Accepted: 27 May 2021

DOI: 10.1111/1440-1630.12748

FEATURE ARTICLE

Australian Occupational Therapy Journal | WILEY

Personal narratives of learning self-management: Lessons for practice based on experiences of people with serious mental illness

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Abstract

Introduction: Clinicians are challenged to deliver self-management interventions in recovery-oriented services for individuals living with serious mental illnesses. Little is known about how people learn self-management skills and questions remain about how best to deliver support. To offer insights for delivery, this research describes the lived experiences of learning self-management and the meaning of those experiences within recovery journeys and the context of health-care delivery.

Methods: Design followed van Manen's approach of phenomenology through an occupational therapist's lens. Using purposeful criterion sampling until saturation, 25 adults with psychosis experiences (8–40 years) from six community-based specialised mental health programs were interviewed. Conceptual maps were cocreated depicting key learning experiences, intersections with services, and recommendations. Data reduction, reconstruction and explication of meaning occurred concurrently, and multiple strategies were used to transparently support an open, iterative, reflexive process.

Findings: Participants described eight essential tasks to live well, learned often serendipitously, taking up to 15–30 years to find the right combination of supports and self-management strategies to achieve what they felt was a life of quality. Self-management needs were not routinely addressed by services and extended beyond illness or crisis management while participants grappled with emotions, self-concept, relationships, and occupational issues. Participants asked providers to "teach us to teach ourselves"; "invite clients" to the decision table; and deal directly with emotions of fear, shame, and trust with respect to self and relationships. Findings challenge conventional conceptualisations of self-management to consider clients living interdependent lives with tasks performed in context, dynamically influenced by complex personal, socio-ecological relationships.

Conclusions: Participants' narratives compel increasing access to strategic personalised self-management learning opportunities as an effort to shorten the prolonged recovery paths. Findings offer ways providers can understand and address eight self-management learning tasks from the perspective of lived experiences. Self-management was enmeshed with recovery, health, and building a life.

KEYWORDS

chronic disease, delivery of health care, health policy, learning, mental health recovery, occupational therapy practice, psychotic disorders, qualitative, self-concept, self-help, self-management

1 | INTRODUCTION

Practice guidelines direct clinicians to deliver self-management interventions within the context of recovery-oriented services for individuals living with schizophrenia (Health Quality Ontario, 2018). There is sufficient evidence to support integration of self-management into routine practice (Lean et al., 2019). Self-management interventions with people with schizophrenia had significant effect on medication adherence (2.57-fold greater odds); relapse and re-admission (45%–46% less likely) (Zou et al., 2013); length of hospital stay; symptom severity; functioning; quality of life; and recovery-related outcomes such as sense of empowerment, hope, and self-efficacy (Lean et al., 2019). Health planners call for self-management support with shared decision-making for patient and family engagement (Menear et al., 2020). Although self-management interventions can offer important potential benefits for engagement, health, and wellbeing, less is understood about how clients with serious mental illness learn self-management and what clients need to support learning self-management. An in-depth understanding in the context of their daily lives is essential to meaningfully deliver client-centred, self-management support.

Self-management is often referred to as individuals actively making decisions and engaging in activities to manage or reduce the impact of a health condition on their daily lives in collaboration with health-care providers (Epping-Jordan et al., 2004). Our understanding initially was shaped by a large seminal longitudinal study of individuals living with a range of chronic illnesses, albeit no mental illnesses (Adams et al., 2004). Finding a common set of day-to-day tasks faced by these individuals, they concluded "self-management relates to the tasks that an individual must undertake to live well with one or more chronic conditions" (p. 57). These tasks involved taking care of medical regiments and dealing with a condition's impact on carrying out regular activities, roles, relationships, sense of self, and emotions. A nuanced, transactional understanding of health, wellbeing, and participation in activities in context is offered from a grounded theory study by occupational therapists of community dwelling adults treated for multiple chronic conditions, including mental illnesses (White et al., 2020). From the perspective of individuals living with schizophrenia, self-management is a component of recovery that makes the difference between "coping" and "thriving" (Martyn, 2003, p. 8). Self-management, recovery, and wellness are seen as interrelated, distinct concepts to be addressed by programs (Sterling et al., 2010).

Standardised self-management programs have expanded internationally to build self-management capacity. In these programs, the extent to which the individual is viewed as taking sole responsibility, including mobilising local resources and working in partnership with their family and health-care providers, vary. At times, however, the demands of increased responsibility may result in amplified challenges. Some programs were designed as generic interventions for all chronic conditions such as Flinders Chronic Condition Management Program (https://www.flindersprogram.com.au/), Expert Patients Programme (https://www.nelft.nhs.uk/epp/), and Stanford Chronic Disease Self-Management Program (https://www.selfmanagementresource.com/). Other programs are condition specific, designed for people with mental illness such as Illness Management and Recovery (IMR) (https://www.samhsa.gov/), Integrated IMR (Mueser et al., 2012), and Admire Plus (https://www.freerehab.center/li/az-admire_plus_dual_diagnosis_program). Occupational therapists have added a lens of occupation participation to self-management of multimorbidity in OPTIMAL (Garvey et al., 2015; O'Toole et al., 2013). Recognising the expertise from lived experience and integrating recovery with self-management, others used strategies such as peer-therapist co-led e.g., Modified Recovery Workbook (Barbic et al., 2009), peer-led e.g., Health And Recovery Peer Program (Druss et al., 2010) and Wellness Recovery Action Planning (Jonikas et al., 2013), and peer-to-peer interventions (Sterling et al., 2010). Further, co-designed, co-produced, and co-led interventions for persons with lived experience and health professionals to learn from each other have emerged in supportive learning environments of Recovery Colleges (Theriault et al., 2020) and Recovery Education Centres (Reid et al., 2020). Questions remain about how best to deliver self-management support. Understanding how clients learn self-management could inform the design and implementation of existing approaches.

The aim of this research was to understand the experiences of individuals with serious mental illnesses learning about self-management to improve the delivery of specialised mental health services. The pre-supposition was that individuals were learning self-management with and without services. The intention was to describe and to understand the meaning of those experiences within individuals' recovery journeys and the broader sociopolitical context of health-care delivery.

2 | METHODS

van Manen's (1997) hermeneutic phenomenology was selected to guide study decisions because the approach matched the study's objectives of interpreting experiences within life's situational constraints, and aligned with the first author's views of the world (ontology) and ways of knowing (epistemology). The researcher was embedded in the co-construction of understanding with participants, enabling the first author to use experiences and insights working 30 years in various roles as an occupational therapist in specialised mental health services. Purposeful criterion sampling ensured participants

had diverse life (sex, age, length of illness, and occupational roles) and mental health service (service tenure and services utilised) experiences for schizophrenia and related psychotic disorders. A sample of 25 participants provided saturation or redundancy of information and the opportunity to search for experiences that were inconsistent with evolving understandings (Lincoln & Guba, 1985). De Witt and Ploeg's (2006) interpretive phenomenology criteria were used to support the study's quality. Approval was obtained by the Hamilton Integrated Research Ethics Board (study #09-3277).

2.1 | Recruitment and data collection

Participants were recruited from six specialised service locations mandated to provide different types of services for the group of interest (outpatient treatment, rehabilitation and community outreach programs). Student occupational therapists obtained informed written consent and conducted interviews. Participants were offered a small honorarium and bus tickets. As a starting point, self-management was defined as "the process of learning about your own mental illness and what you can do to manage your condition and be more in control of your life." During 1-hr semi-structured audio-recorded interviews, participants were asked to describe self-management learning events, what they took away from those experiences, and what they learned (Appendix A). They were asked to reflect upon their experiences and make recommendations to peers and providers. During these conversations, the participant and interviewer co-created a drawing that mapped each participant's self-management learning journey. Using participants' own language, experiences were labelled with participants' interpretations, messages taken away, and recommendations. Maps kept interviews focused, supported reflections and dialogue, and became a repository of participants' learnings.

2.2 | Analysis

In keeping with van Manen's (1997) approach, data reduction, reconstruction, and explication of meaning occurred concurrently in an iterative, reflexive process. Each transcript and map were read as a whole to gather how learning self-management presented for that individual and summarised in a two-page participant story. Themes were identified through cyclical multiple readings of transcripts and writing thematic statements while actively questioning "What is it like to live with serious mental illnesses and learn self-management? What meaning does this experience hold for this group of people?" Meanings of events were sought by reviewing the two-page stories to relate an event to the whole and reflecting on identified themes. The researcher reflexively considered the influence of personal understandings in tandem with participant-described events shaping and being shaped as part of the person's whole self-management learning within a dynamic ecological context (family, society, and health care). Next, variations on essential themes were searched. Common themes and variations became a coding guide, transcripts were coded, and emerging insights were written in memos within NVivo9 (QSR International Pty Ltd, 2010) computer software. A third of transcripts were coded by both the first author and the PhD supervisor. For reconstruction, the themes were explored across all interviews, using anecdotes, quotations, and story summaries to help recount each theme vividly. To further support openness and reflection, the etymologies of key words were explored. A matrix of themes by participant was used to ensure complete data exploration.

3 | FINDINGS

3.1 | Description of sample

All 25 participants were receiving community specialised mental health services for self-reported illness defined by experiences with psychosis (spectrum of schizophrenia and affective disorders). Sample characteristics are summarized in Table 1. Approximately half of the group

TABLE 1 Sample characteristics

Characteristic	Distribution of attribute in sample ($n = 25$)
Sex	Men ($n = 15$), women ($n = 10$)
Age	Range = 22–69 years ($M = 44.5$, $SD = 12.3$)
Marital status	Single ($n = 12$), divorced ($n = 8$), married/cohabitating ($n = 5$)
Living arrangement	Alone ($n = 12$), with family/spouses ($n = 7$), boarding home ($n = 4$), transitional supported living residence ($n = 2$)
Primary occupation	Competitively employed ($n = 7$), unemployed ($n = 6$), retired ($n = 5$), homemaker ($n = 3$), student ($n = 2$), volunteer ($n = 2$)
Mental illnesses tenure	Range = 8–40 years
Mental illnesses onset	Puberty ($n = 13$), early adulthood (18–22 years old) ($n = 6$), later ($n = 5$)
Managing comorbidities	Addictions ($n = 9$), chronic medical condition ($n = 11$) (diabetes, epilepsy, cardiovascular disease, emphysema, cancer, and rheumatoid arthritis)

(n = 12) accessed formal psychosocial rehabilitation service at some time.

3.2 | The work of learning self-management with serious mental illness

Overall, participants described learning self-management as a gradual growth process that began with illness onset, often years before receiving a diagnosis. This process involved individuals actively taking control, engaging in self-discovery and experimentation across a diversity of living environments and circumstances. Learning was interrupted by "stops," "setbacks" of psychotic episodes, hospitalizations, and medication changes. Although the learning process was a uniquely personal experience with no common timeframe, participants described learning self-management as putting in place the "essentials": taking a series of "baby steps," accomplishing "stepping stones" on a difficult journey of "ups and downs," and persistent "work" that accumulated to laying a "foundation" for living. They talked about learning specific "things" necessary for self-management and made recommendations about what clients needed to learn or put in place to live well. These "things" were interpreted as *tasks*. The work of learning self-management took the form of eight self-management tasks in the eight emerging themes below and summarised in Appendix B. Growth in individual tasks appeared to influence the learning of other tasks but no sequential order was implied.

3.2.1 | Reaching personal understanding of illness experiences

Participants often hid their early symptoms from others for years, with little or no knowledge of mental illnesses and generally not connecting with services until hospitalised with psychosis. Consequently, few had heard of schizophrenia before being diagnosed. The exceptions were a few who secretly researched information or who knew of schizophrenia through family members living with schizophrenia. Most participants did not remember receiving information or guidance beyond advice to continue taking psychiatric medications and attending follow-up appointments. Participants who requested more information received mixed responses. Meaningful information affirmed their experiences, brought realisation that others have psychosis experiences, and enabled them to interpret and act on their experiences. For example, Ryan noted "[it] taught me to understand that what I have isn't common but it can be treated" which was interpreted as having the potential for change, hope for a better life: "[the diagnosis] gave me the opportunity to see that there is, I know it's a cliché, but a light at the end of the tunnel." "Brad" spoke to translating the facts into a personal understanding of his role in living well: "You could take any medication you want. [But] if you can't identify with symptoms and identify your own symptoms, you're going to be walking around in circles." Gaining such knowledge added significance amidst the intangibility of psychosis and the broad spectrum of mental illnesses uniquely and individually experienced.

3.2.2 | Finding medications and services that "work with me"

Despite the varied therapeutic effects of medications, everyone endorsed taking medications as essential to mental stability ("Those are the cornerstones of my recovery, my stability") and functioning ("Without the medication I can't function. It's just that simple."). Participants talked about the lengthy trial and error process they went through to find medications "that worked" for them and the trade-offs between holding psychosis at bay and compromising reasoning ability. Tom discovered which medications were right for him by working at different jobs while trialling new medications and reporting bi-weekly to the psychiatrist how the medications were alleviating symptoms or interfering with his ability to work. For him and many others, finding the right medications went hand in hand with finding the right follow-up services.

Participants described enduring ordeals of taking years to find service providers willing to work *with* them. They told of a gauntlet of obstacles to navigate the health-care system. Participants went from provider to provider to access specialized mental health services, negotiating control issues with providers as service gatekeepers, coming to realise that they needed to take medications, and all the while living in periods of psychosis. After negative experiences with different psychiatrists, Carl found a psychiatrist who treated him as a person, "not an object … or diagnosis," openly discussed options for dealing with symptoms and engaged him in shared decision-making, "I'm part of my treatment … part of that decision."

Finding service providers who "work with me" meant being given credibility as a person managing their own life, being recognised as an expert of their experiences living with mental illness and forming partnerships with providers. Angrily, Sheila recalled the many hospitalisations for suicide attempts with numerous providers who had not listened to her:

> Nobody was helping me. I was getting the proverbial pat on the hand, "you're alright dear… You'll be fine. I've been fifty-two years like this! I was ten years old when I first was taken to a doctor for seeing things and hearing things… For many, many, many years I knew there was

> something wrong with me… there again the pat on the hand.

Referred a year ago to a specialised mental health clinic, she worked with a psychiatrist who supported negotiation, experimentation, and discovery to arrive at the right medications for schizophrenia. "He took time to talk to me. And we kind of experimented with different meds until we found the right stuff." Through the clinic, she accessed an occupational therapist who helped her put her plans concretely into action with goal setting and review, incorporating motivational strategies to get through the difficult times and facilitated self-reflection to learn from life experiences. Her story, similar to others', described helpful client–provider partnerships that supported self-determination, self-discovery, and access to personally tailored services. Participants recommended to peers to find providers who "listen," "find out who you are human to human," and "not just focus on the medication." Participants recommended providers proactively and directly deal with power-control issues. In one person's words, "invite people to learn … invite them in [to the partnership table]."

3.2.3 | Trusting self and managing thoughts

The psychosis experiences of living periods of time in an altered reality meant this group described difficulties with trusting themselves, others, and the world around them. Everyone had blocks of time for which they had no recollections. They carried frightening memories of losing control, responding to hallucinations or delusions and external control forced on them. These visceral experiences, which may have occurred years before, were remembered as if they occurred recently. For some, psychosis was experienced as discrete events and for others as dynamic experiences that seeped periodically into their lives for moments or days at a time. Participants requested providers "give a course on fear" and "teach you to trust."

Learning to trust self involved learning to distinguish reality from effects of illness. While navigating daily activities, participants were "second guessing" themselves, wondering if perceptions of what was happening around them "might just be my mind playing tricks on itself." Participants told of learning to challenge delusions and hallucinations, carrying on inner dialogues and experiments to test out reality, and gaining confidence to believe in their interpretations. On-going management involved a "different way of thinking." Participants spent considerable time self-monitoring by conducting surveillance of their mood, thinking, behaviour, and responses from the environment to confidently maintain control. Carol moved from vigilantly self-monitoring ("six times a day I'm checking in"), to a less intensive routine. "Sometimes managing illness is just keeping tabs on it … kind of like a diabetic that monitors their sugar levels." Self-monitoring was not formally taught by providers. Rather, participants learned self-monitoring themselves, sometimes fostered by surveillance questions during provider visits.

3.2.4 | Dealing with stigma and self-acceptance

Encountering stigma through acts of discrimination and policies promoting marginalisation was a daily reality. Participants recounted using different strategies to deal with stigma, learning not to internalise stigma from others and work towards accepting themselves: "We're only as sick as our secrets … I tried hiding it. There was shame." They learned subtleties of disclosure, to "open up" and risk trusting another in order to have an intimate relationship. Sarah put on "armour" to deflect negative messages. Subsequently, she began accepting herself once she received empathy, acceptance from her husband-to-be, "someone who's gone through it themselves." Stan learned to skillfully deal with interpersonal situations and misconceptions about mental illnesses, "being schizophrenic, people think you're crazy. You know that's not the case." Others learned to be kind to themselves, picked supportive environments, and/or gathered courage resolving "I'm going to have another life. Make my life heaven not hell," rejecting the life of on-going trauma. Participants dealt with the emotional fallout when mental illness became known at work. Jack spoke of working hard to earn a full-time position putting in extra hours. Under the stress, he began experiencing voices. His story illustrated being branded with mental illness such that he resigned. Stigma touched whole families. Family members "cut off their relationship [with others] and that was it." Participants were left with added feelings of guilt and shame.

3.2.5 | Developing and using a support network

Socially disadvantaged and living with a complex all-encompassing illness, participants actively took steps to develop a network of people and services. Relationships had to be mended and renegotiated in the aftermath of psychotic episodes. Participants faced challenges to connect, communicate, and trust others. For those with an early illness onset who lived an isolated life, this meant learning social skills and self-efficacy in dealing with others. Russel reflected on his collective kitchen experiences, "I learned to communicate a lot better with people … I'll open up and just have regular conversations with people." Establishing supports presented additional challenges for participants affected by trauma.

Support networks provided a variety of functions. Interpersonal relationships provided an interdependent opportunity for emotional support and assistance with instrumental living needs. Others acted as sounding boards for reality testing and gauging what was "normal" by societal standards. Nick discovered how being around others warded off negative thoughts and the voices that followed. "As soon as I start isolating, all the negative thoughts [were] coming to my head … Surround yourself with people is the way to move ahead." "Justin" commented how a support network provided a sense of safety, "Since they are always there for me, I always believe I have some kind of safety net … [if I] misstep." Overall, support networks were an important foundation for growth and self-management.

3.2.6 | Discovering ways to accomplish daily living activities

Performing routine self-care and home management activities fulfilled the necessities of living and brought reassurance of control and routine. By successfully accomplishing routine activities of daily living, participants demonstrated to themselves and others that they were taking control of their lives as competent, capable people and in the process developed self-confidence.

To perform daily living activities meant participants experimented and discovered a range of personalised strategies to overcome emotional and cognitive challenges, sustain motivation, and engage in healthy habits. The diversity of approaches included mental strategies (e.g., self-talk, reality testing, self-monitoring, and goal setting); controlling physical space and routine; restructuring activities (e.g., ensure reward and physical activity for arousal or release); and connecting to faith, spiritual selves, or sources of hope and strength. One option was to delegate tasks to others. Chris who lived independently realised he had "a spending habit." He decided to give his mother his bank card and have her "dole out the money for me once a week, kind of like a trustee … that will help me because I won't think about the card and I won't use it … that's self-management."

3.2.7 | Finding meaningful occupations that fit

Participation in meaningful activities was associated with a "normal" life, health, and wellness. A life interrupted by illness and hospitalisations meant needing to (re)connect with meaningful occupations. There were periods with few roles and responsibilities. The story of meaningful activity generating feelings of usefulness, pride, and enjoyment was common. "[I] go to my stepdaughter, and watched that baby until eight o'clock at night. I changed diapers and I take bottles and I was really proud of myself. Yeah, so that was one normal thing."

Meaningful meant that occupations "fit" or matched how people viewed themselves, their future plans, and enabled use of their stress management strategies. Participants searched for supportive environments to engage in occupations that felt safe with sufficient flexibility for managing stress. Ian found the expectations that accompany being paid a wage stressful, so negotiated exchanging food for his services to reduce his anxiety.

> I don't have to worry about that, what I'm worth. Like when I was hired, you're worth so much an hour … I don't have to think about it … I can fulfill my responsibilities … they didn't pay me. They fed me … I don't have to worry about it.

3.2.8 | Integrating management of comorbidities

Participants managed other mental health and medical conditions (e.g., trauma, addictions, acquired brain injury, and diabetes). They learned to integrate the management of comorbidities into a life of managing serious mental illness. Participants described management of all conditions as intertwined. Managing a medical condition brought worry, fear, and further setbacks. Some physical health issues, although significant and intrusive, were time limited. Half of the participants lived with on-going chronic illnesses that required learning another medical regimen and lifestyle changes.

Experiences managing comorbidities offered learning opportunities for managing mental illness and vice versa. Christine who lived with schizophrenia, substance use, and abuse experiences returned to swimming for a new medical illness. Swimming helped her deal with stress and provided a venue to make friendships. From addiction services, she incorporated "cognitive therapy … changing the way you think … how to get our lives in order" and began creatively "treating my weight loss as an addiction as well." She applied strategies learned to manage addictions (e.g., goal setting with personal rewards, social networks, and mentors) to manage mental illness.

4 | DISCUSSION

Overall, participants reported taking up to 15–30 years to find the right combination of supports and necessary self-management strategies to achieve what they felt was a life of quality. The length of their journeys compels asking: Can we shorten these prolonged paths and support learning self-management more efficiently? While self-management is a lifelong process, how

can supports and opportunities be provided earlier for more rapid learning and integration of learning in clients' journeys? Findings confirmed that individuals were engaged in learning self-management at the onset of symptoms, irrespective of intervention by service providers. Participant accounts depicted unmet self-management learning needs. Services were needed beyond medications, crisis, and risk management. Specifically, support was needed for learning eight self-management tasks. These tasks can be used to communicate, understand needs, and plan responsive interventions. Self-management tasks involved addressing an evolving sense of self and the impact of the condition on emotions, relationships, and occupations. Learning needs were dynamic, changing with evolving health conditions and unfolding demands of life circumstances. The process of learning self-management was enmeshed with recovery, health, and building a life.

Participants' narratives challenge conventional definitions of self-management. These definitions imply choice when often none exists from the viewpoint of people living with chronic conditions. Choices are impeded by social structural inequities and internal fears, vulnerabilities, and the inability to count on the world for support. Participants' lives were constrained with limited opportunities to use their abilities or to access necessary information to make informed decisions. Further, they recounted self-management tasks as being undertaken within the context of interdependent lives dynamically shaped by evolving life circumstances rather than as discrete tasks. For these participants, self-management was possible when survival did not dominate their journeys. At those times, self-management represented a process of focusing on reclaiming a satisfying life within situational constraints and supports.

Findings suggest thinking of self-management as an ongoing learning process involving the whole person over a lifelong journey requiring early intervention within a continuum of on-going services that are not time limited. Further, findings support focusing self-management within the context of each individual's recovery journey, addressing life challenges and the barriers/supports to building a life, consistent with the approach taken by Recovery Colleges (Theriault et al., 2020). Conversations and client–therapist assessments of the eight self-management tasks can be used to understand learning needs, how each individual learns, and together plan responsive, tailored interventions. Matching different ways of learning will require access to diverse self-management intervention approaches (individual, group-based, peer-led or co-led, colleges or education centres, and online). Internet-based self-management support, while pursing personal recovery goals, is emerging as an option (Williams et al., 2019) for those with access to internet, hardware, and digital literacy. Findings urge all programs to reflect upon participants' requests to "teach us to teach ourselves"; "invite clients" to the decision table; and deal directly with emotions of fear, shame, and mistrust.

Findings reflected insufficient integration of collaborative client-centred practices. They bring further attention to the growing body of knowledge linking client–provider shared decision-making and personalised care planning with better health outcomes (Coulter et al., 2015). Participants looked to health professionals for advice, expertise, and generally wanted to work in partnership if participants' expertise was recognised and credibility given for their own self-management work. To deal with power imbalances and historical relationships, we recommend therapists invite participation, repeatedly voice permission for clients to own self-management, explicitly share how client–therapist roles may be different than previously experienced, directly ask for and act on clients' ideas. Further, powerful messages are conveyed by recommending peer support and offering peer-therapist co-designed and co-led services. Traditional power hierarchies are deconstructed in co-production (Reid et al., 2020).

Participants clearly recommended that therapy facilitate a process of self-discovery, experimentation which suggested using a coaching approach to strengths-based learning from life experiences. This will require some providers to move away from a disease-based practice model organised to manage risk and care. Rather, a collaborative, negotiated partnership is needed that focuses on client perceptions of self, illness, health, and life challenges; joint assessment of self-management needs, strengths, and resources; and learning together what works or does not work for the client. Self-discovery and experimentation inherently hold risk, shared trust, and proactive planning. The complexity of self-management meant participants had to gain a level of expertise, develop personalised ways to manage, and employ judgement. The implication is that individuals need more than sterile facts to interpret life experiences and make decisions. They require frameworks that provide an active role to understand and proactively act on experiences, such as the Stress Vulnerability Model of Psychosis (Zubin & Spring, 1977) and Recovery Model (Mueser et al., 2013). There was evidence of self-monitoring and self-regulation which suggests that a self-regulation model of self-management based on social cognitive learning (Clark, 2003) may be useful to support understanding and guide coaching decisions. Social cognitive learning strategies (Bandura, 1997) often used by occupational therapists for skill acquisition, self-efficacy development, and creating supportive environments would apply to learning self-management.

The self-management tasks for this participant group appear to hold commonalities to tasks identified by others (Clark et al., 1991). Although several tasks have a common focus (e.g., gaining knowledge, developing a support network, and performing activities of daily living), the context for learning and managing self-management diverges. Two tasks in particular, "trusting self and managing thoughts" and "dealing with stigma," assumed unique meaning and

requirements for individuals managing psychosis. The population with serious mental illnesses is disproportionately negatively influenced by social determinants of health (poverty, social exclusion, and unemployment) which suggests these individuals begin learning self-management from a different place. Findings from this study suggest that when social determinants of health are not addressed, survival dominates individuals' lives, suggesting limited personal resources are available for learning and implementing self-management strategies. The context for living with serious mental illnesses, and by extension the particular knowledge and skills required to manage tasks, can be different than other health conditions. Therefore, findings suggest that condition-specific intervention programs rather than generic interventions designed for managing all long-standing conditions may be helpful when these two tasks are learning priorities and/or the context of living with mental illness predominates. We recommend the eight self-management tasks be addressed and integrated into condition-specific intervention programs. By extension, for individuals further along in recovery or who do not view those with mental illnesses as peers, generic self-management programs may be helpful.

Self-management was found enmeshed in recovery, wellness, and building a life that is consistent with others' understanding (Martyn, 2003; Sterling et al., 2010). Findings furthered the understanding of the work involved in self-management and the meaning of the work within a recovery framework. Participants connected mastery of self-management tasks with advancing sense of self and control similar to White et al. (2020), although the sense of self and control had additional layers of meaning for this group. Recovering a sense of self as a "well" person was interconnected with performing the eight tasks while recognising that performance was not dependent on the person alone; aspects were shared, delegated, and supported by others. Success in recovery relied on growth in tasks and vice versa. Participants looked to self-management as an indicator of recovery. Self-management required the individual to apply skills and resources to engage in activities and sustain performance to accomplish tasks. In this way, self-management is a personal resource for self-determination and living well. Participants' accounts described their capabilities for self-management growing with self-directed experimentation and experience. The active process of engaging in self-management to diminish the effects of illness and regain a sense of control is in essence an application of recovery.

For some participants, self-management was an occupation dynamically influenced by the multiple environments in which they lived. The Person–Environment–Occupation Model (Law et al., 1996; Strong et al., 1999) can be used to identify and examine these influences and frame conversations about self-management. Therapists can plan structured, targeted learning opportunities through client participation in activities surrounding the occupation of self-management. Therapists can have a significant role in creating or linking clients to those learning opportunities, shaping life experiences into learning opportunities and developing support networks. There was a range of influences on learning related to the social, physical, and policy environments. Essential resources for daily living and learning self-management were barriers to be overcome. Therapists can advocate and coach clients to successfully navigate social and health-care systems for the necessary supports and resources. Using a socio-ecological framework for planning services and setting policy, Greenhalgh (2009) urged self-management capacity building, by helping individuals respond to life challenges and constraints in their lives, coupled with providing the necessary supports and resources.

In general, participants learned largely through their own trial and error efforts with life as the "teacher" and little formalised guidance. In White et al.'s (2020) study, after individuals received self-care information, they too were left on their own to learn implementation. Perhaps the self-management learning journey could be shortened and learning made more effective if these needs were routinely targeted and integrated into care processes. Occupational therapists' understanding of people as occupational beings, respect for clients' expertise, and valuing clients' moral rights to make life choices (Hammell, 2013) positions therapists to support the work of learning self-management.

5 | LIMITATIONS

Phenomenological methodology provides rich findings that can be used to characterise and explain the meaning of learning self-management for individuals living with serious mental illness. Findings are limited to participant-defined key learning experiences and perspectives in a group with self-reported psychoses receiving diverse publicly funded urban specialised mental health services. Interviews rely on participants' recall, and there can be differences between what is said and what is done. However, the study was designed to confidently capture the messages taken away from experiences by those individuals who are the experts of their own learning.

6 | CONCLUSION

Participants' narratives compel increasing access to strategic personalised self-management learning opportunities as an effort to shorten the prolonged recovery paths. Findings offer ways providers can understand and address eight self-management learning tasks from the perspective of lived experiences and life realities. Self-management was enmeshed with recovery, health and building a life.

KEY POINTS FOR OCCUPATIONAL THERAPY

- Learning self-management when living with serious mental illness is important to living well.
- Occupational therapists are encouraged to implement the eight learning tasks early to coach clients in developing self-management strategies and to support recovery.
- Creating partnerships with clients will support self-management strategies that best support individual needs.

ACKNOWLEDGEMENTS

This research was conducted as part of the first author's PhD studies supervised by retired Seanne Wilkins. We thank student occupational therapists for conducting the interviews: Katie Denby, Eunice Kim, Tracy (Martin) Gerber, Alexis Moll, Lynda Rolleman, and Carolyn Scrafield. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. This research is supported in-kind by St. Joseph's Healthcare Hamilton and McMaster University, Hamilton, Ontario, Canada.

CONFLICT OF INTEREST

The first author declared potential conflict of interest with respect to research and no conflict of interest with respect to authorship and/or publication. The first author was employed by St. Joseph's Healthcare Hamilton, the administrative organisation of sites. The second author was a PhD committee member and had no potential conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

First author was primarily responsible for the conceptualization, design, acquisition, analysis, and interpretation of findings. Second author significantly contributed to critical reflection, revisions, and application to occupational therapy.

DATA AVAILABILITY STATEMENT

Data are available upon request from authors.

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How to cite this article: Strong, S., & Letts L. (2021). Personal narratives of learning self-management: Lessons for practice based on experiences of people with serious mental illness. *Australian Occupational Therapy Journal*, 68, 395–406. https://doi.org/10.1111/1440-1630.12748

APPENDIX A

Interview guide—questions and probes

The following is a guide to hold a conversation about key self-management learning events accompanied by drawing a map of the learning process and what took away from those experiences. The order of questions will follow participant's lead.

We are together to talk about your experiences learning about your own mental illness and what you can do to manage your condition and be more in control of your life.

1. Tell me about what took place. How did the learning process happen?
   - How did it start? When and where did this event take place?
   - What were the important events that followed? [Clarify link with learning] When and where did these events take place? Who was present?
   - When in these events/map did you learn you had a mental illness?
   - When in these events/map did you receive formal services?
   - When in these events/map did you receive information about your mental illness? … about what you can do to manage your condition and be in more control?
2. Let us look at what people or events were telling you about mental illness and self-management at each of these key events on this map.
   - Tell me about what people said, what you saw, what happened.
   - What was your reaction (feelings, thoughts, and actions)? What happened next?
   - What do you make of it? What messages did you take away? How do you interpret events? What did it mean to you?
   - What were the consequences? What happened as a result?
   - Was there a key event in your life?
3. Looking on the map of how things were when you began and how things are today, what has changed or not changed as a result of these experiences?
   - Changes in daily activities, routines?
   - Changes in relationships?

- Changes in how you see yourself? your situation?
- Changes in your health? your illness?

4. Based on your life experiences, what do you believe would need to happen for yourself/others to be engaged in learning and maybe take action about self-management?
   - Describe what helped or hindered your learning.
   - What supported you, gave you strength to take action?
   - Earlier you mentioned an issue with … How can we help people deal with this issue?
   - What do you recommend health-care staff do to support people's learning? Family/friends/care givers?
   - When and how should people be offered information?
   - Based on your life experiences, learnings, what would you say to someone just starting out? What would you say to health service planners?

APPENDIX B

Description of the eight tasks comprising the work of learning self-management

Eight tasks	Description
Reaching personal understanding of illness experiences	Obtaining a personal understanding of what mental illness means for my life and actions for managing illness: • Understand my diagnoses and translate the facts to my life context and how illness affects my daily life • Understand my role in living well and potential for a life of quality • Apply knowledge to interpret my experiences, identify own symptoms and early warning signs, work with my triggers, and develop strategies
Finding medications and services that "work with me"	Finding medications and services that work in partnership with me: • Find medications that improve symptoms, making trade-off decisions to hold psychosis at bay with medication side effects, until medications provide both stability and functioning • Form collaborative partnerships with providers that treat me as a person "not as an object … or diagnosis" and give me credibility as a person managing my own life, recognized as an expert of my experiences living with health conditions • Services support open discussion, negotiation, experimentation, self-reflection, discovery, and learning the self-management expertise; "teach clients to teach themselves" • Services tailored to me, directed at all aspects of me and living well (beyond medications, psychiatric management, or crisis/risk management)
Trusting self and managing thoughts	Learning to trust myself and learning different ways of thinking to manage thoughts and emotions (fears and shame): • Learn to distinguish "what is real and what is not" • Challenge delusions and hallucinations and hold inner dialogues/experiments • Deal directly with fears and gain confidence in own actions • Establish habit of self-monitoring, "checking in" with self, and "keeping tabs on it"
Dealing with stigma and self-acceptance	Learning ways to address and manage encounters with stigma and all its effects: • Learn to accept self and counter internalizations of stigma • Learn subtleties of self-disclosure and balancing protection and risk • Navigate others' misconceptions and deal with the "emotional fallout" • Deal with impact on family and feelings of guilt and shame
Developing and using a support network	Engaging and developing relationships with individuals and/or organizations to counter socially disadvantages, isolation and to assist with self-management tasks: • Mend and renegotiate relationships in aftermath of psychotic episodes • Overcome challenges to connect and communicate and trust others and learn skills and self-efficacy in dealing with others • Use supports to provide sounding boards for reality testing and gauging what is "normal"; sense of safety to take other risks, experiment, and grow; and resources
Discovering ways to accomplish daily living activities	Discovering ways to deal with impact of mental illness on performing routine self-care and home management activities to fulfil the necessities of living, reassure control, and create daily structure: • Learn to use a range of personal strategies to overcome barriers to performance such as mental strategies (e.g., self-talk, reality testing, self-monitoring, self-assessment and goal setting, reframing, distraction, and mindfulness), controlling physical space, restructuring activities, and connecting to faith or spirituality • Develop healthy habits and strategies for sustaining motivation and self-regulation • Consider alternatives (e.g., delegated/purchased/bartered services of others)

Eight tasks	Description
Finding meaningful occupation that "fits"	Finding occupation that is meaningful and fits me and my self-management strategies: • Finding (or for some reconnecting with) occupations that are meaningful involved contributing roles and responsibilities for a "normal" life • "Fit" means (a) finding occupations that match how I view myself (e.g., consistent with values, interests, future plans) and (b) finding the right environment for engaging in the occupation, that is, an environment that offers a sense of safety (feels valued and competent) and provides sufficient flexibility for using stress management strategies
Integrating management of comorbidities	Learning to manage in daily life comorbid mental and physical health conditions while managing a mental illness: • Learn how one condition affects the other • Implement another health regiment and lifestyle change • Use strategies/skills learned from managing mental illness to managing comorbidities and vice versa