilities in three provinces, (ii) a psychometric evaluation of measures used in the cross-sectional assessment, (iii) qualitative interviews with clinicians and people with psychiatric disabilities, and (iv) the development and testing of a clinical outcome assessment for personal recovery. The results of these later phases will be reported elsewhere.

Setting and Participants

Data were collected in the spring of 2014 in the greater Toronto region, Canada's largest city with a population of 6.4 million people. Our study received approval from the institutional ethics board at the Centre for Addiction and Mental Health (CAMH).

Selection Criteria and Survey Sample

We recruited adults aged 18 years and older who were receiving community outpatient services from one of six community-based outpatient clinics and outreach services. Advertisements were placed at recruitment sites, outlining dates that our research team would be present to provide information about the study. Interested individuals met with a trained researcher to review study objectives and provide written consent. We gave questionnaire packets to individuals who agreed to participate in the study and remunerated participants for their time. Our target sample size for Phase 1 of the C-PROM study was 200.

Measures

Using a structured form, research staff collected information on participant sociodemographic characteristics, diagnoses, and employment history. Participants filled in the six PROs described in Table 1. The first three PROs measure personal recovery, whereas the three other PROs measure hope, mastery, and depression. The latter three PROs were administered to gain more detailed information about domains of recovery and, later, to test concurrent and divergent validity for psychometric purposes in Phase 2. At five of the six recruitment sites, a researcher read questionnaire items aloud to each participant and recorded his/her response. In order to test the feasibility of participants filling in the questionnaires independently, those at the sixth site completed packets on their own.

Statistical Analysis

We performed independent-sample t-tests and chi-square goodness-of-fit tests to compare the socio-demographic characteristics of participants. We used Levene's test for equality of variances and corrected for any violated assumptions. We inspected all data for missing values. Specifically, we noted the number of participants who were unable to complete the full questionnaire packet. We also noted the number of times specific items were skipped or missed. We compared the recovery scores of participants who completed questionnaires independently to those who had the questions read to them using independent t-tests using a Bonferroni correction for multiple comparisons adjusting the significance threshold to $p \leq 0.008$. Due to violations of normality, we compared total scores on the recovery PRO measures with Spearman rank-order

Table I
Summary of the Rating Scales Used in the Personal Recovery Study

PRO*	Abbr	Description
Recovery		
The Questionnaire about the Process of Recovery	QPR	The QPR is a 22-item self-report questionnaire scored on a 5-point Likert Scale (1 = strongly disagree, 5 = strongly agree). The QPR possesses internal consistency, construct validity and reliability.(Neil et al., 2009). Scale divided into “intrapersonal” (17-items, range 0–68) and “interpersonal” (5 items, range 0–20) subscales, with higher scores indicating increased recovery on both subscales.
The Recovery Assessment Scale	RAS	The RAS is a self-report instrument with 41 items scored on a 5-point Likert scale. Respondents report the degree to which they agree (e.g., 1 = strongly disagree, 5 = strongly agree) with each statement. Satisfactory test–retest reliability ($\alpha = .88$) and internal consistency (Cronbach’s $\alpha = .93$) have been reported (Corrigan et al., 2004).
The Illness Management and Recovery Scale	IMR	The IMR is a 13-item self-report measure of self-management and pursuit of recovery goals. Each item has a unique response set. The IMR has adequate internal reliability ($\alpha = .72$) and good test-re-test reliability ($\alpha = .81$; Salyers et al., 2007).
Other		
Centre for Epidemiologic Studies Depression Scale	CES-D	Commonly used 20-item, short, self-report scale to measure depressive symptoms in the general population. Scale known to have very high internal consistency and adequate test-retest repeatability.(Cole, Rabin, Smith, & Kaufman, 2004; Covic, Pallant, Conaghan, & Tennant, 2007; Radloff, 1977).
Herth Hope Index	HHI	12-item, 5-point Likert scale. Found to have good scale reliability (α) of 0.75–0.94; test-retest reliability (3 weeks) ranged between 0.89 and 0.91; and a negative correlation to Becks’s Hopelessness Scale (Herth, 1992).
Self-Mastery Scale	MS	7-item instrument that assesses the extent to which a person generally feels as though he or she possesses mastery over life outcomes. Although this is the most commonly cited measure of self-mastery for people with serious mental illness, the scale does not have available psychometrics to support its use (Pearlin & Schooler, 1978).

* PRO = Patient Reported Outcome

Source: Authors’ compilation.

correlations. We tested correlations between the total scores of each recovery PRO measure, and between the three additional scales (depression, mastery, and hope).

To organize the information collected about personal recovery from different scales, we used the CHIME (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011) framework, which outlines five recovery-related processes: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment. We identified items from our pool of PROs that captured each process/domain. Based on previous applications of this conceptual framework for clinical purposes, we selected items that captured each domain of the CHIME framework. Items in each PRO were coded by six experts in the field, including two clinicians and four service users. Consensus was reached using a Delphi technique to agree upon a set of items that could capture each subcomponent of the CHIME framework (80% agreement). For each item, we reported the frequencies of responses.

RESULTS

Sample Flow and Characteristics

We invited 265 potential participants across the six sites over three weeks. Individuals were those who were attending regular appointments with health professionals or attending day programs. Of the 265 individuals approached, 250 were eligible for the study and 228 (86%) volunteered to complete the questionnaire package. Table 2 shows the sociodemographic characteristics of participants. Participants included 116 males and 112 females, with a mean age of 45.8 years (standard deviation = 12.5). One hundred and thirty-five participants (59%) reported having a primary diagnosis of schizophrenia, 56 reported a depressive disorder (25%), 24 reported bipolar disorder (11%), and 13 (6%) reported another primary diagnosis (e.g., anxiety, borderline personality disorder, obsessive compulsive disorder, post-traumatic stress disorder). Participants had been born in 41 different countries, with nearly half (48%) born outside of Canada. No differences were noted between demographic characteristics of participants reporting different diagnoses or receiving care from the different centres in terms of sex, education (dichotomized to *<high school* and *other*), or ethnicity (dichotomized to *white Canadian/other*).

We found that 224 (98%) participants completed the full questionnaire packet (115 items). Thirty participants completed the packet independently, and all of these participants completed the full questionnaire pack with no missing data. These participants did not significantly differ from those who had questions read to them in terms of their demographic or diagnostic profile or total recovery scores ($t_{29} = 0.90$, $p = 0.37$).

As shown in Table 3, the correlations between recovery scales were moderate to high ($r = 0.50$ – 0.71). All recovery scales were negatively associated with depression ($r = -0.39$ to -0.60), positively associated with hope ($r = 0.53$ – 0.74), and exhibited slight but significant associations with mastery ($r = 0.12$ – 0.30).

Global Assessment of Recovery

Table 4 shows the scores on rating scales for participants on the recovery scales by diagnosis. Significant differences were observed for total scores on the CES-D and Hope Herth Index, with participants with depression reporting lower scores when compared to people reporting their primary diagnosis to

Table 2
Participant Demographics (n = 228)

Variable		Variable	
Age		Primary Diagnosis (<i>n</i> , %)	
Mean (SD)	45.8 (12.5)	Schizophrenia	135 (59.5)
Median	48	Depression	56 (24.7)
Range	19-74	Bipolar	24 (10.5)
Gender		Other	12 (5.3)
Men	115 (50.7)	Productive Roles*	
Woman	112 (49.3)	Full Time	31 (13.7)
Education (<i>n</i> , %)		Part Time	84 (37.0)
Less than high school	56 (24.6)	None	112 (49.3)
High school	58 (25.6)	Site (<i>n</i> , %)	
Some college	29 (12.8)	Pathways	80 (35.2)
Some university	17 (7.5)	Archway	19 (8.4)
College or technical degree	35 (15.4)	Dufferin	27 (11.9)
Bachelor's degree	22 (9.7)	Richmond Street	52 (22.9)
Master's degree	3 (1.3)	Learn	21 (9.3)
PhD/MD/other professional degree	2 (0.9)	What's next	28 (12.3)
Other/missing	5 (2.2)	Number of countries of birth represented(<i>n</i>)	41
Ethnicity (<i>n</i> , %)		*Includes working, parenting, or volunteering	
White Canadian	75 (33.0)		
White other	40 (17.6)		
African	10 (4.4)		
African Caribbean	38 (16.7)		
South Asian	29 (12.8)		
East Asian	14 (6.3)		
South American	12 (5.3)		
Aboriginal	3 (1.3)		
Other	6 (2.6)		

Source: Authors' compilation.

Table 3
Spearman Correlations of Recovery, Depression, Mastery, and Hope Measures

	QPR	RAS	IMR	CES-D	Mastery	Hope
QPR	1	.717*	.502*	-.394*	.394*	.384*
RAS		1	.542*	-.455*	.190*	.738*
IMR			1	-.595*	.298*	.529*
CES-D				1	-.315*	-.325*
Mastery					1	.209
Hope						1

Note: QPR = Questionnaire about the Process of Recovery; RAS= Recovery Assessment Scale; IMR= Illness Management and Recovery Scale; CES-D= Centre for Epidemiological Scale- Depression

*=p<0.008

Source: Authors' compilation.

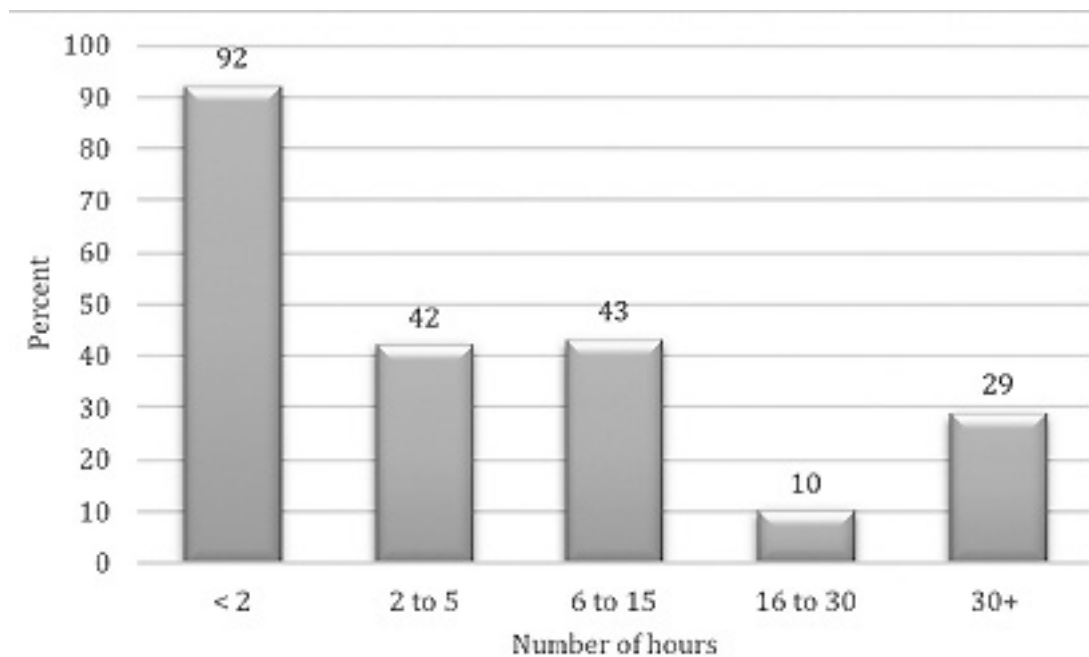
Table 4
Scores on Rating Scales for Participants with Schizophrenia Compared to Participants with Depression

	Schizophrenia (n = 130)		Depression (n = 56)			
Rating Scale	M	SD	Mean	SD	F(df)	p
QPR Total Scale	86.7	10.6	84.6	12.6	1.1 (2,179)	.621
Intrapersonal Subscale	54.2	8.7	51.1	10.9	1.4 (2,179)	.219
Interpersonal Subscale	15.7	2.8	16.1	3.1	2.1 (2,179)	.057
IMR Scale	44.1	8.6	43.8	9.4	3.1 (2,182)	.832
Recovery Assessment Scale	167.8	21.0	164.1	25.9	2.9 (2,181)	.088
Herth Hope Index	46.8	6.7	44.1	9.1	6.9 (2,186)	.009
Mastery Scale	21.1	4.2	22.5	4.4	0.8 (2,183)	.388
CES-Depression Scale*	15.9	12.1	23.2	17.6	20.7 (2,183)	<0.001

Note: M = mean; SD = standard deviation; QPR = Questionnaire about the Process of Recovery; RAS = Recovery Assessment Scale; IMR = Illness Management and Recovery Scale; CES-D = Centre for Epidemiological Scale-Depression; *A higher score on the CES-D indicates higher depression; IMR=Illness Management Recovery

Source: Authors' compilation.

Figure 1
Time Use Patterns of Participants



Note: Participants were asked question #5 on the Illness Management Recovery Scale which asks “How much time do you spend working, volunteering, being a student, being a parent, taking care of someone else or someone else’s house or apartment? That is, how much time do you spend doing activities for or with another person that are expected of you?”

Source: Authors’ compilation.

be schizophrenia. Recovery scores were lower for participants with depression when measured by the Questionnaire about the Process of Recovery and Illness Management Recovery Scale. No significant differences were observed between total scores on the Mastery Scale or the Recovery Assessment Scale.

As shown in Table 5, we mapped PRO items to all five domains and 18/20 subcomponents of the CHIME framework. Table 5 shows the percentage of participants who endorsed each item as “agree” or “strongly agree.” In the first domain, *connectedness*, participants varied in their perceived sense of social support and sense of being part of the community (67% agreed or strongly agreed). In the second domain, *hope and optimism*, the majority of participants endorsed each item (range: 77–89%), with the subdomain “belief in the possibility of recovery” being the most strongly endorsed (89%). For the third domain *identity*, most participants reported “liking” and “understanding” themselves, but only 60% endorsed that they were knowledgeable about their illness or symptoms. In the fourth domain, *meaning in life*, 83% identified that they had goals in life they wanted to reach; however, only 35% reported that they had made any progress towards goals in the last three months. As shown in Figure 1, less than 18% of participants reported that they spent more than five hours per week engaged in structured meaningful activity. In the last domain, *empowerment*, most participants endorsed that they believed they were the person most responsible for their own recovery (88%), can control their life (81%), and can recognize personal strengths (84%).

DISCUSSION

This study describes a profile of personal recovery for a sample of community-dwelling Canadians with mental illness. A critical issue in mental health services is the gap between what is known regarding effective treatment and what people actually experience during routine care in community-practice settings (S. P. Barbic et al., 2018; S. J. Cano et al., 2018; Proctor et al., 2009). PROs have a significant role in modern mental healthcare policy decision-making and evidence-informed practice (S. Cano et al., 2016). The information gathered in this study provides preliminary evidence towards how PROs can be used to understand the recovery needs of Canadians. The total scores from commonly used recovery PROs were examined, in addition to looking carefully at the individual items for trends. For this study, we used the CHIME framework as a theoretical guide to organize data from individual items on the scales. We recognize that several theoretical models of recovery exist (Stuart, Tansey, & Quayle, 2017). However, the CHIME framework provided an initial way to organize this data and observe for response patterns, needs, and priorities of participants in this study. Increasingly, other examples exist supporting this framework to understand the recovery needs and priorities of diverse populations of people with serious mental illness. (Bird et al., 2014; Brijnath, 2015; Stickley, Wright, & Slade, 2018; Stuart et al., 2017).

Using this framework, our study found several key findings. First, as expected the three PROs targeting recovery (IMR, RAS, QPR) were moderate–highly correlated ($r = 0.502\text{--}0.717$) with each other and the Herth Hope Index ($r = 0.394\text{--}0.738$). Data from these PROs suggest that participants were typically hopeful and motivated. For example most people reported “If I keep trying I will continue to get better” (90%) and “I am strongly motivated to get better” (87%). However it was clear from this data that hope did not translate into feelings of connectedness and empowerment, key domains of the CHIME framework. Over 32% did not endorse the item “I feel part of society rather than isolated” (QPR#4). As shown in Figure 1, the extent to

Table 5**Endorsement of Single Recovery Items Selected Based on the Conceptualization of the CHIME Framework**

CHIME Recovery Processes	Item	Description	% Agree or SA
Connectedness			
Peer support and support groups	IMR12	Involvement in self-help activities	79.0
Relationships	QPR2	I am able to develop positive relationships with other people	72.6
Support from others	RAS37	I have people I can count on	82.9
Being part of the community	QPR4	I feel part of society rather than isolated	67.7
Hope and optimism about the future			
Belief in possibility of recovery	RAS19	If I keep trying, I will continue to get better	89.7
Motivation to change	QPR9	I am strongly motivated to get better	86.7
Hope-inspiring relationships	QPR16	Meeting people who have had similar experiences makes me feel better	80.0
Positive thinking and valuing success	HHI1	I have a positive outlook toward life	79.8
Having dreams and aspirations	RAS20	I have an idea of who I want to become	77.1
Identity			
Dimensions of identity	QPR11	I am able to understand myself better	81.9
	IMR2	Knowledge about symptoms	56.8
Rebuilding/redefining positive sense of identity	RAS15	I like myself	77.8
Overcoming stigma	n/a	Not asked	-
Meaning in life			
Meaning of mental illness experiences	RAS17	My experiences have changed me for the better	69.6
Quality of life	n/a	Not asked	-
Meaningful life and social roles	IMR5	Time in structured roles*	17.7*
	RAS33	Being able to work is important to me	78.0
Meaningful life and social goals	RAS3	I have goals in life I want to reach	83.1
	IMR 1	Progress towards personal goals	35.7
Rebuilding life	QPR8	I have been able to come to terms with things that have happened to me in the past and move on with my life.	67.8
Empowerment			
Personal responsibility	RAS23	I am the person most responsible for my own improvement	87.5
Control over life	QPR21	I can take control of aspects of my life	80.9
Focusing upon strengths	QPR10	I recognize the positive things I have done	83.6

Note: n/a = no item mapped back to sub-domain; HHI= Herth Hope Index; IMR=Illness Management Recovery Scale; QPR = Questionnaire Process of Recovery; RAS=Recovery Assessment Scale

* Percent who endorsed that they spend more than five hours of structured activity/week.

Source: Authors' compilation.

which participants were actively engaged in meaningful activities was strikingly low, where most participants (83%) reported doing modest amounts of structured activity each week (<15 hours/week), with 40% reporting doing *less than two hours* of activity each week. As well, only 35% of the sample reported making progress on any personal goals in the last three months. These results are consistent with other research indicating that, in spite of considering it important, many people with serious mental illness spend little time involved in meaningful activity (Krupa, McLean, Eastabrook, Bonham, & Baksh, 2003; Yanos & Robilotta, 2011).

The association between social participation and mental and physical health is well documented (S. P. Barbic et al., 2018; Firth, Cotter, Elliott, French, & Yung, 2015; Kelly et al., 2017; Rifkin, 2014; Shor & Shalev, 2014). Yet, recently it has been highlighted that mental health services rarely routinely intervene to improve an individual's social participation (Carr, 2017; Webber & Fendt-Newlin, 2017). As increasing evidence emerges about the life expectancy of people with mental illness and the causes of death (e.g., cardiovascular, respiratory, and obesity related diseases; (Kondo et al., 2017; Laursen, Nordentoft, & Mortensen, 2014; Walker et al., 2015), participation in activity has a prominent place in the current dialogue in recovery-oriented care. International data continues to show a 20-year mortality gap for men and a 15 year gap for women in high-income countries (Honer et al., 2017; Jones et al., 2015; Kisely et al., 2013; Kondo et al., 2017; Walker et al., 2015). As (Thornicroft, 2011) notes:

The combination of lifestyle risk factors, higher rates of unnatural deaths and poorer physical healthcare contribute to this scandal of premature mortality that contravenes international conventions for the 'right to health.' (p. 441)

Our study suggests that participation, isolation and community belonging are areas that mental health services can target to address the recovery needs of this sample. Our data also support that understanding these key factors in the wider context of the importance of social determinants of health and "health as a human right" is essential. As (Rifkin, 2014) notes:

The evidence that directly links community participation to improved health status is not strong. Its absence continues to be a barrier for governments, funding agencies and health professionals to promote community participation. (p. ii99)

In this study, social connectedness—either with friends, family, or society as a whole—was an area of deprivation for many participants. Rifkin (2014) highlights that robust community participation intervention studies are illusive. Although activity limitation is recognized as a component of disability, very little is known about how persons with mental health disabilities spend their time and how these patterns of activity can affect health and well-being outcomes (Pentland & McColl, 1999). Future research is needed to understand the barriers to participation and the types of interventions that can optimize recovery and the health trajectories of Canadians with mental illness.

Another key finding was the lack of perceived knowledge of illness and treatment reported by participants. For example, only half of participants reported having knowledge of their symptoms. Given the average age of participants (45 years), and the typical age of onset of the primary diagnoses (e.g., 17–20 for schizophrenia), our results suggest mental health literacy is another important need for recovery. Health literacy has been described as the ability to obtain, read, and use healthcare information to make appropriate health decisions and follow instructions for treatment (Public Health Association, 2008). Low levels of mental health literacy have been reported in community samples elsewhere (Andrade et al., 2014; Brosnan, Barron,

& Sahm, 2012; Krishan, von Esenwein, & Druss, 2012). Our results suggest that greater attention should be given to helping community-dwelling individuals with mental illness obtain the skills necessary to access, understand, and utilize information about personal recovery to optimize their health outcomes and quality of life. This may include more education at the level of primary care or the more widespread implementation and dissemination of evidence-based illness-management programs such as the Wellness Recovery Action Plan (Cook et al., 2010), Recovery Workbook (S. P. Barbic, Krupa, & Armstrong, 2009; Spaniol, Koehler, & Hutchinson, 1994), the Illness Management Recovery Program (K. T. Mueser, Deavers, Penn, & Cassisi, 2013; K.T. Mueser, Meyer, & Penn, 2006), and Action Over Inertia (Edgelow & Krupa, 2011).

Implications for Measuring Personal Recovery in the Community

Thornicroft and Slade (2014) note that “assessment of the outcomes of interventions in mental health care is both important and challenging” (Thornicroft & Slade, 2014). In the absence of a gold standard to measure recovery, we included three existing recovery PRO measures in this study to comprehensively assess the construct. Although psychometric evidence exists regarding the robustness of each PROs on their own, our team felt it was necessary to look beyond the total scores of each PRO (i.e., beyond completing simple correlational analysis) and compare scores from individual items as well. The individual item level data was agreed to be richer to inform fundamental decisions in clinical practice, health policy, and research (Brundage et al., 2012; S. J. Cano et al., 2011; Gnanasakthy et al., 2012; Hobart et al., 2007).

Implications for Recovery-oriented Patient-centred Care

As noted earlier, patient- or person-centred care is at centre stage in the discussion of quality health systems (Canadian Institutes for Health Research, 2015, 2016; Mental Health Commission of Canada, 2015; Slade et al., 2014). The results of this study provide timely new evidence to support ways to gather person-centred recovery data from community-dwelling people with mental illness using PROs. Despite long-standing concerns for patient-centred care being at odds with evidence-based practice, there is now international agreement that these concerns should be put to rest. As noted by Epstein & Street (2011):

...proponents of evidence-based medicine now accept that a good outcome must be defined in terms of what is meaningful and valuable to the individual patient. (p. 100)

The routine use of PROs in mental health provides an opportunity to drive how healthcare is organized and delivered (Ahmed et al., 2012; Kirwan et al., 2014; Kirwan et al., 2017; Reeve et al., 2013). As the demand increases for accountability of a broad range of mental health services to be person- and family-centred, PROs have the potential to capture outcomes such as sustained symptom reduction, return to functioning, and optimization of mental health and recovery (Slade et al., 2014; Thornicroft & Slade, 2014).

STUDY STRENGTHS AND LIMITATIONS

The strength of this study was the use of the CHIME framework and recovery PROs to inform a detailed profile of the recovery needs of a sample of individuals living with mental illness in the community.

In addition, our study included a diverse sample representing varying diagnoses, service delivery sites, and socio-demographic backgrounds. Our study is not without limitations. First, we relied on a convenience sample and we recruited individuals from only one city, which may limit the generalizability of the findings. Second, our study design was cross-sectional, limiting possibilities for inference about causal relationships among variables. In spite of these limitations, our findings contribute to the growing body of evidence that supports the need to evaluate personal recovery as a primary outcome for mental health services.

CONCLUSIONS

We provide a comprehensive overview of the areas that patients with severe mental illness consider as priorities for personal recovery. In particular, we found that engaging in meaningful activity and work, and making progress toward goals were areas that require further improvement. Altogether, these results may guide clinicians to better assist patients with obtaining their own understanding of recovery, which is becoming the primary goal of all mental health services. Also, this study shows the feasibility of using items from recovery patient reported outcome measures to assess recovery outcomes over time. By targeting the precise needs of service users to maximize recovery, mental healthcare services may help realize the objective of the World Health Organization, and optimize the meaningful outcomes and quality of life for individuals who experience mental illness or mental health problems.

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