

SELF-MANAGEMENT SUPPORT IN A RECOVERY FRAMEWORK

**LAYING THE FOUNDATION FOR SELF-MANAGEMENT SUPPORT
IN A RECOVERY FRAMEWORK**

BY

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LAYING THE FOUNDATION FOR SELF-MANAGEMENT SUPPORT IN A RECOVERY FRAMEWORK

ABSTRACT

Introduction

Despite international pressure to implement self-management support for individuals living with chronic illnesses, little direction is available for integration into specialized mental health services. The premise of the dissertation is that self-management support can be provided and be beneficial within a recovery framework for individuals living with serious mental illnesses.

Methods

A large regional service was studied as an exemplar of specialized service delivery. Using a van Manen phenomenological study through an occupational therapist lens, the meaning of clients' experiences with self-management learning events in a diverse sample was examined. Conditions shaping clinicians' experiences and actions enabling self-management across eight varied settings were identified in a Yin case study with embedded units. Provider triads (occupational therapist-nurse-social worker) from each setting, allowed an examination of patterns by individual, discipline and practice environment. With an integrated knowledge translation approach, both studies informed the strategic creation of an innovation and implementation plan for organizational change.

Results

Findings created a rich picture of clients' lifeworlds learning self-management and conditions and mechanisms influencing clinician self-management support practices. Client self-management needs were not routinely addressed by services. Clients experienced eight tasks shaped by contextual structures represented in a model of the work of learning self-management. Self-management was enmeshed in recovery and a personal resource for self-determination and living well. Another model illustrated the complex dynamic relationships underpinning clinicians' intentions and actions, and key features of clinicians enabling client self-management. A structured approach to delivering self-management support and a learning and embedding initiative were generated.

Conclusions

The dominance of practice environments offers an opportunity for organizational change. Direction is given to customize self-management support in a conventional mental health service. The conceptualization of self-management support within a recovery framework may benefit all client groups with long-standing conditions.

MeSH Keywords: Self-Care; Chronic Disease; Health Services Research; Patient-Centered Care; Organizational Innovation; Models, Theoretical; Models, Organizational

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DECLARATION OF ACADEMIC ACHIEVEMENT

For all studies:

Susan Strong envisioned the concept, selected the theoretical approach, formulated the study design, developed the study protocol and completed the ethics approval process, obtained and organized resources for implementation, managed the research projects including supervising research assistants (RA) and maintaining databases, negotiated relationships with research sites, completed the data collection with RA assistance, derived research data analysis and interpretation, and created manuscripts. Dr. Seanne Wilkins assisted with refining the research questions, my reflexivity, analysis and interpretation of the findings, and provided editorial assistance with manuscript preparation. Also, Dr Seanne Wilkins co-reviewed interview transcripts. Dr. Lori Letts assisted with refining the research questions, interpretation and communication of the findings and provided editorial assistance with manuscript preparation. Dr. Sheryl Boblin assisted with case study design, interpretation and communication of findings and provided editorial assistance with manuscript preparation.

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CHAPTER ONE

INTRODUCTION

The purpose of the dissertation is to inform the implementation of self-management support with individuals with serious mental illnesses during the delivery of specialized mental health services. The intent is to study a local health service for individuals with schizophrenia and related psychotic disorders as an exemplar of current service delivery, and to provide evidence for customizing self-management to a conventional mental health service delivery environment. Self-management is new to the mental health field, largely developed to date in other populations and healthcare sectors, and as such is considered an innovation. It is my basic premise in this dissertation that self-management support can be provided and be beneficial within a recovery framework for individuals living with serious mental illnesses.

There are many different definitions of self-management. However, the common core concept is that **self-management** refers to people actively making decisions and engaging in activities to manage or reduce the impact of a chronic or persistent condition on their daily lives in collaboration with healthcare providers. An example of a frequently cited definition: “Self-management relates to the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with the medical management, role management and emotional management” (Adams, Greiner, & Corrigan, 2004, p.57). Medical management refers to such activities as keeping appointments, communicating symptoms to providers, and following a medication regimen. Role management refers to carrying out the usual occupational

activities to maintain self/family in spite of the illness, and emotional management includes dealing with changes to self-image and self-efficacy arising from the illness experience. The Canadian ‘New Perspectives: International Conference on Patient Self-Management’ adopted this definition because it focused on the person and his/her behaviours, highlighted the importance of confidence, embraced medical management and clearly indicated the objectives for providers’ interventions (McGowan, 2005).

In the literature and this dissertation, the terms **self-management interventions** and **self-management support** are used interchangeably (VonKorff, Gruman, Schaefer, Curry, & Wagner, 1997). Self-management is what the client does whereas support is what is provided by the healthcare providers. A preliminary literature search revealed that self-management interventions have evolved to refer to a myriad of strategies for client education, health promotion, participation in care and enhancement of client coping capabilities. This dissertation is concerned with interventions that support: a) self-management as a whole rather than target a particular aspect (e.g., medication management) or part of what is involved (e.g., illness management) in managing a life with a chronic illness; and b) self-management within a recovery framework.

The term **serious mental illness** commonly refers to a spectrum of schizophrenia and mood disorders characterized by episodes of psychosis, cognitive and affective impairment that pervasively affects participation in all life domains (employment, education, self-care, home management, interpersonal relationships and leisure pursuits). Serious mental illness is defined by those disorders classified as Axis 1 in the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV-R) (American

Psychiatric Association., 2000). While recognizing heterogeneity in how illness is manifested in people's lives, in general, from a medical perspective, **schizophrenia** is a manageable condition requiring on-going vigilance and diligent action by clients in collaboration with specialized treatment teams in long-term follow-up (Canadian Psychiatric Association [CPA], 2005). The symptoms of psychosis are episodic and for most individuals treatable by psychotropic medications and psychosocial interventions (CPA, 2005). A significant segment of the schizophrenia population contends with cognitive and social impairments even when stable on medications and these persist over time (Green, 2006). Cognitive impairment rather than symptoms tends to predict performance in daily living activities (Green, Kern, Braff, & Mintz, 2000) and taking medications (Heinrichs, Goldberg, Miles, & McDermid, 2008). While recognizing that level of impairment does not directly translate to performance in given environments, the impairments can manifest as difficulty with problem-solving, planning, and setting priorities due to diminished attention; difficulties with working memory to hold onto and manipulate concepts for reasoning or issues with verbal retrieval of information; and generation of ideas and initiation of actions. In social situations, some individuals may have difficulties with emotional processing and misinterpret intentions, while others experience apathy and social withdrawal. Self-management support may require accommodation for these cognitive and social difficulties. However, individuals with schizophrenia and psychotic disorders can benefit from health education. A Cochrane systematic review estimated that 12 relapses could be avoided or postponed for a year for every 100 clients with schizophrenia who received health education and dialogue in

addition to standard care (Pekkala & Merinder, 2002). The CPA “Clinical Practice Guidelines – Treatment of Schizophrenia” (2005) recommended education “accompanied by training in practical illness management strategies to achieve medication adherence and to prevent relapse” (p.35S).

The World Health Organization (2001) ranked schizophrenia among the top 10 leading causes of disability and premature death globally for persons aged 15-44 years. The life expectancy for individuals with schizophrenia is shortened by 25-30 years (Brown, 1997; Colton & Manderscheid, 2006) with the most frequent cause of death attributed to coronary heart disease (Curkendall, 2004; Newcomer & Hennekens, 2007). People with serious mental illnesses are at significantly greater risk than the general population for a range of chronic physical conditions including diabetes, heart disease, respiratory conditions and some types of cancer (Canadian Mental Health Association [CMHA] - Ontario [ON], 2008b). The high rates of medical co-morbidity are related to multiple factors and complex relationships among biology (hormonal interactions, illness symptoms, antipsychotic medications), behaviour (smoking, alcohol and substance abuse, obesity, poor diet and sedentary lifestyle), the illness experience (stress, stigma, sense of self) and social determinants of health (poverty, unstable housing, unemployment, social exclusion) (Canadian Diabetes Association, 2008; CMHA-ON, 2008). Recognition of these transactional complexities has prompted integration of mental and physical, health and social services and adoption of a social ecological model of health. Studies have pointed to the modifiable or preventable risk factors (sedentary lifestyles, poor eating habits, smoking and anti-psychotic medication related weight gain) that potentially could

be addressed by health promotion strategies to improve medical mortality and morbidity (Goff et al., 2005).

Self-management for Canadians with schizophrenia is further challenged by contending with high rates of unemployment (62%), poverty (80-85%), social isolation and stigma (Smith et al., 2006). Stigma is a recognized central barrier to healthcare (Mental Health Commission of Canada, 2009) substantiated by evidence of growing disparity in mortality outcomes and access to physical health services (CMHA-ON, 2009). Despite Canada's universal health system and heart disease being the main cause of death, in-patients with a psychiatric disorder are less than one-third as likely as the general population to receive standard cardiac interventions such as cardiac catheterization, angioplasty or bypass graft even after adjustments for income, age, sex and comorbid illness (Kisely et al., 2007). Outpatients were more likely to access these services but with significantly less utilization than the general public. Patients seen in specialized mental health services had significantly higher mortality ratios (1.80, 95% CI 1.63-1.99) compared to patients seen in primary care (1.25, 95% CI 1.20-1.30) (Kisely et al., 2007, p.781). Sometimes physical problems are not taken seriously or go unnoticed by mental health professionals who view their primary function as controlling symptoms of the mental illness (Millar, 2008). Mueser et al. (2006) cited clinicians' protective paternalism, treatment plans not addressing clients' goals and lack of information sharing as contributing to a lack of active collaboration. Within this context, there is a great deal to be gained by efforts towards health promotion and client-clinician collaborations such as self-management support.

The Promise of Self-Management Support with Serious Mental Illnesses

Chronic disease management approaches that have become expected practice in other health sectors are equally important for people living with schizophrenia despite the potential challenges in implementation. Evidence-based models of effective health care emphasize the role of informed individuals actively making decisions and engaging in activities to manage or reduce the impact of long-term condition(s) on their daily lives in collaboration with healthcare providers (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). Self-management interventions are gaining a political profile as a credible cost-effective strategy for chronically ill patients to reduce preventable health complications and improve effective use of medical services (Canadian Health Services Research Foundation, 2007). Self-management interventions are being promoted in the health policy of Australia (National Health Priority Health Council [NHPAC], 2005), the United Kingdom (Wilson, 2001), the United States (U.S. Department of Health & Human Services, 2000) and parts of Canada (MOHLTC, 2007). With disadvantaged groups, such as those with schizophrenia, self-management support is viewed as one strategy to improve their health and address health inequities (CMHA-ON, 2009). According to the World Health Organization (1998), people having access, understanding and using health information to take action to improve their own health is a basic right. Tension is being exerted from rising public expectations for access to health information as a basic right and for participation in healthcare decision making.

By being informed about health conditions and taking part in their own care, self-management offers people the potential to live well with chronic conditions

(Bodenheimer, Lorig, & Holman, 2002). Having the ability to obtain and use health information in their daily lives is essential for clients to look after themselves and make healthy decisions (Coulter & Ellins, 2006). This holds true for people living with schizophrenia. No matter the degree of illness severity, managing the tasks of day-to-day living with schizophrenia is key to a life well lived (Martyn, 2003). An in-depth phenomenological study of self-management while living with schizophrenia found self-management was essential to participants living well and made the difference between “an ordinary life: coping... [and] an (extra)ordinary life: thriving” (Martyn, 2003, p.6). There is scant research regarding individuals with schizophrenia managing co-morbid chronic illnesses. However, a grounded theory study (El-Mallakh, 2006, 2007) examining living with diabetes and serious mental illnesses found participants applied what they learned about managing schizophrenia to managing diabetes. Relative choices and trade-offs, often to manage one condition at the expense of the other, meant the mental illness was given priority because the diabetes could not be managed when psychotic symptoms were overwhelming.

A preliminary literature review indicates individuals with schizophrenia can benefit from a chronic disease management philosophy and can engage in informed decision-making in a way that benefits their health. They can learn strategies to manage diseases (much like people living with diabetes or arthritis) that help them gain control and get on with life. For example, studies demonstrated people with schizophrenia learned to recognize the early warning signs of decompensation and take preventative actions (Morriss, 2013), learned strategies to decrease the negative aspects of hearing

voices that are not amenable to medications (Buccheri et al., 2004), and learned to use cognitive strategies to deal with delusions (Martyn, 2003). Lifestyle interventions have shown behavioural changes in areas such as smoking cessation, weight management and healthy eating (Cabassa, Ezell, & Lewis-Fernandez, 2010) particularly when interventions addressed cognitive disability and limited access to resources (Cimo, Stergiopoulos, Chiachen, Bonato, & Dewa, 2012). Demonstration projects with individuals with serious mental illnesses providing practical strategies and structured problem-solving for self-management suggested benefits to increased client engagement and participation in decision-making, decreased relapse or hospitalization rates and improved health specific outcomes (Anzai et al., 2002; Hasson-Ohayon, Roe, & Kravetz, 2007; Lawn et al., 2007; Roe, Hasson-Ohayon, Salyers, & Kravetz, 2009).

With respect to established self-management approaches (i.e., formalized in manuals/protocols and supported by governments or healthcare systems), there are six main approaches to self-management support:

1. **Stanford Chronic Disease Self-Management Program (CDSMP)** (Lorig et al., 1999; 2004; Swerissen et al., 2006; Yip et al., 2007),
2. **Expert Patients Program (EPP)** (Kennedy et al., 2007; Kennedy, Rogers, & Crossley, 2007; Rogers et al., 2008),
3. **Flinders Model of Chronic Condition Self-Management (CCSM)** (Battersby et al., 2007; 2008; Lawn et al., 2007; 2009),
4. **Illness Management and Recovery (IMR) and Integrated IMR** (Anzai et al., 2002; Fardig, Lewander, Melin, Folke & Fredriksson, 2011; Hasson-Ohayon, Roe &

- Kravetz, 2007; Levitt et al., 2009; Mueser et al., 2006; Roe et al., 2009; Salerno et al., 2011; Salyers et al., 2010; Salyers, Rollins, Clendenning, McGuire & Kim, 2011; Whitley, Gingerich, Lutz, & Mueser, 2009),
5. **Admire Plus (SMART Model)** (Brooks & Penn, 2003; Penn & Brooks, 1999; Penn, Brooks, Gallagher, & Brooke, 2009),
 6. **Health Coaching** (Department of Human Services, 2007; Kubina & Kelly, 2007).

Appendix A: Matrix of Six Self-Management Approaches describes each approach including development and context of operation, view of person, conceptual basis, key components, and implementation structure, anticipated outcomes, research support, and use with individuals with serious mental illnesses. All were designed to augment regular treatment and other rehabilitation interventions. Although each arose from different traditions, sectors and locations around the world, over time they converged to create interventions that addressed the impact of both physical and mental illness needs of individuals with serious mental illnesses, including dealing with addictions. While the approaches vary in how they are structured (disease-specific or generic), they have the following key components in common:

- Focus on changing health behaviours,
- Use motivational strategies to engage and sustain behavioural changes based on Social Cognitive Theory (Bandura, 1989) and borrow from Motivational Interviewing techniques (Miller & Rollnick, 2002),

- Involve interactive, structured teaching of problem solving and coping strategies to increase knowledge, skills and self-efficacy for managing the day-to-day tasks of living with a chronic condition(s),
- Use problems and concerns identified by clients and clients' life experiences to direct the focus and content of sessions, and
- Engage and facilitate clients to use local resources and supports.

The Australian government has operationalized 'self-management interventions' in a Self-Management Mapping Guide (State Government of Victoria, 2007) for organizations to map existing services in local catchment areas. Based on the Stanford, Flinders and Health Coaching approaches, the Guide defines self-management interventions as those which: a) promote three or more of the five **skills** described in the Chronic Care Model (Wagner et al., 2005) (problem-solving, decision making, resource utilization, patient-provider relationships, taking action) or b) focus on three or more of the five **client outcomes** described in the Flinders Model (know their condition and various treatment options; negotiate a plan of care; engage in activities that protect and promote health; monitor and manage the symptoms and signs of the condition(s); and manage the impact of the condition on physical, emotional and social role function such as interpersonal relationships).

Arising from primary care, the generic self-management programs which serve clients with all chronic conditions (Stanford, EPP, Health Coaching) are built upon the assumption that people with different chronic diseases have similar problems and concerns. It is not known to what extent this holds true for people with serious mental

illnesses. Therefore, the following questions arise. What do we know about the similarities and differences between the self-management challenges faced by people with serious mental illnesses and people with other chronic illnesses? Are there differences between groups in not only what are the most relevant challenges but in how the challenges are being met by the people themselves and the health services being delivered? Do people with serious mental illnesses start from a different place when confronted with a chronic physical illness? Condition-specific programs developed in specialized mental health and/or addictions sectors specifically for individuals with mental illnesses (IMR, Flinders, Admire Plus) have had to expand to address issues related to physical conditions and addictions, and are just beginning to deal with implementation issues (Battersby et al., 2010) as they are adopted more broadly. Generic programs are being adapted to respond to the needs of groups living with specific conditions and healthcare delivery systems. For example, the CDSMP (Lorig et al., 1999) was adapted to peer led programs tailored to specialized services for individuals with serious mental illnesses and medical illnesses (Druss et al., 2013; Goldberg et al., 2013). Self-management support with individuals with serious mental illnesses is an emerging area with many fundamental questions to be answered.

Recovery and Chronic Disease Management Dissonance

A key driver of self-management is governmental adoption of chronic disease management models. However, this has taken place largely outside the mental health

sector. The following explains some of the controversy relative to chronic disease management and mental illness occurring in Ontario.

Internationally, countries have developed health care policies based on various forms of the Chronic Care Model (Wagner, Austin, & VonKorff, 1996; Wagner et al., 2005) which depict a health system composed of informed, activated patients productively interacting with prepared, proactive practice teams. Patients and teams are sustained by self-management support, a delivery system, decision support and clinical information systems that produce clinical and functional outcomes, address patient satisfaction and consider cost. To better direct the management of health care and include health promotion with disease management, the World Health Organization and the MacColl Institute for Healthcare Innovation revised and enhanced the Chronic Care Model (Wagner et al., 1996) creating the Innovative Care for Chronic Conditions (ICCC) (Epping-Jordan et al., 2004). Further, a group in British Columbia created the Expanded Chronic Care Model (McGowan, 2003) in which the interest shifted to a triad of patients/families-health care teams-community partners and the community gained prominence.

The Ministry of Health and Long-Term Care (MOHLTC) adopted the **Ontario Chronic Disease Prevention and Management (CDPM) Framework (Figure 1)** (MOHLTC, 2007), a further iteration of the original Chronic Care Model (Wagner et al., 2005). The framework is comprised of a cluster of interconnected, mutually dependent practice and system changes (i.e., personal skills and self-management support, delivery system design, provider decision support, information systems). Individuals are viewed

as “equal partners in their own health and full collaborators in managing their conditions” (p.9) supported by “multi-faceted, planned, pro-active seamless care” (p.9) and community strategies for health promotion and prevention of secondary morbidity. Core system changes, including the provision of self-management supports, will be required to produce the triad of ‘informed activated individuals/families’, ‘activated prepared proactive community partners’ and ‘prepared proactive practice teams’.

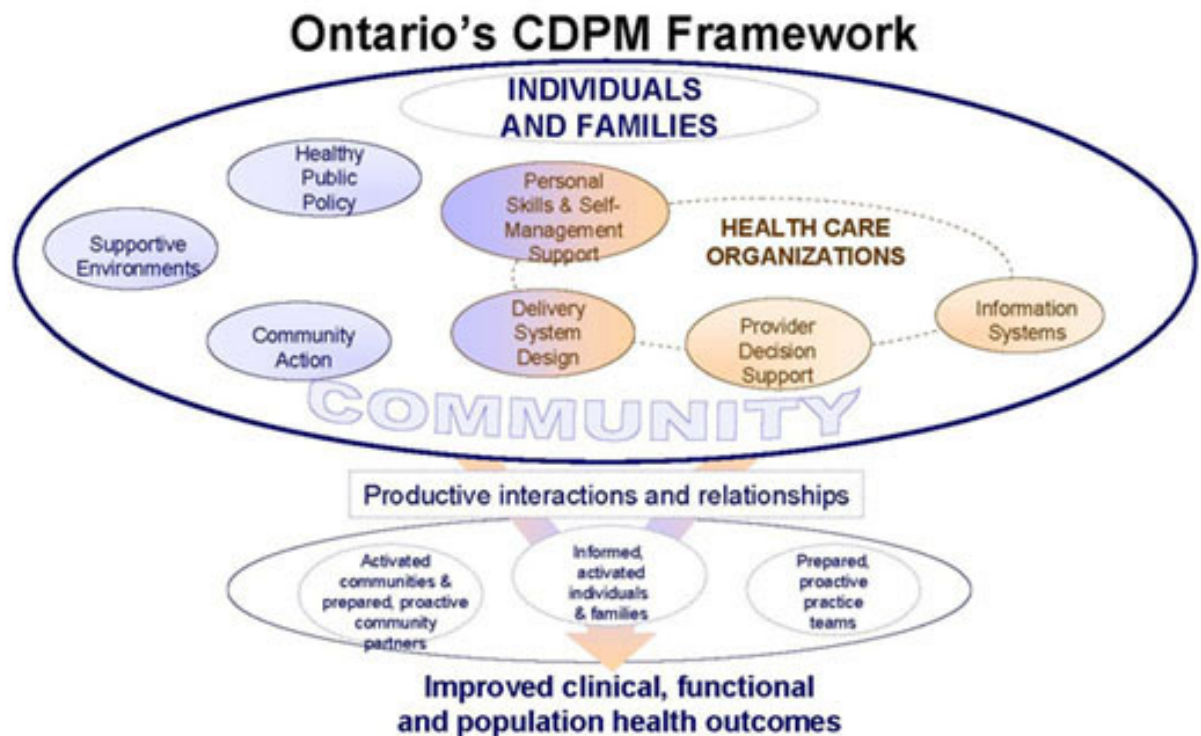


Figure 1. Ontario's Chronic Disease Prevention & Management Framework. Reprinted from “*Preventing and Managing Chronic Disease: Ontario's Framework*,” (p.8), by MOHLTC, 2007, Toronto, ON: Author. © Queen's Printer for Ontario. Reprinted with permission.

The Ontario CDPM (MOHLTC, 2007) framework and proposed policies are being discussed in the mental health sector. Consumers of mental health services have

criticized the CDPM's language of 'chronic' and 'disease management' as connoting people as passive recipients of problem-based, illness care that is provided indefinitely and not properly reflecting consumers' values and expectations of healthcare (Cheng, 2010). For example, Cheng (2010) argued that "coming as I do from a consumer/survivor perspective, I bridle at the idea that individuals with a mental health diagnosis have a chronic disease that needs to be managed" (p.20). The dissonance is that although the chronic disease literature views serious mental illnesses as chronic conditions, the mental health community frames serious mental illness around the concept of recovery (CMHA-ON, 2008).

According to CMHA (2005), "mental health **recovery** is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential" (p.16). **Recovery philosophy** is the belief that individuals with mental illnesses can recover a positive sense of self beyond the limitations of an illness, regain some control over their lives and find a meaningful place in the world (CMHA, 2005). For 30 years, a consumer movement lobbied to integrate a recovery philosophy into healthcare delivery. Within this broader view of illness experiences and the impact of mental illness, mental health services shift from clinical illness-based care to a social model of health focused on restoring or regaining a life. Currently, the recovery philosophy guides the mental health sector reform under way nationally (Mental Health Commission of Canada, 2009) and provincially (Provincial Forum of Mental Health Implementation Task Force Chairs & MOHLTC, 2002). The concern is that adoption of the CDPM (MOHLTC, 2007)

framework may be a step backwards, where individuals with schizophrenia are labelled chronically disabled, destined to progressively deteriorate, with little hope for a satisfying life forever defined by the illness (CMHA-ON, 2008). Others have voiced positive reactions to a ‘chronic illness’ label saying it can combat stigma and shame by viewing mental illness as any other illness that can be managed while having a full life (Neuwelt, 2009).

At this point, the CDPM approach has not been tested in the serious mental illness arena. In a CMHA Ontario discussion paper (CMHA-ON, 2008), it is posited that serious mental illnesses may benefit from a CDPM approach but asks whether the recovery approach and current services/supports fit within the CDPM (MOHLTC, 2007) framework. The authors recognized the value of integrating physical and mental health care while suggesting important differences between serious mental illnesses and chronic physical illnesses regarding disease prevention, course and impact. They argued that additional strategies beyond the CDPM prevention/management approach may be needed and emphasized addressing the population-based social determinants of health (income, housing, education, employment, social inclusion) to reduce risk and strengthen protective factors. The CMHA-ON paper pointed to the CMHA-ON’s own policy **‘Framework for Support’** and the **‘Three Pillars of Recovery’ (Figure 2)** (2004) proposed to address mental health, social inclusion and self-determination for a full recovery to citizenship.

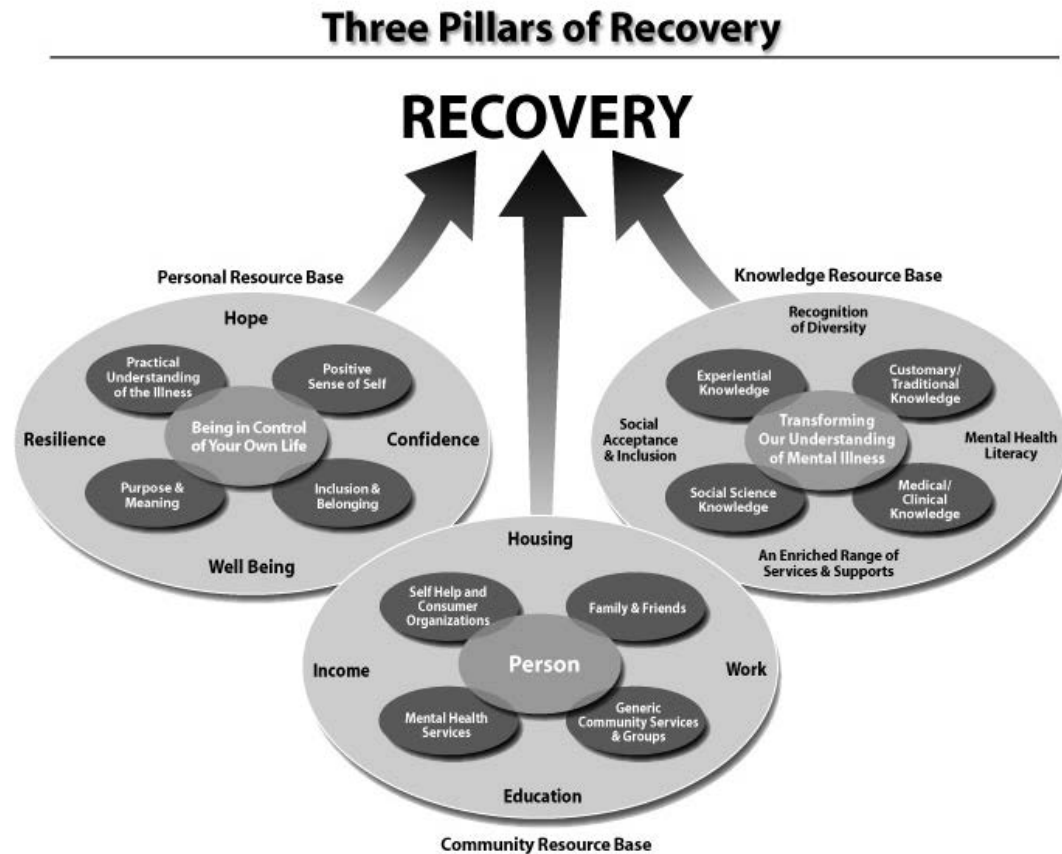


Figure 2. Framework for Support. Reprinted from “A Framework for Support (3rd ed),” (p.24), Retrieved from http://www.cmha.ca/BINS/content_page.asp?cid=7-13-981. © 2004 by the Canadian Mental Health Association, National Office. Reprinted with permission.

The ‘Framework for Support’ (CMHA-ON, 2004) depicts three ‘pillars’ or three essential foundational elements for recovery:

1. Community resources (family, friends, mental health services, self-help and community organizations) for establishing instrumental living requirements (e.g., home, job, friends);

2. Personal resources or “the tools people with mental illnesses need to achieve a sense of control in their lives: purpose and meaning in life, a sense of belonging, a positive sense of self and a practical understanding of the illness” (p.9);
3. Knowledge resources in which our shared knowledge of mental illness and life with mental illness is expanded, incorporating a diversity of knowledge and ways of knowing to promote social inclusion and support responsive services and supports.

In CMHA’s ‘Framework for Support’ (CMHA-ON, 2004), health care is an important component of recovery but is not given the central focus depicted by the Ontario CDPM (MOHLTC, 2007) framework. Instead citizenship, family, self-help and the community as a whole are emphasized with the person with mental illness at the centre. In other words, the CMHA Framework illustrates that the CDPM is insufficient for addressing recovery for individuals with serious mental illness (Neuwelt, 2009).

Although CMHA-ON expressed concerns, opportunities were recognized also as the CDPM Framework has the potential to address health inequities regarding access to primary and preventative healthcare (CMHA-ON, 2009). The CMHA released a policy paper (CMHA-ON, 2008a) outlining 13 recommendations for addressing co-morbid physical and mental illnesses. The recommendations focus on the prevention and management of chronic physical conditions in people with serious mental illnesses, the prevention and treatment of depression in people with chronic physical conditions, and actions to improve Ontarians’ mental health literacy (knowledge and understanding of mental illness) and the broad social determinants of health. In the context of addressing chronic physical health conditions among people with serious mental illnesses,

recommendation three endorses providers, community organizations and mental health consumers working together to remove barriers viewed as particular to this group and “develop approaches to [support] healthy behaviours and self-management of chronic conditions” (p.3).

Also, the CMHA is building alliances with other organizations with similar views. The CMHA-ON joined the Ontario Chronic Disease Prevention Alliance (OCDPA), a grass-roots collaborative of non-governmental health-related organizations that promote public policies to use a socio-environmental approach rather than a focus on the individual. As rationale, they point to accumulating evidence of global and social conditions in which people live, significantly influencing the development of chronic disease (Haydon, 2006). Using a social determinants of health perspective, the OCDPA emphasizes comprehensive systems-based actions to create conditions for health such as promoting access and availability of resources (Ontario Chronic Disease Prevention Alliance [OCDPA], 2009), including those in the Three Pillars of Recovery.

Despite the voiced concerns with the CDMP Framework, CMHA-ON is engaging in discussions and planning with the MOHLTC. Diabetes was selected as the first priority area for implementation of the CDPM Framework (MOHLTC, 2007). CMHA-ON partnered with MOHLTC planners, policy analysts, diabetes clinicians and program managers for a one-day think tank to identify strategies and create an action plan for cross sectoral collaboration to improve diabetes prevention and management for people with serious mental illnesses (CMHA-ON, 2009). The group reviewed the Ontario CDPM Framework (2007) and evidence of individuals with serious mental illnesses being

disproportionally affected by diabetes. Key drivers of the disproportionate burden are the higher prevalence, lack of screening and underdiagnoses, and undertreatment compared to the general population (CMHA-ON, 2009). One of the 20 generated strategies included collaborative partnerships between mental health, public health and diabetes sectors to build capacity to address healthy living, education and self-management with social recreation and peer support group-based programs (CMHA-ON, 2009).

In summary, the MOHLTC's implementation of CDPM Framework (2007) has met with controversy in the mental health sector. There is a disconnect in culture and the meaning of terminology. The mental health sector has a rich history of incorporating recovery into policy. The CDPM Framework is insufficient to convey the foundational concepts and meaning of recovery yet offers an integration of mental health care, an attractive prospect amidst historical marginalization and inequitable service delivery. During my dissertation, I am examining the conceptualization and potential implementation of self-management support within a recovery framework for individuals with serious mental illnesses using the Ontario CDMP Framework.

Self-Management Support within a Recovery Framework as an Innovation in Specialized Mental Health Services

For this dissertation in the context of delivering specialized mental health services, the implementation of self-management support within a recovery framework is considered an innovation. The provision of self-management support within a recovery framework represents a departure from traditional medical model disease-based services.

Recovery-based services require a fundamental shift in attitudes and practices (Farkas, Gagne, Anthony, & Chamberlin, 2005; Mental Health Commission, 2002). In practical terms, self-management can be seen as the application of recovery by allowing people to take responsibility for their lives and collaborate with health professionals as equals.

Accompanying a change in service delivery model are changes in what become the goals of treatment, client-therapist relationships and treatment approaches. Moving from a disease-based to a recovery-based framework requires a transformation in how the client is viewed, what is emphasized in service delivery and client-provider roles. **Table 1.**

Comparison of Frameworks and Application of Self-Management outlines this shift in views, roles and practices as applied to self-management in a recovery framework. The transition will also require changes for clients. It is expected some clients may prefer service delivered traditionally. In a recovery framework, such a choice is respected while continuing from time to time to offer alternatives.

Adoption of Innovations by Providers in Healthcare Organizations

Research has identified characteristics or attributes of adopters (providers), innovations, and organization environments that support adoption of innovations in service organizations (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004). However, little is known about why and how these attributes work together to spread the use of an innovation within an organization or sustain an innovation's use over time for integration into routine practices, prompting a call for studying provider-innovation-practice environment relationships at the program level (Greenhalgh et al., 2004).

Table 1. Comparison of Frameworks and Application of Self-Management

	Disease-Based Framework	Recovery-Based Framework (Farkas, 2007; Mental Health Commission, 2002)	Self-Management within a Recovery Framework (Adaptation of Greenhalgh, 2009; Lorig & Holman, 2003)
View of Person	<ul style="list-style-type: none"> Deficits, limitations Uninformed Recipient of care 	<ul style="list-style-type: none"> Whole person, resilient, potential for growth, transformation Expert, responsible, competent Requires social determinants of health and regaining a sense of control over life & illness; 	<ul style="list-style-type: none"> Chooses whether to engage in self-management Ability to build capacity for self-management; building on experiential knowledge Interdependence re: resources, supports Balancing dynamic contextual demands of home, community and healthcare system
What is Emphasized in Therapy	<ul style="list-style-type: none"> Treatment of disease, symptoms Treatment driven by results of medical tests & procedures and providers' expert formulation of the problem Adherence to treatment regiment Regain independence, self-sufficiency 	<ul style="list-style-type: none"> Wellness & recovery planning Person orientation; Clients' preferences, values, goals, experiences, strengths Person involvement in planning, implementing & evaluating services Self-determination/choice Hope & growth potential; expressed belief, opportunity to engage in meaningful, normalizing roles as citizens beyond maintenance of illness Accessing resources, including information & supports, including peer support, self-help groups Developing supportive living/learning/working environments 	<ul style="list-style-type: none"> Life goals and community living challenges, including illness management Health & illness toward recovery & well-being Client defined concerns & problems re: SM tasks (medical, role, emotion management); including managing stigma, discrimination, marginalization, occupational deprivation Provided opportunities for gaining SM knowledge, skills & self-efficacy: problem-solving, decision-making, resource utilization, client-provider partnerships, taking action Learn principles for changing behaviours & “self-tailoring” (Lorig & Holman, 2003, p.3); self-monitoring Social integration, reciprocity & social capital Accessing, using & appraising available community resources
Client-Provider Roles	<ul style="list-style-type: none"> Provider works for, takes care of client. Provider as expert; assesses, treats 	<ul style="list-style-type: none"> Collaborative partnership Client is expert in own recovery Provider as consultant 	<ul style="list-style-type: none"> Reciprocal/full partnership Client is engaged informed citizen, self-determined Provider is enabler, coach, resource, advocate Learning together; challenging barriers to health together

Literature reviews of dissemination or knowledge translation interventions to change clinicians' practice behaviour concluded interventions have had only small to moderate effects (Greenhalgh et al., 2004; Sudsawad, 2007). Reviews recommended the following:

- Change requires strategies targeted at different levels (individual, discipline group, clinical team, program level, organization level) (Grol & Grimshaw, 2003; Sudsawad, 2007).
- Interventions need to be tailored to specific settings and target groups (Grol & Grimshaw, 2003) facilitated by dialogue between knowledge producers and knowledge users (Jacobson, Butterill, & Goering, 2003). User needs assessments supported perceived relevance and planning applicable educational interventions (Davis et al., 1999).
- Active rather than passive dissemination strategies (e.g., traditional didactic teaching with reading materials) are more effective to effect behaviour change (Grimshaw et al., 2001; Lavis et al., 2003). Experiential learning, reminders, audit and feedback, outreach visits or academic detailing, credible opinion leaders and client-mediated interventions have demonstrated changes in provider behaviours but vary with different types of providers, practice settings and targeted behaviours (Leff et al., 2007; Sudsawad, 2007).
- Change is facilitated by opportunities for clinician self-reflection and discussion with workplace colleagues. People are social beings and learn through social interaction assigning meaning to actions. Knowledge “is socially constructed and frequently

contested and must be continually negotiated among members of the organization” (Greenhalgh et al., 2004, p.606). An exploratory study found the credibility of the trainers and training together with colleagues from their own workplace were the critical elements for transfer into clinical practice (Gauntlett, 2005). During discussions, Milne and colleagues (2003) found they needed to provide specific support for mental health providers “to reframe the challenging [client] behaviours with which they must deal” (p.97) for successful transfer.

- Change requires the systematic use of multifaceted theory-based strategies rather than the use of a single strategy (Grol & Grimshaw, 2003; Sudsawad, 2007).
- Change needs to be supported by restructuring workplaces (Leff et al., 2007). Key organizational aspects include: the creation of a continuous learning culture and the organizational commitment to a particular change (Kontoghiorghes, 2004), on-going support through organized meetings with colleagues and supervisors, sufficient opportunities and time to practice and enact new learning, and administrative support (Milne, Gorenski, Westerman, Leck, & Keegan, 2000).

In sum, multi-faceted interventions are required that support a social learning process for clinicians to adopt and integrate new ways of working into existing practices coupled with organizational restructuring.

This speaks to the need for a participatory approach of active, meaningful partnerships in which the end-users (clients, providers, policy-makers) are integrated into the process of translating research findings into actions during routine service delivery. The intent is that by researchers and users collaboratively working together, research

results are more likely to be relevant and likely to be used by knowledge users. The integration of end-users into the process affords opportunities for obtaining the necessary information to target and tailor information relevant to the end users, for identifying the necessary workplace processes and structures that need to be modified or added for routine implementation, and for supporting the dialogue essential to the social learning process so critical for ownership and commitment to implementation of the innovation. In what has come to be known as an **Integrated Knowledge Translation (IKT)** approach, knowledge is co-produced, exchanged and translated into practice within a collaborative knowledge user-researcher partnership (Parry, Salsberg, & Macaulay, 2013). In the context of this dissertation, knowledge users are clients, clinicians, managers, and the director of the service.

The Opportunity for Research

Given the promise of self-management for individuals with serious mental illnesses and how health policies around the world are adopting chronic disease prevention and management models, self-management and the design of service delivery to support self-management is a priority area for research. Currently self-management initiatives are largely supported by self-determination values as the research with this population is in the early stages of development. Self-management support with individuals with serious mental illnesses is an emerging practice. There is the need for foundational research. Debates are taking place over the fit between conceptualizations of

self-management, self-management support, recovery and models of service delivery in the mental health sector. Research is needed to provide conceptual clarity and direction.

How can self-management support using the CDPM Framework (MOHLTC, 2007) be operationalized in the delivery of specialized mental health services at the program level? There are many unanswered questions about what needs to be delivered and how best to deliver self-management support in this context. In other health care sectors, self-management programs have been criticized for not serving those individuals who would most benefit (e.g., low socioeconomic backgrounds, ethnic groups), and in doing so, may be further contributing to health inequalities (Rogers et al., 2008). Access to interventions targeting needs related to self-management is not routine practice in many settings (Coulter, Parsons, & Askham, 2008). With the exception of the Australian Flinders Model, the reviewed approaches to self-management support are singular stand-alone programs not embedded in service delivery which provide limited service access to small groups of individuals. How can systems and services be aligned to facilitate access and participation by this marginalized group of people?

A reasonable first step is to examine the current situation regarding clients learning self-management and provider self-management support practices used in specialized mental health service delivery. Although a rich body of longitudinal research exists about the recovery process with serious mental illnesses (Davidson, Harding, & Spaniol, 2005), little is known about the intersection of recovery with health services and mental health providers' efforts to support individuals' self-management. How are clients with serious mental illnesses learning about self-management while currently receiving

services in a service delivery system not targeting self-management? Although mental health providers are not familiar with the term self-management, providers are conversant with recovery philosophy and talk about enabling clients to have access, understand and use health information (i.e., health literacy). How are providers enabling clients' health literacy in the context of delivering specialized mental health services? Health literacy is a fundamental component of self-management which self-management support programs have been criticized for inadequately addressing (Jordan, Briggs, Brand, & Osborne, 2008). What are clinicians' attitudes towards and experiences with supporting client self-management? What are the conditions and mechanisms shaping providers intentions and actions enabling self-management? How can self-management support be integrated into services for individuals with serious mental illnesses? Would an integrated knowledge translation approach facilitate the process of translating knowledge into actions during routine service delivery?

The Dissertation

The purpose of the dissertation is to inform the implementation of self-management support with individuals with serious mental illness during the delivery of specialized mental health services. The intent is to study a local specialized mental health service for individuals with schizophrenia and related psychotic disorders as an exemplar of current service delivery from which to learn, and to provide evidence for customizing self-management support to a conventional mental health service delivery environment. By increasing understanding of the current context, we will be positioned to build upon existing conditions and processes that support self-management and develop strategies to

target potential barriers to implementation. In this way, a future intervention will be well matched to the local needs, capabilities and culture.

Research Objectives

1. Describe **clients'** critical self-management learning events, including intersections with service delivery from the perspective of clients as outpatients of a specialized mental health service, and offer interpretations of the meaning of events with respect to recovery, self-management and implementation of self-management support.
2. Identify **clinicians'** perspectives, experiences and practices with enabling self-management in the context of routine service delivery across a specialized mental health service.
3. Discover the **conditions and drivers that shape clinicians' intentions and actions** in this regard.
4. Use study findings from objectives #1-3 to inform the **operationalization of self-management support within a recovery framework** at a program level.

Specifically, customize a self-management support tool, provide an assessment of innovation-adopters-practice environment supports/strengths and barriers/weaknesses and plan an initiative to implement self-management support.

My underlying **assumptions** are that: a) recovery is not an intervention providers can make happen but rather a uniquely personal journey that is the work of the person with the mental illness; b) health literacy is a right as is the opportunity to choose to engage in self-management; c) self-management is a shared individual and community

responsibility; and d) implementation of self-management support is envisioned within a social-ecological perspective (Greenhalgh, 2009).

The basic premise of the dissertation is that self-management support can be conceptualized and be beneficial within a recovery framework during delivery of specialized services with individuals with serious mental illnesses.

Research Design

Three studies were conducted to lay the foundation for future implementation of self-management support. Each study's design was selected to match the particular study's focus and questions being asked. Sequentially, each study's findings informed strategic planning of an innovation and implementation plan for organizational change. Collectively, the three studies provided the necessary evidence, and initial plan for integration of self-management support into practice.

The first study explored, from clients' perspectives, the context of clients learning about self-management, intersections with healthcare delivery, the labels clients attach to experiences and what clients take away from life experiences with critical learning events. A hermeneutic phenomenological design using van Manen's approach (van Manen, 1997) was selected because van Manen intertwines descriptive and interpretive (hermeneutic) elements by both describing the essential structures of lives as they are lived (critical learning events) and grasping the meaning of those experiences (interpret the meaning of critical learning events within the broader socio-political context and personal recovery journeys). Van Manen's (2002) epistemology views

understanding as “not primarily Gnostic, cognitive, intellectual, technical – but rather it is pathic, that means situated, rational, embodied, and enactive” (Practice as pathic knowledge, para. 1). This resonates with me as an occupational therapist who understands people engaged in the world as pathic occupational beings: learning about ourselves and the world through participation in daily occupations within given environments through transactional person-environment-occupation relationships (Canadian Association of Occupational Therapists, 2007).

The second study focused on conditions influencing providers’ perspectives and practices of enabling clients to access, understand and use health information in the context of routine service delivery. Since self-management is not talked about by providers, health literacy was used initially to spur discussions of providers’ perceptions and actions surrounding enabling clients to learn about their own illness(es) and what they can do to manage their condition and be more in control of their lives. Although unfamiliar with the term self-management, providers readily described self-management support practices. Yin’s (2009) single case study approach with embedded units (individual, discipline, locations) was selected to obtain a rich picture of the practices of three provider disciplines (nursing, social work and occupational therapy) and the conditions that shaped the process of enabling self-management at eight locations. Case studies are best suited to provide a comprehensive description of a phenomenon within its natural context using multiple sources of evidence and to go beyond describing ‘lived’ experiences to evaluating a process (Yin, 2003). The case study design facilitated going beyond descriptions of clinicians’ perspectives and practices to offer explanations of how

clinicians' intentions and behaviours were shaped by the individual, discipline and practice environment.

The **third study** used an integrated knowledge translation approach (Parry, Salsberg & Macaulay, 2013) to adapt a tool for teaching healthcare providers a structured approach to self-management support. In a collaboration, guided by theory, findings from the first two studies were built upon using evidence-based strategies to plan a Learning and Embedding Initiative for integration into routine service delivery. The messages, materials and protocol provide the operationalization of self-management support within a recovery framework at a program level.

Conceptual Framework

All three studies will be used to operationalize self-management support within a recovery framework at a program level. Also, all three studies inform the barriers and facilitators to clients and providers engaging in self-management support in the context of specialized service delivery. Two models were selected as a framework to guide the synthesis, interpretation and communication of findings from the three studies: the Ottawa Model of Research Use and the Person-Environment-Occupation Model described below.

a) Ottawa Model of Research Use (OMRU) (Graham & Logan, 2004a) (Figure 3) is designed to facilitate integration of research evidence into healthcare organizations by policymakers at the level of individual clinicians, healthcare teams and/or organizations. The OMRU frames the process or steps of an innovation's implementation: assessment, monitoring and evaluation. The model describes an assessment of characteristics and

transactional relationships among the innovation (self-management support), potential adopters (providers, clients) and practice environment (healthcare and community environments) that can act as supports or barriers to the innovation implementation.

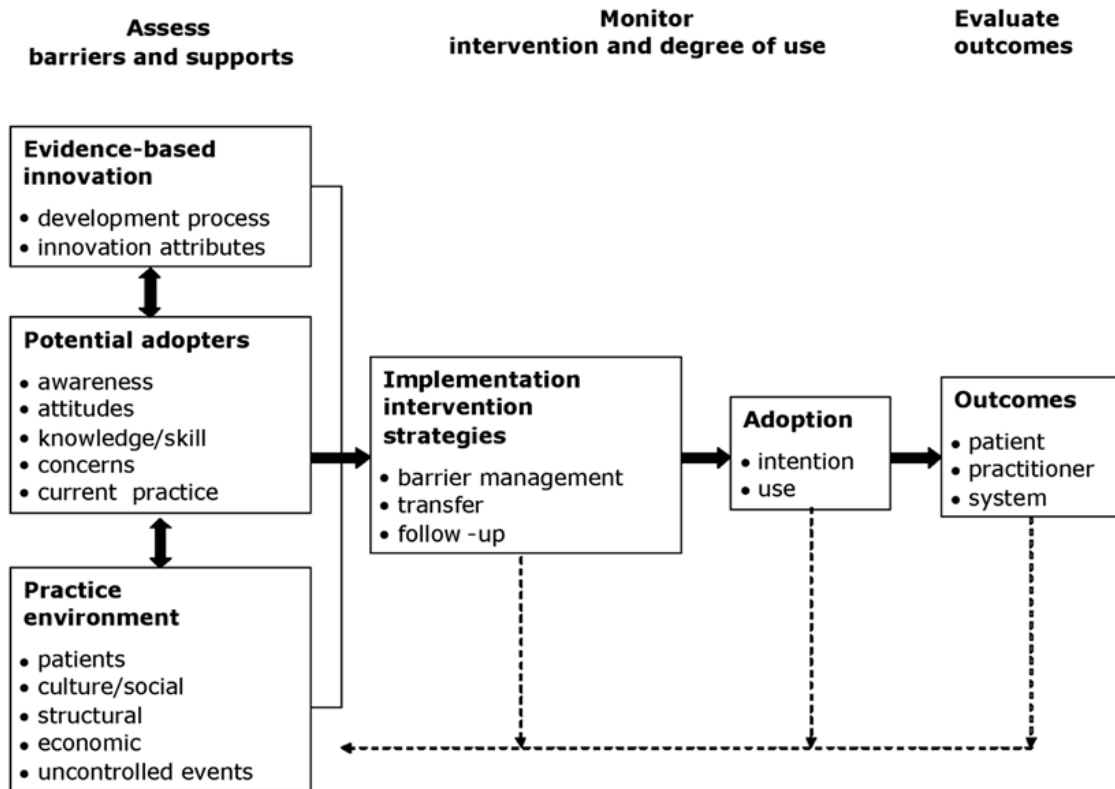


Figure 3. Ottawa Model of Research Use (OMRU). Reprinted from “Translating Research: Innovations in Knowledge Transfer and Continuity of Care,” by I. Graham and J. Logan, 2004, *Canadian Journal of Nursing Research*, 36, p.94. © 2004 by the Canadian Journal of Nursing Research. Reprinted with permission.

For this dissertation’s context, practice environment is wherever practice takes place and for many providers that includes a variety of healthcare (hospital psychiatric units, outpatient clinics) and community locations (clients’ homes, stores, buses). Also, given supporting self-management requires a client-provider partnership, the OMRU is further

modified by moving client from practice environment to potential adopter. In this way for any self-management intervention planners will need to consider the client as an adopter and his or her self-management practices and self-management environments.

The OMRU was chosen to be used as an overarching framework because it matches the dissertation's purpose and operates within a constructivist paradigm in which reality is a social construction of relativism (ontology) and pluralism (epistemology). The OMRU not only considers the interdisciplinary nature of healthcare delivery from multiple perspectives, but offers a contextual framework of provider/client-innovation-practice environment relationships that impact adoption of the innovation (self-management support). Also, the OMRU would assist policy-makers to link findings with potential interventions. The model was developed from the diffusion of innovations literature over a series of research utilization projects regarding skin care in tertiary hospitals, long-term care, a community nursing agency and family needs assessment in neonatal intensive care coupled with review by the Ontario Healthcare Evaluation Network (Graham & Logan, 2004a; Graham & Logan, 2004b; Logan & Graham, 1998).

b) Person-Environment-Occupation (PEO) Model (Law et al., 1996) (Figure 4) is widely used in occupational therapy to analyze occupational performance issues and depicts my way of knowing the world. The PEO Model describes the transactive, dynamic relationships that occur when people (providers) engage in occupations (implementation of practice innovations) within given environments (clients with serious mental illness with varying circumstances, multidisciplinary teams, clinical programs)

over time. Similarly the PEO Model is used to describe the evolving relationships when clients (person) engage in self-management tasks (occupations) within living environments supported by specialized service delivery (living environments with varying supports/barriers, providers, services).

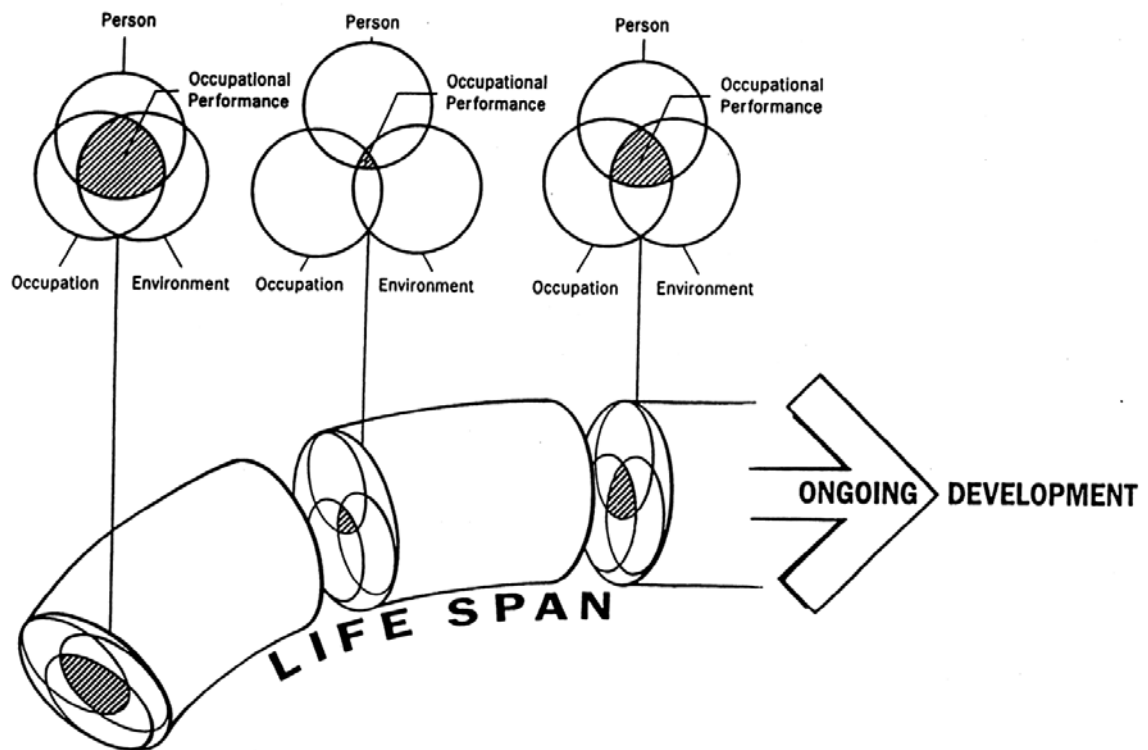


Figure 4. Person-Environment-Occupation (PEO) Model. Reprinted from the “Person-Environment-Occupation Model: A Transactive Approach to Occupational Performance,” by M. Law, B. Cooper, S. Strong, D. Stewart, P. Rigby and L. Letts, 1996, *Canadian Journal of Occupational Therapy*, 63 (1), p.11. © 1996 by the authors. Reprinted with permission.

In this way, the PEO Model supports the shifts in perspectives taken in this dissertation. The PEO Model complements the OMRU by offering a way to conceptualize and potentially explain the dynamic changing relationships among elements.

Environments, occupations, and people are viewed as having both enabling and constraining effects on one another; they shape each other, change over time, and ascribe meaning in the process. The transactive relationships are interwoven, and interdependent, with the result being greater than the sum of individual elements. Occupational performance is the product of these relationships (i.e., self-management when client is the ‘person’ or self-management support when provider is the ‘person’). Occupational performance refers to both the subjective experience of engaging in an occupation in a given environment and the observable performance. The greater the congruence, or person-environment-occupation fit, the more optimal the occupational performance.

Setting and Population of Dissertation Studies

The mission of the Schizophrenia and Community Integration Service is to provide specialized mental health and addiction services for individuals with schizophrenia and related psychotic disorders to achieve their personal goals through symptom reduction, better management of their health, and meaningful participation in life. The individuals served have an Axis 1 diagnosis and have diverse and complex psychiatric, physical, psychosocial, behavioural, and legal needs requiring specialized service. The service is mandated to serve people in Hamilton-Wentworth and surrounding regions of Halton, Niagara, Brant, Haldimand-Norfolk, a population of 1.6 million people or an estimated 16,000 individuals with schizophrenia at 1% of population worldwide (Hafner & an der Heiden, 1997).

Given the specialized nature of treatment for tertiary schizophrenia and the way Ontario’s services are organized, almost all people with severe and persistent

schizophrenia receive services through this particular service for those regions. It is a large diverse service comprised of: three inter-disciplinary inpatient units (84 beds); a community case management outpatient clinic (Community Schizophrenia Service); an outpatient early psychosis consultation clinic (Cleghorn); outreach teams that provide transitional services or intensive case management (Transitional Outpatient Schizophrenia Service -TOPSS, Public Health Street Outreach, four Assertive Community Treatment Teams - Hamilton ACT Teams 1 & 2, Haldimand-Norfolk ACTT, Brant ACTT); a Club House Program (Inspiration Place); a Centralized Rehabilitation Program (vocational, addictions services); Homes For Special Care (residential care home program) and Skills Centre. Inpatient areas and outpatient clinics have full inter-disciplinary teams (psychiatrists, medical physicians, nurses, social workers, occupational therapists, recreational therapists, vocational counsellors) with auxiliary services (e.g., Peer Support Services, spiritual care, pharmacists, music therapists). The ACT Teams have full compliments coupled with Peer Specialists as staff.

The diversity of services, disciplines and concentration of people with serious mental illness being served makes this an ideal site for research. I recruited participants for the three dissertation studies from different locations within the Schizophrenia and Community Integration Service (**Table 2**). Study participants were clients (#1), clinicians and managers (#2) and managers (#3).

Table 2. Location of Participant Recruitment by Study

Location	Study #1	Study #2	Study #3
Inpatient Unit – A2		<input checked="" type="checkbox"/>	}
Inpatient Unit – C2		<input checked="" type="checkbox"/>	
Inpatient Unit – D2		<input checked="" type="checkbox"/>	
Outpatient Clinic - Community Schizophrenia Service	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Outpatient Early Psychosis Clinic - Cleghorn		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Hamilton ACT Team 1	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Hamilton ACT Team 2	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Brant ACTT		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Haldimand-Norfolk ACTT			<input checked="" type="checkbox"/>
Club House Program - Inspiration Place	<input checked="" type="checkbox"/>		}
Centralized Rehabilitation	<input checked="" type="checkbox"/>		
Skills Centre	<input checked="" type="checkbox"/>		

Layout of Dissertation

This PhD dissertation is organized as an integrated document consisting of an introductory chapter, three chapters written as manuscripts and a final concluding chapter. Together the chapters describe the process of gathering evidence about the current practices and context and propose an innovation for integration of self-management support within a recovery framework.

Chapter One: Introduction

The introductory chapter provides background information about the dissertation's purpose, terminology, and research design together with key contextual information concerning the importance, controversy and potential for considering self-management within a recovery framework. The authorship and submission or publication status of each manuscript is provided below and at the start of each chapter.

Chapter Two: Clients Learning Self-Management Study

**“The work of learning self-management when living with serious mental illnesses”
(Strong, Letts, Boblin, Wilkins), submitted to the *Psychiatric Rehabilitation Journal***

A foundational component to implementing self-management support locally is to understand from the clients served the issues surrounding learning self-management and obtain evidence about what needs to be done differently. The chapter presents the methods and findings from **study #1, here after called Clients Learning Self-Management Study**, a phenomenological study about client defined critical events of learning about their own mental illness and what they can do to manage their condition and be more in control of their lives. Attention was given to self-management tasks, characteristics and patterns of learning events, dilemmas encountered, clients' perceptions and interpretations of experiences, including others' efforts to provide health information and facilitate the individuals' self-management. Van Manen's (1997) approach to phenomenological studies and hermeneutic analysis was used to describe and interpret the meaning of events within each individual's recovery journey and within the socio-political context of healthcare delivery. The findings provide important evidence

from clients' perspectives about the barriers and supports to implementing self-management support locally.

Chapter Three: Clinicians Enabling Self-Management Study

“Unpacking the black box of conditions influencing clinician behaviour: An embedded case study of self-management support during specialized mental health services” (Strong, Letts, Boblin, Wilkins), submitted to the *Journal of Health Services Research and Policy*

Another foundational element is providers' perceptions and practices surrounding provision of health information and self-management support services within the context of routine delivery of specialized mental health services. The chapter presents the methods and findings of **study #2, here after called Clinicians Enabling Self-Management Study**, a single case study using Yin's (2009) approach with embedded units (individual, discipline, location). Specific attention was given to identify clinicians' perspectives, experiences and practices with enabling self-management, and to discover the conditions and drivers that shaped clinicians' intentions and actions. Findings add providers' perceptions and practices, and aspects of the workplace environment to the assessment of the barriers and supports to implementing self-management support locally.

Chapter Four: Operationalization of Self-Management Support

“Integrating self-management support into routine specialized mental health

services: A learning and embedding initiative” (Strong, Letts, Boblin, Wilkins), submitted to the *Canadian Journal of Community Mental Health*

The chapter presents **study #3**, an integrated knowledge translation approach to developing an implementation strategy to integrate self-management support into routine services. The study **here after is called the Operationalization of Self-Management Support Study**. The study creatively applied theory-driven strategies and translated evidence (including findings from studies #1 and #2) to operationalize self-management support at a program level with the innovation, the 5A’s of Self-Management Support within a Recovery Framework. In a manager collaboration, a Learning and Embedding Initiative was developed as a strategy to implement the innovation. The study informs working within an integrated knowledge translation approach and generated the protocol, materials and collaborations for a future evaluation study.

Chapter Five: Discussion and Conclusions

The chapter is a summary of the dissertation impact and implications. After revisiting the strengths and limitations of the dissertation studies, this work will be reviewed to summarize the contributions (discoveries, innovations, assumptions challenged). Studies’ findings are revisited to discuss elements related to the basic premise that self-management support can be provided and be beneficial within a recovery framework during delivery of specialized mental health services. Implications and recommendations are outlined for practice, the participating organization and mental health services, policy and research. The chapter concludes with personal reflections concerning the impact of the PhD experience.

CHAPTER TWO

CLIENTS LEARNING SELF-MANAGEMENT STUDY

Title of Paper: The Work of Learning Self-Management when Living with Serious Mental Illnesses

Strong, S., Letts, L., Boblin, S., & Wilkins, S. (2013). The work of learning self-management when living with serious mental illnesses. *Under review for publication.*

This paper presents methods and partial findings from the Clients Learning Self-Management Study, specifically this paper focused on the self-management tasks illustrated in the model Learning Self-Management when Living with Serious Mental Illnesses. Findings regarding the structures or contextual themes that shaped participants' experiences learning self-management and an analysis of co-created concept maps as knowledge translation products will be given in later papers.

Abstract

Objective: Self-management is a key component of health policy yet little is known about what needs to be learned to live well with serious mental illnesses. This research described the lived experiences of learning self-management and the meaning of those experiences within recovery journeys and the context of healthcare delivery. **Methods:** Study design followed van Manen's approach of phenomenology through an occupational therapist's lens. From six community, specialized mental health services, 25 individuals with psychosis experiences were interviewed. Conceptual maps were co-created depicting key learning experiences, intersections with services, messages taken away and recommendations. **Results:** Self-management needs extended beyond psychiatric management or crisis management and were not routinely addressed by services. The work of learning self-management comprised eight tasks shaped by seven contextual structures. **Conclusions and Implications for Practice:** Self-management can be considered an application of recovery, a personal resource for living well shaped by physical, social, economic and policy environments and requiring access to resources including learning opportunities. A framework is offered for planning programs, policies and further research. Findings have implications for generic and condition-specific interventions. Self-management support services that are expected in other health sectors are equally important for persons living with mental illnesses.

Key Words: self-management; self-care; recovery; illness and disease, experiences; mental health services

Evidence-based models of effective healthcare delivery emphasize the role of informed individuals with long standing health conditions actively participating in self-management in collaboration with healthcare teams while supported by communities (Ministry of Health and Long-Term Care, 2007). Self-management refers to individuals making decisions and engaging in activities to manage or reduce the impact of a health condition on their daily lives (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). Based on studies that identified a commonality of day-to-day tasks faced by individuals without mental illnesses, “self-management relates to the tasks that an individual must undertake to live well with one or more chronic conditions” (Adams, Greiner, & Corrigan, 2004, p.57). These tasks encompass taking care of the illness, carrying out regular activities and roles, and dealing with the impact on self and emotions (Lorig & Holman, 2003). Self-management interventions are gaining a political profile as credible cost-effective strategies to reduce preventable health complications and improve effective use of medical services (Canadian Health Services Research Foundation, 2007). With disadvantaged groups, such as those with schizophrenia, self-management support is viewed as one strategy to improve their health and address health inequities (Canadian Mental Health Association - Ontario, 2009). Although self-management is a key component of chronic disease health policy and planning internationally, self-management is new to the mental health sector.

The aim of this research was to understand the current context of individuals with serious mental illnesses learning about self-management to improve the delivery of specialized mental health services. The assumption was that individuals were learning to

manage with and without services that addressed self-management. The intention was to describe the experiences of learning self-management while living with serious mental illnesses and to understand the meaning of those experiences within individuals' recovery journeys and the broader sociopolitical context of healthcare delivery. Recovery is a self-directed, transformative process in which individuals with mental illnesses recover a positive sense of self beyond the limitations of an illness, regain some control over their lives and find a meaningful place in the world (CMHA, 2005). A literature review revealed one study (Martyn, 2003) that directly examined the experiences and views of self-management by individuals with schizophrenia (n=52). Self-management was seen as a component of recovery that made the difference between “coping” and “thriving” (p.8). Although a rich body of longitudinal research is available about the recovery process for this population (Davidson, Harding, & Spaniol, 2005), little is known about recovery's relationship with learning self-management or the role of health services. For example, what do persons living with serious mental illnesses need to learn to self-manage within a recovery framework? How does this group learn self-management and how can providers support that learning?

Methods

The phenomenon of interest was learning about self-management by individuals with serious mental illnesses receiving specialized community mental health services. 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’. Van Manen's (1997) hermeneutic approach was selected to guide study

decisions because the approach matched the study's objectives and aligned with the first author's ontology and epistemology. The approach embedded the researcher 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 specialized mental health services. Purposeful and criterion sampling ensured participants had diverse experiences and perspectives of the phenomenon of interest. To capture diversity, participants were sought with a range of life (sex, age, length of illness, occupational roles) and mental health service (service tenure, services utilized) experiences. A sample of 25 participants enabled 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 as the framework for demonstrating rigor.

Recruitment and Data Collection

Upon approval from the research ethics review board, participants were recruited from six specialized 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 the interviews. Participants were offered a small honorarium and bus tickets. During one hour semi-structured audio-taped interviews, participants were asked to describe important self-management learning events, what they took away from those experiences and to give opinions about what they learned. They were asked to reflect upon their experiences as a whole and make recommendations to peers and providers

about supporting self-management learning. 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.

Analysis

In keeping with van Manen's (1997) approach, praxis was obtained through a concurrent process of data reduction, reconstruction and explication of meaning. The researcher iteratively moved between texts and writing 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?" The researcher reflexively considered the influence of pre-understandings in tandem with the described events shaping and being shaped as part of the person's whole self-management learning within a dynamic ecological context (family, society, healthcare). Given the researcher was embedded in the process, an occupational therapist lens was used to understand participants engaging in the world. Each transcript and map was read as a whole to gather how learning self-management presented for that individual and summarized in a two-page participant story. Themes were identified through an iterative process of multiple readings of transcripts isolating thematic statements. Meanings of events were sought by reviewing two-page stories to relate an event to the whole and reflecting on identified themes. Next, using van Manen's 'selective reading approach' variations on essential

themes were searched. Common themes and variations became a coding guide, transcripts were coded and arising insights were written in memos within NVivo9 (QSR International, 2010) computer software. 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 sample exploration. A figure depicting findings further supported reflections and communication of interpretations.

Results

Description of Sample

Table 1 demonstrates the sample's diversity. All 25 participants were receiving community specialized mental health services for self-reported illness defined by experiences with psychosis (spectrum of schizophrenia and affective disorders). Approximately half of the group (n=12) accessed at some time a formal psychosocial rehabilitation service, including four individuals received stand alone, time limited self-management services (i.e., Illness Management and Recovery groups, Wellness and Recovery Action Plan).

The Work of Learning Self-Management with Serious Mental Illnesses

Overall, participants described learning self-management as a gradual process of growth that began with the onset of illness, often years before receiving a diagnosis. This process involved individuals actively taking control, engaged 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 shared timeframe, participants’ stories commonly described learning self-management as putting in place the “essentials”: taking a series of “baby steps” or 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**. Eight self-management tasks were revealed. Learning self-management took the form of ‘the work of learning self-management’ (**tasks**) and the overarching contextual **structures** that shaped the learning process as depicted in **Figure 1**. Growth in the tasks appeared to influence the learning of other tasks but no sequential order was implied.

Gaining knowledge. Growing up, mental illness was not talked about.

Participants often hid their early symptoms from others for years, with little or no knowledge of mental illnesses. They generally did not connect with services until hospitalized with a psychotic episode. 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.

When given a diagnosis, most participants did not remember receiving information or guidance beyond advice to continue taking psychiatric medications and attend follow-up appointments. Participants who requested more information received mixed responses of varying helpfulness. Meaningful information affirmed their

experiences, brought realization that others have psychosis experiences, and enabled them to interpret and act on their experiences. For example, a middle-aged man 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.” A man in his 20’s 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 had added significance amidst the intangibility of psychosis and the broad spectrum of mental illnesses uniquely and individually experienced.

Finding medications and services that work with me. Despite the varied extent to which medications held psychosis in check across participants, 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. A young man discovered which medications were right for him by working at different jobs while trialing new medications and reporting biweekly 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 15-30 years to find service providers who work **with** them. They told of a gauntlet of obstacles to navigate the healthcare system. Participants went from provider to provider to access specialized mental health services (sometimes moving cities), negotiating control issues with providers as service gatekeepers, coming to some realization that they needed to take medications and all the while living in periods of psychosis. After negative experiences with different psychiatrists, a 40 year old man 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 still part of my treatment... part of that decision”.

Finding service providers who **work with me** meant being given credibility as a person managing her/his own life, being recognized as an expert of her/his experiences living with mental illness and forming partnerships with providers. Angrily a woman recalled the many hospitalizations for suicide attempts with numerous doctors 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 was first taken to a doctor for my seeing things and hearing things... For many, many, many years I knew there was something wrong with me, and would be there again the pat on the hand, “you suffer from depression”.

Referred a year ago to a specialized mental health clinic, she worked with a psychiatrist 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.” He

supported negotiation, experimentation and discovery. Through the clinic, she accessed a psychotherapist who suggested various strategies. Also, an occupational therapist helped her put her plans into action. Her story, similar to others', described how client-provider partnerships supported self-determination, self-discovery and access to personally tailored services directed at the whole person for participants to further develop self-management expertise. Participants recommended to peers to find providers who "listen", "find out who you are human to human", and focus on the "whole person" not just 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]".

Trusting self and managing thoughts. The psychosis experiences of living periods of time in an altered reality meant this group brought to learning difficulties with trusting themselves, others and the world around them. Every participant 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 during hospitalization. These visceral experiences which may have occurred years before were felt and remembered as if they occurred recently. For some participants, 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 specifically requested providers to "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. Also, 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. A 50 year old woman was at one point vigilantly self-monitoring (“six times a day I’m checking in” with self) and now conducts 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 or discussed with providers. Rather, participants learned self-monitoring themselves, sometimes fostered by surveillance questions asked of them during provider visits.

Dealing with stigma. Encountering stigma through acts of discrimination and policies promoting marginalization was a daily reality. Participants recounted learning not to internalize stigma from others and accept themselves: “We’re only as sick as our secrets... I tried hiding it. There was shame.” “[I was] afraid... I wouldn’t be able to show the true face of the illness.” They learned the subtleties of disclosure, to “open up” and risk trusting another in order to have an intimate relationship. An older man learned to skillfully deal with interpersonal situations in which others brought misconceptions about mental illnesses, “being schizophrenic, people think you’re crazy. You know that’s not the case.” Participants dealt with the emotional fallout when mental illness became

known at work. A man spoke of working hard to earn a full-time position putting in extra hours to beat competitors. Under the stress he began experiencing voices at work. His story illustrated being marked, branded with mental illness such that he resigned. Stigma touched whole families. Family members “cut off their relationship [with family] and that was it”. Participants were left with added feelings of guilt and shame.

Developing 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. Also, participants needed to overcome challenges to connect, communicate and trust others. For participants with an early illness onset who lived an isolated life, this meant learning social skills and self-efficacy in dealing with others. A young man 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... I like my circle of friends.” Establishing support networks presented additional challenges for participants left with the effects of 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. A young man 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.” Another participant 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.” These and other accounts told of how support networks were an important foundation for growth and self-management.

Performing activities of daily living. 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.

I can say look at me. I bought these dishes. They’re mine. I paid for them and I picked the pattern and I like them and it’s me making my own decisions, not someone doing it for me. And saying... I’m up for it.

To perform daily living activities meant participants experimented and discovered a range of personalized 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, goal-setting), controlling physical space, restructuring activities, and connecting to faith or spirituality. Another option was to delegate tasks to others. A man in his mid-20’s living independently realized 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”.

Finding meaningful occupation that fits. Participation in meaningful activities was associated with a ‘normal’ life, health and wellness. A life interrupted by illness and

hospitalizations meant needing to (re)connect with meaningful occupations. There were periods with few roles and responsibilities. A woman's 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 that I could relate to." Meaningful meant that occupations 'fit' or matched how the person viewed her/himself and future plans.

Participants searched for a supportive environment that was safe with sufficient flexibility for managing stress. A resourceful young man, who found the expectations that accompany being paid a wage stressful, 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.

Integrating co-morbidities. While managing mental illnesses, participants managed addictions and medical conditions. This task involved learning to integrate the management of co-morbidities into a life of managing serious mental illnesses. Participants described management of addictions and mental illnesses as intertwined, giving equal importance to their management. Managing a medical condition brought worry, fear and further setbacks and barriers to overcome. Some physical health issues, although significant and intrusive, were time limited and life proceeded. Half of the

participants lived with on-going chronic illnesses that meant learning another medical regiment and significant lifestyle changes.

Experiences managing co-morbidities offered learning opportunities for managing mental illnesses and vice versa. For example, a middle aged woman with schizophrenia, substance abuse and spousal abuse experiences returned to swimming for a medical illness. She found swimming helped her deal with stress and provided a venue to make friendships. From years of specialized addiction services, she had incorporated “cognitive therapy... changing the way you think... how to get our lives in order” into her life 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, mentors) to manage mental illness.

The Structures that Shaped Learning Self-Management

Structures or contextual themes pervasively shaped participants’ experiences learning self-management by influencing engagement, decision-making and participation in the eight self-management tasks. They experienced the present, learning self-management, with recollections of past experiences which in turn coloured anticipations of future events. What follows are the structures within which the work took place:

- **Safety as a priority** – Living with fears, and emotional and physical vulnerabilities.
- **‘Not knowing’** – Dealing with unknowns and uncertainties.
- **Striving for control** – Attempting to restore or maintain a sense of control amidst losses and loss of control experiences.

- **Access to learning opportunities** – Isolation, marginalization, occupational deprivation and poverty limited opportunities to learn from others and own actions.
- **Stigma as a ‘filter’** – Filtering relationships with illness, self, others and daily living experiences through the lens of stigma.
- **Interdependence** – Living an interdependent life “helping each other”; using social capital to share resources, carry burdens to live well.
- **Self-Management enmeshed in recovery** – Recovering a sense of self as a ‘well’ person was interconnected with performing the eight tasks. Success in recovery relied on growth in tasks and vice versa. Participants looked to self-management as an indicator of recovery.

I’m able to manage my life really, really well. You know, I can manage the money. I can manage... the whole shebang... I’m able to function like a normal person... I’m not always walking around thinking, “Oh well, you know, I’m bipolar,” and stuff... [I’m] a person, like anybody else... I have my illness. It doesn’t have me!

Discussion

Although phenomenological methodology will not establish cause and effect relationships, the rich findings can be used to characterize and explain the meaning of learning self-management for individuals living with serious mental illnesses. Findings are limited to participant-defined key learning experiences and perspectives in a group with self-reported psychoses receiving diverse publically-funded urban specialized 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.

Findings confirmed our assumption 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 the provision of medications and psychiatric management or crisis and risk management. Specifically, support was needed for learning eight self-management tasks depicted in Figure 1. Learning needs were dynamic, changing with evolving health conditions and unfolding demands of life circumstances. Findings suggest thinking of self-management as an on-going learning process that considers the whole person over the course of a life-long learning journey shaped by the seven identified contextual structures. This figure offers a framework to describe and understand the self-management learning needs of individuals living with serious mental illnesses for planning responsive interventions.

In general, persons with serious mental illnesses were portrayed as learning self-management largely through their own trial and error efforts with life as the ‘teacher’ and little formalized provider guidance. Perhaps the self-management learning journey could be shortened and learning made more effective if these needs were routinely targeted by service providers. There was a desire to learn and grow. Participants looked to health professionals for advice, expertise and generally wanted to work in partnership with providers if participants’ expertise was recognized and credibility given for their own self-management work. To deal with power differentials and historical relationships, we

recommend providers give clients permission to partner and own self-management.

Findings bring further attention to the growing body of knowledge linking client-provider shared decision-making with better health outcomes (Coulter, Parsons, & Askham, 2008).

Participants clearly recommended providers facilitate a process of self-discovery, experimentation, in one participant's words, "teach clients to teach themselves". This is consistent with psychosocial rehabilitation principles of deprofessionalization and strengths-based learning. The complexity of self-management meant participants had to gain a level of expertise, develop personalized ways to manage and employ judgement. The implication is that individuals need more than sterile facts to interpret life experiences and make decisions independently. 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 further examine the process of individuals using self-management strategies. Social cognitive learning strategies (Bandura, 1997) for skill acquisition, self-efficacy development, and creating supportive environments are core components of psychosocial rehabilitation. Potentially more widespread integration of psychosocial rehabilitation into services would bring recovery and self-management supports together, positioning psychosocial rehabilitation services as a platform on which to build self-management support services.

The self-management tasks for this participant group appear to hold commonalities to tasks identified by groups with other conditions (Clark et al., 1991). Although several tasks have a common focus (e.g., gaining knowledge, developing a support network, performing activities of daily living), the context for learning and

managing self-management diverges as found by Clark and colleagues (1991). However, findings suggest that the context for living with serious mental illnesses, and by extension the particular knowledge and skills required to manage tasks, can be exceptionally different than other health conditions. For two tasks in particular, ‘trusting self and managing thoughts’ and ‘dealing with stigma’, the context predominated and the tasks assumed unique meaning and requirements for individuals managing psychosis. The study design does not support direct between-group comparisons. However, the population with serious mental illnesses is disproportionately negatively influenced by social determinants of health (poverty, social exclusion, unemployment) which suggests these individuals begin learning self-management from a different place. 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 illnesses predominates. We recommend the eight self-management tasks be addressed and integrated into condition-specific intervention programs such as Illness Management and Recovery (IMR) and Integrated IMR (Mueser et al., 2006; Roe, Hasson-Ohayon, Salyers, & Kravetz, 2009), Flinders Chronic Condition Management Program (Battersby et al., 2010) and Admire Plus (Brooks & Penn, 2003). 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 such as: Expert Patients Program (Rogers et al., 2008) and Stanford Chronic Disease Self-Management Program (Lorig, Sobel, Gonzalez, McGowan, & LaBossiere Huebner, 2004). We recommend the seven contextual

structures be considered by all programs to understand the context of learning self-management while living with serious mental illnesses.

Finding self-management enmeshed in recovery, wellness and building a life is consistent with the ReThink project (Martyn, 2003) viewing self-management as a component of recovery. Participants connected mastery of self-management tasks with advancing sense of self and control. Our findings furthered the understanding of the work involved in self-management and the meaning of the work within a recovery framework. Self-management required the individual to select, organize and 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 over life is in essence an application of recovery.

The work of self-management required access to resources, including access to learning opportunities. Also, there was a range of influences on learning outside the characteristics of the individual learner related to the social, physical and policy environments. Essential resources for daily living and learning self-management were barriers to be overcome for this group. Each task required access to resources and the learning process was shaped, helped and hindered by families, community, social and health policy. Therefore, findings supported an ecological framework for planning services and setting policy (Fisher et al., 2005; Greenhalgh, 2009) to integrate the

building of an individual's capability for self-management with the necessary supports and resources.

Conclusions

Participants' accounts of spending 15-30 years to find medications and providers that work with them speaks to the need to improve timely access to resources and supports for self-management. Self-management offers persons living with serious mental illnesses the potential to live well. Our findings confirm that no matter the degree of illness severity, managing the tasks of day-to-day living is key to a life well lived. We recommend service recipients be offered self-management learning opportunities by integrating self-management support into routine services. A framework of common tasks and contextual learning considerations is offered for planning services and further research. Self-management can be considered an application of recovery, a personal resource for living well shaped by physical, social, economic and policy environments and requiring access to resources. Self-management support services that have become expected in other health sectors are equally important for persons living with mental illnesses.

References

- Adams, K., Greiner, A., & Corrigan, J. (2004). *Report of a summit. The 1st Annual Crossing the Quality Chasm Summit-A focus on communities*. Washington, DC: National Academic Press.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W.H. Freeman.
- Battersby, M. W., Harris, M., Reed, R., Harvey, P., Woodman, R., & Frith, P. (2010). A randomised trial of the Flinder's Program to improve patient self-management competencies in a range of chronic conditions: Study rationale and protocol. *Australian Medical Journal*, 1(3), 198-204.
- Brooks, A., & Penn, P. (2003). Comparing treatments for dual diagnosis: Twelve-Step and Self-Management and Recovery Training. *The American Journal of Drug and Alcohol Abuse*, 29(2), 359-383.
- Canadian Health Services Research Foundation. (2007). *Self-management education to optimize health and reduce hospital admissions for chronically ill patients*. Ottawa, ON: Author.
- Canadian Mental Health Association. (2005). *Discussion guide on recovery. Back to basics: Enhancing our capacity to promote consumer participation and inclusion*. Retrieved from <http://www.cmha.ca>
- Canadian Mental Health Association - Ontario. (2009). *Diabetes and serious mental illness: Future directions for Ontario. A report from the March 30, 2009 think tank on diabetes and serious mental illness*. Toronto, ON: CMHA.

- Clark, N. M. (2003). Management of chronic disease by patients. *Annual Review of Public Health, 24*, 289-313. doi:10.1146/annurev.publhealth.24.100901.141021
- Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W., & Anderson, L. (1991). Self-management of chronic disease by older adults: A review and questions for research. *Journal of Aging and Health, 3*(1), 3-27.
- Coulter, A., Parsons, S., & Askham, J. (2008). *Where are the patients in decision-making about their own care?* Policy Brief written for the WHO European Ministerial Conference on Health Systems, 25-27 June 2008, Tallinn, Estonia: World Health Organization ISSN 1997-8073. Retrieved from www.euro.who.int
- Davidson, L., Harding, C., & Spaniol, L. (2005). *Recovery from severe mental illness: Research evidence and implications for practice*. Boston: Boston University Center for Psychiatric Rehabilitation.
- de Witt, L., & Ploeg, J. (2006). Critical appraisal of rigor in interpretive phenomenological nursing research. *Journal of Advanced Nursing, 55*(2), 215-229. doi:10.1111/j.1365-2648.2006.03898.x
- Epping-Jordan, J., Pruit, S., Bengoa, R., & Wagner, E. (2004). Improving the quality of health care for chronic conditions. *Quality and Safety in Health Care, 13*, 299-305. doi:10.1136/qshc.2004.010744
- Fisher, E., Brownson, C., O'Toole, M., Shetty, G., Anwuri, V., & Glasgow, R. (2005). Ecological approaches to self-management: The case of diabetes. *American Journal of Public Health, 95*(9), 1523-1535.

- Greenhalgh, T. (2009, March). Patient and public involvement in chronic illness: Beyond the expert patient. *British Medical Journal*, 338, 629-631.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Thousand Oaks, CA: Sage.
- Lorig, K., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1-7.
- Lorig, K., Sobel, D., Gonzalez, V., McGowan, P., & LaBossiere Huebner, T. (2004). *Living a healthy life with chronic conditions: Self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others* (Canadian ed.). Boulder, CO: Bull.
- Martyn, D. (2003). *Self-management: The experiences and views of self-management of people with a diagnosis of schizophrenia*. Surrey, UK: Rethink. Retrieved from <http://www.rethink.org/publications>
- Ministry of Health and Long-Term Care. (2007). *Preventing and managing chronic disease: Ontario's framework*. Toronto, ON: Author. Retrieved from <http://www.health.gov.on.ca/english/providers/program/cdpm/index.html>
- Mueser, K. T., Meyer, P. S., Penn, D. L., Clancy, R., Clancy, D. M., & Salyers, M. P. (2006). The Illness Management and Recovery Program: Rationale, development, and preliminary findings. *Schizophrenia Bulletin*, 32(Suppl), 1-43.
- QSR International. (2010). NVivo qualitative data analysis software (Version 9).
- Roe, D., Hasson-Ohayon, I., Salyers, M., & Kravetz, S. (2009). A one-year follow-up of Illness Management and Recovery: Participants' accounts of its impact and uniqueness. *Psychiatric Rehabilitation Journal*, 32(4), 285-291.

Rogers, A., Kennedy, A., Bower, P., Gardner, C., Gately, C., Lee, V. et al. (2008). The United Kingdom Expert Patients Programme: Results and implications from a national evaluation. *Medical Journal of Australia*, 189(10), S21-S24.

van Manen, M. (1997). *Researching the lived experience: Human science for an action sensitive pedagogy* (2nd ed.). London, ON: Althouse Press.

Table 1

Characteristics Demonstrate Diversity of Sample

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/co-habiting (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)
Co-morbidities	Addictions (n=9), chronic medical condition (n=11) (diabetes, epilepsy, cardiovascular disease, emphysema, cancer, rheumatoid arthritis)

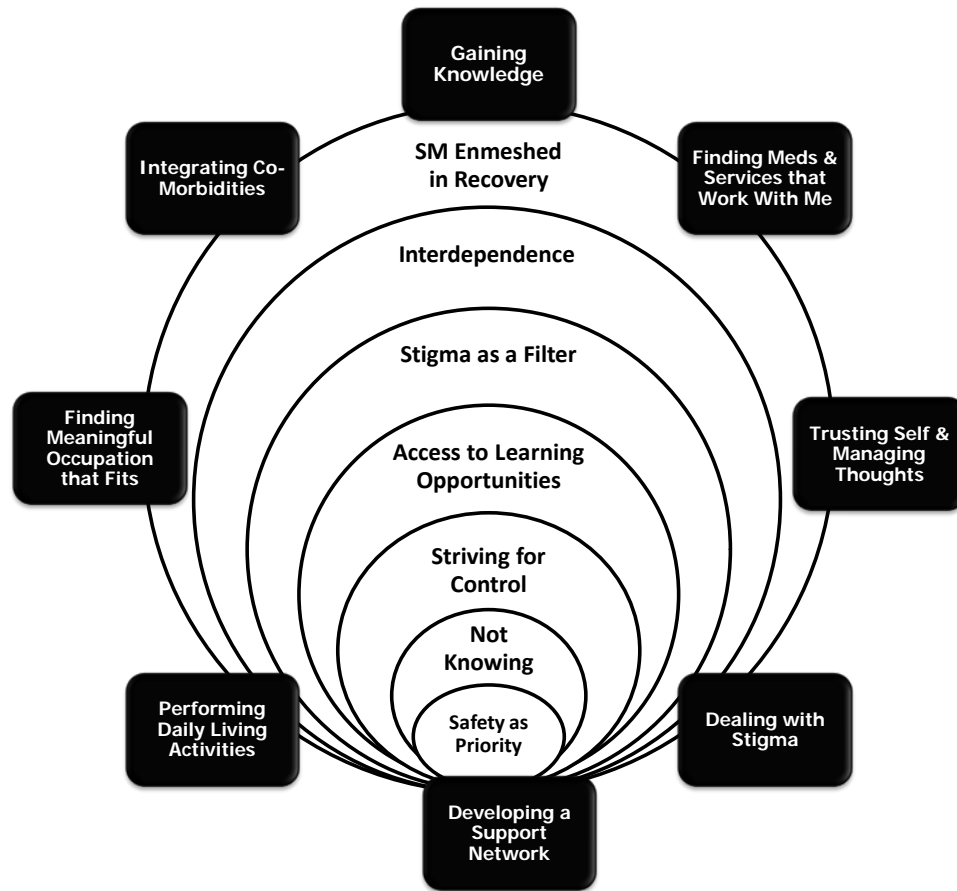


Figure 1. Learning Self-Management when Living with Serious Mental Illnesses (SM = Self-management). The figure illustrates the work of learning self-management when living with serious mental illnesses. Meaning is derived from experiencing eight common tasks (circumference) shaped by seven contextual structures (inner circles).

CHAPTER THREE

CLINICIANS ENABLING SELF-MANAGEMENT STUDY

Title of Paper: “Unpacking the black box of conditions influencing clinician behaviour: An embedded case study of self-management support during specialized mental health services”

Strong, S., Letts, L., Boblin, S., & Wilkins, S. (2013). Unpacking the black box of conditions influencing clinician behaviour: An embedded case study of self-management support during specialized mental health services. *Under review for publication.*

This paper presents methods and partial findings from the Clinicians Enabling Self-Management Study. Results relating to clinician behaviour influenced by practice environment, discipline and individual attributes were reported here (the right half of the Process of Enabling Self-Management figure). Results will be reported elsewhere regarding the client-clinician self-management support encounters shaped by client characteristics, self-management tasks and learning environment (left half of the figure).

Abstract

Objectives: Internationally, health policies are promoting self-management interventions. Our aim was to understand conditions influencing clinician behaviour for the design of self-management support services within a specialized mental health organization. **Methods:** In a single case study with multiple embedded units, clinician triads (nursing-social work-occupational therapy) were selected from eight varied service locations. Thematic analyses of multiple sources of experiential understanding and naturalistic observation (clinician and manager interviews, service delivery products, educational and archival materials) created a rich picture of practices and conditions. Key elements of what and how self-management was/not enabled were depicted in 16 dimensions. Each clinician was mapped on the 16 dimensions. Patterns by individual, discipline and practice environment were examined using replication, pattern matching and explanation building analytical strategies. **Results:** Clinicians faced dilemmas trying to balance clients’ and clinicians’ needs while building clients’ capacity in a world that sometimes undermined self-determination and health. Clinicians grappled with facilitating client-directed learning and changing behaviour amidst power issues. An emergent model depicted the complex dynamic relationships underpinning clinicians’ intentions and actions toward enabling client self-management. **Conclusions:** The dominance of practice environments offers an opportunity for further integration of self-management into routine practice. This study provides an exemplar of how conditions shape clinician actions, and provides evidence for customizing self-management support within a conventional mental health service environment.

Self-management support, defined as clinicians and services helping clients to successfully self-manage the impact of long-standing health conditions, is integral to evidence-based models of effective healthcare (1). High rates of medical co-morbidity and premature mortality of 25-30 years signal persons' with serious mental illnesses need for health promotion interventions (2). Studies demonstrated self-management interventions with individuals with schizophrenia benefit client engagement, participation in decision-making, relapse or hospitalization rates, condition-specific outcomes and service satisfaction (3-6). However, these interventions were stand-alone, time-limited or demonstration projects. Researchers are examining what needs to happen to integrate self-management support into routine practices prompted by health policy promoting self-management interventions in Australia (7), the United Kingdom (8), and the United States (9). However, what goes on during client-clinician encounters and the conditions shaping the complex social behaviour of self-management support remains a black box.

Implementation of self-management support requires shifts in clinician beliefs and practices. Services are expanded beyond medical treatment and crisis management to include rehabilitation and support services that address capacity-building of both the individual and support network to live 'well' with the condition. Client-centred care is embraced to fully enable self-management (i.e., people actively making decisions and engaging in activities to manage or reduce the impact of a chronic condition on their daily lives). A central underlying driver is clinicians working in partnership with clients as

equals (10). Enabling clients to take responsibility for their health, sustained by a community support network, necessitates a re-orientation of client-clinician roles and “who is defining the rules” (11, p.e7). For some clinicians, this means reframing understanding of illness and health and service needs within a socio-ecological framework (12). In the mental health field, these fundamental shifts in beliefs and practices are echoed in literature calling for recovery-based programs and systems (13). Phenomenological studies of clients’ lived experience identify self-management as a key component of recovery (14;15). Self-management support can be considered an application of recovery-based programs (14).

A local phenomenological study of clients living with serious mental illnesses identified client needs for self-management learning and offered a framework of self-management tasks and contextual structures for designing responsive self-management interventions (14). As a logical next step, this paper reports a study that identified clinicians’ perspectives and practice conditions. The research questions asked were: what conditions are in place for enabling self-management in this context and how can these findings inform our understanding of clinician behaviour?

Methods

Study Design

A single case with multiple embedded units using Yin’s (16) approach was selected as the design best suited to answer the research questions. Qualitative case studies allow an examination of practice within the context of what is being done, how

and why. They uncover the conditions and drivers that support or hinder clinicians taking action (16). Further, sampling clinician triads (occupational therapist [OT], registered nurse [RN], social worker [SW]) at eight service delivery locations created embedded units which offered the opportunity to analyze the case within, between and across each embedded unit (location, discipline, participant). This replication design permitted pattern matching and explanation building as analytical strategies and provided the rigour to purposefully seek, define and test rival explanations (16) to the propositions below. The focus was on process, not outcomes or to determine the best pattern or practice.

The setting was specialized mental health service (i.e., multidisciplinary services delivering inpatient and outpatient tertiary care for people with serious mental illnesses). Clinician participants practiced at eight locations administered by one public, teaching, mental health service mandated to serve individuals with schizophrenia and other psychotic disorders living in a large Canadian urban centre and surrounding urban and rural regions.

The case or unit of analysis was the process of enabling self-management. The case was bounded by: the practices involved in enabling self-management, the viewpoints of participants through which practices and experiences were recounted, the eight locations and the people served. As directed by Yin (16), the study was designed to uphold tests of quality regarding: construct validity (multiple sources of evidence, ‘chain of evidence’ or audit trail); internal validity (replication design); external validity

(theoretical framework); and reliability (study protocol, database). Ethical approval was obtained from the service organization's Research Ethics Board.

Theoretical Framework and Initial Propositions

A theoretical framework was used to guide the study. The Person-Environment-Occupation (PEO) model (17) was selected to understand the dynamic transactional relationships amongst clinicians and practice environments that enabled clients to perform self-management tasks in living environments. Clinicians were viewed as part of client environments. To assess how clinicians' beliefs, perceptions of personal control and social norms do/do not support clinicians' enabling self-management, the Theory of Planned Behavior (18) was added to the framework. This theory accounts for 27% and 39% of the variance in behaviour and intention to take action respectively (19), and supports strategic planning tailored by the local context to change clinician-targeted practice behaviours (20).

Yin's case study research builds on sets of propositions (21). The study began with propositions to inform the research questions, two of which are the focus of this paper:

1. Clinicians hold similar range of perspectives regarding beliefs and perceptions of personal control and social norms towards enabling self-management irrespective of discipline.
2. Clinician self-management support intentions and behaviours are shaped by clinicians' practice environments and disciplines.

Data Collection

The sampling frame was clinical programs of the specialized mental health service described earlier. All programs were sampled but one assertive community treatment team due to logistics. To prove or disprove the propositions, the following data collection strategies were used to collect information about the case from a variety of sources across the eight locations. In single case studies, the sample is the data sources. The sample is described in the Box. Outline of Data Sources.

Clinician interviews. From each location, one of each discipline (OT, RN, SW) was selected. These disciplines were targeted because self-management support is within each discipline's scope of practice. When multiple individuals per discipline were available per location, individuals considered by managers with the most exemplary practices were invited. One location did not employ a social worker and a registered nurse family educator was substituted and accounted for the larger number of nurses in the sample.

With written informed consent, a research assistant conducted audio-taped in-depth, semi-structured interviews in a private location of participants' choosing. Since the term 'self-management' was not used at these locations, interviews began by asking participants to describe example experiences of enabling clients to access, understand and use health information. The interviews unfolded to descriptions of supporting client self-management. From the study's theoretical framework, participants were asked reflective questions to appraise and interpret each experience individually and then

collectively (helps/hinders, social norms, personal control, enjoyment, benefit/harm, dis/advantages) and to make recommendations. After the first author listened to tapes, initial reflections were added to interviewer field notes and became a repository of on-going reflections.

Site Manager Interviews. To understand the clinical context, team functioning and each location's unique characteristics, on-site discussions were held with managers. They were asked to describe operations, client care pathways and reflect upon the integration of self-management support. To document observations and support reflexivity, field notes were written during and immediately afterwards.

Reviews of Service Delivery Products, Client and Archival Materials. Materials were reviewed regarding content, context of use and how the document could be a 'social agent of change' (22) that supported or hindered enabling self-management.

Analyses

In qualitative research, data synthesis, analysis and interpretation occur simultaneously and iteratively beginning at the time of data collection (23). To answer the research questions and test the propositions, the following framework guided analysis:

1. Clinicians' practices were described in-depth (i.e., operations, supporting/impeding conditions, mechanisms generating/ameliorating barriers to enabling self-management). Data displays of person-occupation-environment transactions provided a documented synthesis of clinician experiences. Themes emerging from

- analysis of coded transcripts using QSR NVivo9 (24) software were triangulated with manager interviews, field notes and document reviews.
2. The unique features, variations and applications across the organization were described and considered. From multiple reflections of exemplary and contrasting instances, the features of enabling self-management were identified and explored in reflective narrative summaries and illustrated with quotations. Sixteen key dimensions (Table) emerged.
 3. Conditions that may be different by embedded unit (location, discipline, participant) were identified. Each participant was mapped along each of the 16 dimensions using all data sources. Matrices displayed each dimension by embedded unit.
 4. Patterns emerging across location, discipline and participant were identified. Matrix patterns and trends were graphed with line drawings to support examination as a whole. A model (Figure. The Process of Enabling Self-Management) illustrated emerging understanding of conditions influencing clinician behaviour.

Results relating to clinician behaviour influenced by practice environment, discipline and individual attributes were reported here (the right half of the figure). Results regarding the left half of the figure will be reported elsewhere.

Results

Challenges with the Self-Management Support Process

There were four main challenges or tensions interwoven across all disciplines and locations. All four contributed to the first proposition not being upheld by

identifying how clinicians did not hold the same beliefs and attitudes towards the subject of interest. Also, all four tensions supported and provided insight into the second proposition regarding potential discipline and practice environment mechanisms that shaped clinician actions.

Balancing clinicians' needs or fears with clients' needs or rights. In principle, every participant endorsed clients' right to health information and acknowledged the need for such information to manage living with mental illness. However, one participant shared her team's struggle with fears and perceived risks associated with sharing information:

It can be detrimental, cause confusion. If it is medication related and you are talking about certain side effects and what might happen, they may refuse to take their medication. You have to walk a fine line on where that person is to decide...

Other clinicians acknowledged witnessing the gatekeeping of information by others and after introspection, resolved to proactively openly share information. Their rationale was that inevitably clients would obtain information and it was better to share difficult information directly with clients and have the opportunity to clarify any misunderstandings while developing trusting client-clinician relationships. To them, it was not an issue of whether to share, rather how the information was delivered.

Clinicians grappled with obligations to ensure client safety and health with clients' rights to self-determination. The dilemma was highlighted when clinicians were

faced with trusting clients' decisions and acknowledging "it's their life after all".

Clinicians contended with needing to switch views and approaches with dynamically changing social and legal contexts.

Facilitating client-directed learning. Clinicians spoke of needing to rein in the tendency to rush in and use their training to assist a client: "Start by listening, asking them what they understand as to what they are going through before launching in with a program of education". Clinicians wrestled with their own inadequacies to engage, communicate and tailor interactions with clients. "A lot comes down to the way you interact with a client face-to-face... So they are receptive to what you say, receptive to you as a clinician, if you can't do that first, it's going to be difficult to teach them anything or facilitate their health [learning]".

Clinicians recognized that changing health behaviours was difficult, requiring motivation, persistence and support and that human nature was to return to old habits. Their accounts described negotiating with team mates who labelled and blamed clients when clients were not responding. "In some cases people might label something as 'behavioural' because it's something hard to deal with. It's not the worker's issue. It's the client's fault, rather than how are we going to work to get over this behaviour."

Changing behaviour and dealing with power-control issues. Clinicians described a dynamic dance of nudging clients to take action, planting seeds of possibilities and stepping back to allow clients to make and enact their own decisions and desires. The intent was to "work within what the client wants and what they are open to". This

meant “[you] need to be careful not to overstep your boundaries in making sure the client is on board with you in the plan of care before you start to go ahead”. Concerns were expressed that by virtue of the process of advocating or assisting clients to navigate the system, responsibility and authority were conferred to clinicians. For example, when clinicians deliver medications, clients do not receive “the little leaflet that all of us get from the pharmacy stating what the medication is for... they are not always getting all of the information. It's filtered through us... we end up having some power over our clients' lives”. Clients would turn to clinicians asking them for advice or to make the decision:

‘Tell me that this form is okay to sign’... ‘If you think I should do this, I'll do it’. No. You have to make the decision... ‘Do you think you should get a pap [test]?’ ‘Yes. I think you should do that, but don't do it for me. Do it for yourself’. I think sometimes our clients will do things because we book the appointments and go to things because we tell them they should.

Other clinicians appeared unaware of power dynamics and recounted stories which illustrated coercive practices and paternalism.

Building client capacity in a world that undermines client self-determination/health. Clinicians told of ‘push back’ from team and community members who were accustomed to making the rules and having actions fit within their world views. As one clinician explained:

[It's] when you try to approach other individuals to have those [clients'] needs met, sometimes those needs are minimized. So that becomes a problem, when you see it's a valid issue but whether it's the way the system is set up or people's perception of things... in a facility like this, not everyone is on the same page... Sometimes that can cause friction...

Poverty and the commensurate reduced options were cited as barriers to exercising healthy lifestyle choices.

Self-Management Support Dimensions

The four tensions above were the dynamic backdrop within which the following descriptive dimensions, or key features of self-management support, took place. Key elements of what was being done to enable self-management and how, were classified in 16 dimensions (see Table). Each dimension was conceptualized as a continuum of blended elements to represent a range of clinician behaviour and variations within each dimension. The blended elements were broadly anchored by three descriptive items per dimension. For example, the dimension 'conceptualization of self-management support' (Table, item #2) ranged from 'narrow' conceptualizations limited to providing and assisting understanding of health information to 'broad' conceptualizations that linked supporting health information use with empowerment and as a foundational element for self-management, a capacity to be developed and supported environmentally. The 'mixed' item anchored a middle conceptualization.

Conditions across Embedded Units

The figure depicts a model of the patterns that emerged upon review of matrices (embedded unit x dimension). A location pattern was defined as all three participants mapped on one item and a discipline pattern was considered when the majority within the discipline mapped on one item. In the model, every dimension mapped onto location was placed in the square. Every dimension mapped onto individual clinician was placed into the left triangle (dashed lines). Similarly, those items mapped onto discipline were placed in the right triangle (dotted lines). Some dimensions mapped onto more than one embedded unit and were represented by the overlapping corresponding shapes.

Individual. The dimensions representing clinician ‘risk-taking’ and ‘social norms’ had no cells empty across all three items of each dimension. In other words, individuals’ **risk-taking** practices as a group were characterized by all items: adherence, harm reduction, proactive planning. Discipline and location matrixes revealed no pattern. However, risk was a frequent spontaneous topic of concern with nursing and social work and rarely a topic offered by occupational therapy. We suspect the complexity of risk-taking was not adequately captured by the three descriptive items. Across the group, individuals’ perceptions of **social norms** varied from believing taking action to support self-management was/was not supported by clients and/or teams. This is consistent with the earlier reported four main challenges. However, matrices further revealed

social norms were not specific to discipline or location. This is consistent with self-management support being new to practice and academic programs.

Disciplines – Registered Nursing (RN), Social Work (SW), Occupational Therapy (OT). For the dimension ‘**orientation to health**’, the RN tended to be bio-medical (6/9), SW socio-ecological (4/7) and OT split between rehabilitation (3/8) and socio-ecological (4/8). This is consistent with orientations of disciplines’ education and scopes of practice.

Location – Inpatient Location #1-3, Outpatient Location #1-5. Each location was assigned a number for anonymity and to describe patterns. The dimension ‘**evaluation of outcomes**’ revealed a pattern by location: at 2/3 inpatient locations all participants endorsed ‘mixed disadvantages’ and ‘beneficial’ while 3/5 outpatient locations unanimously emphasized ‘beneficial’ outcomes. Perhaps in an outpatient setting, clinicians were more likely to see firsthand the positive benefits of self-management. Inpatient clinicians reported not knowing the effect of interventions due to symptom acuity and not seeing clients engage in self-management. Only outpatient locations (all 5) consistently viewed taking action as desirable (**‘evaluation of action’**).

Individual and Location. Three dimensions demonstrated patterns by individual and location. An individual was mapped in every item used to describe ‘conceptualization of self-management support’, ‘priorities’, ‘personal control’. Across locations, patterns emerged with different settings: **conceptualization** (Outpatient4 and 5 ‘broad’, Inpatient1 ‘narrow’); **priorities** (Inpatient1 and 2 ‘not a priority’, Outpatient4

‘important addition’); **personal control** (Inpatient3, Outpatient1, 3, 4 ‘empowered’ and Inpatient1 ‘disempowered’). There was no clear polarization between inpatient and outpatient settings as there were location exceptions for each dimension. However, the five participants who endorsed disempowerment were all at inpatient locations and across all disciplines.

Discipline and Location. Four dimensions demonstrated patterns by discipline and location. For **‘client’s growth potential’**, OT (6/8) endorsed ‘all able’ and SW (5/7) endorsed ‘some able’ while Outpatient3-5 mapped on ‘all able’ and Inpatient 1 on ‘some able’. Inpatient areas appeared less likely to believe in growth potential given the ‘unable’ items and the only two OT participants who did not endorse ‘all able’ were at inpatient locations. Inpatient clinicians have less opportunity to observe client growth. Lack of belief in growth potential did not emerge related to years working.

The patterns for **‘decision-making’** were ‘shared’ for OT (5/8) and Outpatient3-5 with Outpatient1 ‘cooperation-collaboration’. **‘Learning opportunities’** patterns were: SW (5/7), OT (5/7), and Outpatient3-4 ‘creates opportunities’. **‘Action on barriers’** patterns were RN (6/9), SW (5/7) and Outpatient1-2 ‘persists’ while OT was split between ‘persists’ (4/8) and ‘target barriers’ (4/8). Those ‘limited by fears’ were all inpatient. Perhaps, these three dimensions required both discipline acquired capability (knowledge, skills) and a practice environment that provided the opportunity to use capabilities.

Individual and Discipline and Location. Four dimensions had patterns by individual, discipline and location related to client-clinician relationships and practice emphasis. An individual was mapped on every item within each of these dimensions. The patterns for **'roles'** were: OT (5/8) and Outpatient3-5 'client expert, clinician consultant'; Inpatient 1 'client passive, clinician expert'; Outpatient1 'client student, clinician teacher'. The patterns for **'power relations'** were: OT (5/8) and Outpatient3 and 5 'negotiated partnership'; RN (5/9) and Inpatient2 'unaware/paternalism'. Building client-centred partnerships and navigating power issues are part of OT education. For **'focus'**, OT was split between 'self-management support' (4/8) and 'illness management' (3/8); whereas the dimension was not discipline-specific for RN/SW. By location, Outpatient5 mapped onto 'self-management support' and Inpatient1 onto 'psychiatric treatment/crisis management'. Patterns for **'capacity-building'** were: OT (5/8) 'client only'; SW (4/7) 'client and social network'; RN split between 'limited/none' (4/8) and 'client and social network' (4/8); Inpatient 1 'limited/none'. This suggests none of the disciplines were working to full scope of practice. Complex individual-discipline-location relationships influenced the performance of these dimensions.

Post-Study Propositions

Based on study findings, the pre-study propositions noted above were modified:

1. Clinicians held a range of perspectives regarding conceptualization of self-management, perceptions of priorities, personal control and social norms towards enabling self-management irrespective of discipline. However orientation to health

- was influenced by discipline. Practice environment shaped beliefs of desirability and benefit. Beliefs of client growth potential were shaped by discipline and environment.
2. Clinicians' self-management support intentions and behaviours were shaped by clinicians' disciplines (orientation, client's growth potential, decision-making, learning opportunities, action on barriers, roles, power, focus, capacity-building) and predominately influenced by practice environments (evaluation of action and outcome, conceptualization, priorities, personal control, client growth potential, decision-making, learning opportunities, action on barriers, roles, power, focus, capacity-building).

Discussion

This study's contribution is to provide insights into the 'black box' of what takes place and how conditions shape clinician action during the process of enabling self-management. The model and study propositions identify dynamic, transactional relationships among elements related to the individual clinician, discipline and practice environment (location). While none of the elements individually represents a new discovery, the model assists planners to 'see the forest for the trees' and offers direction of where to focus efforts amidst the plethora of potential influences. Clinician self-management support behaviours were shaped along 16 key dimensions by the practice environment, discipline and what each individual brought to the mix together with the

particular client encounter circumstances (client characteristics, self-management tasks and environment).

A key finding was the dominance of practice environment. This suggests practice environments offer a tremendous opportunity as a means for facilitating the integration of self-management into clinicians' routine practices. Desirability (evaluation of action) and perceived benefits (evaluation of outcomes) associated with self-management support were primarily shaped by workplace. As social beings, clinicians' interpretations of experiences are labelled through social interactions. The Theory of Diffusion of Innovations suggests facilitated discussions with workplace colleagues can reframe interpretations of experiences and shape attitudes (25). To fully realize integration into practice, clinicians will need support to work through the tensions and dilemmas identified. In part, these challenges can be understood as struggling to deliver client-centred care within the cultural context of large public organizations. Such organizations' structures and implicit norms place priority on minimizing risk, obligations to protect the vulnerable and standardization of procedures for quality and efficiency at the expense of flexibility to meet individual clients' needs (26). The culture collides with our need to take risks inherent in supporting client self-determination, experimentation and growth from experiencing successes and failures - all recognized markers of recovery-oriented organizations (13). Also, the challenges can be understood in the context of a diverse workforce with respect to education and experience. Sophisticated self-regulation skills were needed by clinicians to navigate and negotiate diverse client-

clinician partnerships. When successfully negotiated, partnerships were able to proactively plan for risk-taking and sort out shared responsibilities, clinicians were freed to move forward with enabling someone to live well with serious mental illness and clinicians' fears were less likely to constrain clients' experimentation to learn self-management.

The study drew attention to self-management support not fitting conventional treatment boundaries or silos. Historically programs and disciplines were organized by clinical specialty. On initial scan, findings portrayed nurses with a bio-medical orientation focused on care giving, delivering psychiatric treatment and managing risk. Social workers appeared to have a social-ecological orientation focused on clients accessing the social determinants of health. Occupational therapists operating from rehabilitation and socio-ecological orientations worked in negotiated partnerships to increase client capacity. However, as the model demonstrates, these are only generalisations with many individual exceptions that challenge our assumptions of discipline-specific workplace performance.

Findings suggest a place needs to be carved out for self-management support in all disciplines' roles, work routines and duties. Opportunities need to be created for clients to use and practice self-management during day-to-day operations and transitions between services. The considerable variation in practices highlights the inherent challenges required in supporting clinicians to work from 'the same page'. Self-

management support must be labelled as a core component of services for every client, and as such a priority rather than an extra duty to attend to if time remains.

Overall, the study confirmed clients' perspectives that services have tended to focus on psychiatric treatment, crisis and risk management and not fully addressed the whole person living with mental illness, leaving gaps in clients' self-management learning needs (14). The study is a reminder of how slow organizations are to change despite emphasis on recovery-focused client-centred care over the past 15 years. This case study is offered as an exemplar of current service delivery illustrating behavioural and organizational processes that shape practices, and providing evidence for customizing self-management support within a conventional mental health service delivery environment. Case study methodology offers readers the opportunity to further reflect and interpret findings within readers' own local context using analytical generalizations (16) or reasoning to generalize study results to propose what may be happening elsewhere.

Almost every individual endorsed self-management as part of the organization's mandate and as a fundamental client right. Findings provide the evidence to build upon existing conditions that support self-management and systematically develop strategies to target implementation barriers. We are better positioned, and heartened by the key role of practice environments in influencing clinician behaviour, to strategically take steps toward making health policy a routine reality for clients receiving mental health services.

References

- (1) Epping-Jordan J, Pruit S, Bengoa R, Wagner E. Improving the quality of health care for chronic conditions. *BMJ Qual Saf* 2004;13:299-305.
doi:10.1136/qshc.2004.010744.
- (2) Canadian Mental Health Association - Ontario. Recommendations for preventing and managing co-existing chronic physical conditions and mental illnesses. Toronto, ON: Author; 2008.
- (3) Anzai N, Yoneda S, Kumagai N, Nakamura Y, Ikebuchi E, Liberman RP. Training persons with schizophrenia in illness self-management: A randomized controlled trial in Japan. *Psychiatr Serv* 2002 May;53(5):545-7.
- (4) Cabassa L, Ezell J, Lewis-Fernandez R. Lifestyle interventions for adults with serious mental illness: A systematic review. *Psychiatr Serv* 2010;61:774-82.
- (5) Hasson-Ohayon I, Roe D, Kravetz S. A randomized controlled trial of the effectiveness of the Illness Management and Recovery program. *Psychiatr Serv* 2007;58(11):1461-6.
- (6) Xia J, Merinder L, Belgamwar M. Psychoeducation for schizophrenia. *Cochrane Database Syst Rev* 2011;6:doi:10.1002/14651858.CD002831.pub2.
- (7) National Health Priority Health Council (NHPAC). National Chronic Disease Strategy. 2005 [cited 2013 Jun 3]; Available from:
<http://www.health.gov.au/internet/main/publishing.nsf/Content/pq-ncds>

- (8) Wilson PM. A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health Soc Care Community* 2001;9(3):134-42.
- (9) U.S. Department of Health and Human Services. *Healthy People 2000*. Washington, DC, Government Printing Office; 2000.
- (10) Ministry of Health and Long-Term Care. Preventing and managing chronic disease: Ontario's framework. Toronto, ON: Author; 2007 [cited 2011 Oct 2]; Available from:
www.health.gov.on.ca/en/pro/programs/cdpm/pdf/framework_full.pdf
- (11) Lawn S, McMillan J, Pulvirenti M. Chronic condition self-management: Expectations of responsibility. *Patient Educ Couns* 2011;84:e5-e8.
doi:10.1016/j.pec.2010.07.008.
- (12) Greenhalgh T. Patient and public involvement in chronic illness: Beyond the expert patient. *Br Med J* 2009;338:629-31.
- (13) Farkas M, Gagne C, Anthony W, Chamberlin J. Implementing recovery oriented evidence based programs: Identifying the critical dimensions. *Community Ment Health J* 2005;41(2):141-58.
- (14) Authors. The work of learning self-management when living with serious mental illness. Under review for publication 2013.
- (15) Martyn D. *Self-management: The experiences and views of self-management of people with a diagnosis of schizophrenia*. Surrey, UK: Rethink.; 2003.

- (16) Yin R. Case study research: Design and methods (4th ed.). Newbury Park, CA: Sage; 2009.
- (17) Law M, Cooper B, Strong S, Stewart D, Rigby P, Letts L. The Person-Environment-Occupation Model: A transactive approach to occupational performance. *Can J Occup Ther* 1996;63(1):9-23.
- (18) Ajzen I. The Theory of Planned Behavior. *Organ Behav Hum Decis Process* 1991;50:179-211.
- (19) Armitage C, Conner M. Efficacy of the Theory of Planned Behavior: A meta-analytic review. *Br J Soc Psychol* 2001;40:471-99.
- (20) MacDermid J, Graham I. Knowledge translation: Putting the "practice" in evidence-based practice. *Hand Clin* 2009;25:125-43.
doi:10.1016/j.hcl.2008.10.003.
- (21) Yin R. Enhancing the quality of case studies in health services research. *BMC Health Serv Res* 1999;34(5):1209-24.
- (22) Miller F, Alvarado K. Incorporating documents into qualitative nursing research. *J of Nurs Scholarsh* 2005;37(4):348-53.
- (23) Crabtree B, Miller W. *Doing qualitative research* (2nd ed). Thousand Oaks, California: Sage Publications Inc.; 1999.
- (24) QSR International. NVivo qualitative data analysis software (Version 9) 2010.

- (25) Greenhalgh T, Robert G, MacFarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Q* 2004;82(4):581-629.
- (26) Townsend E. Good intentions overruled: A critique of empowerment in the routine organization of mental health services. Toronto, ON: University of Toronto Press; 1998.

Figure Legend:

Figure. The Process of Enabling Self-Management

Table Legend:

Box. Description of Data Sources

Table. Dimensions Describe Key Elements of Self-Management Support

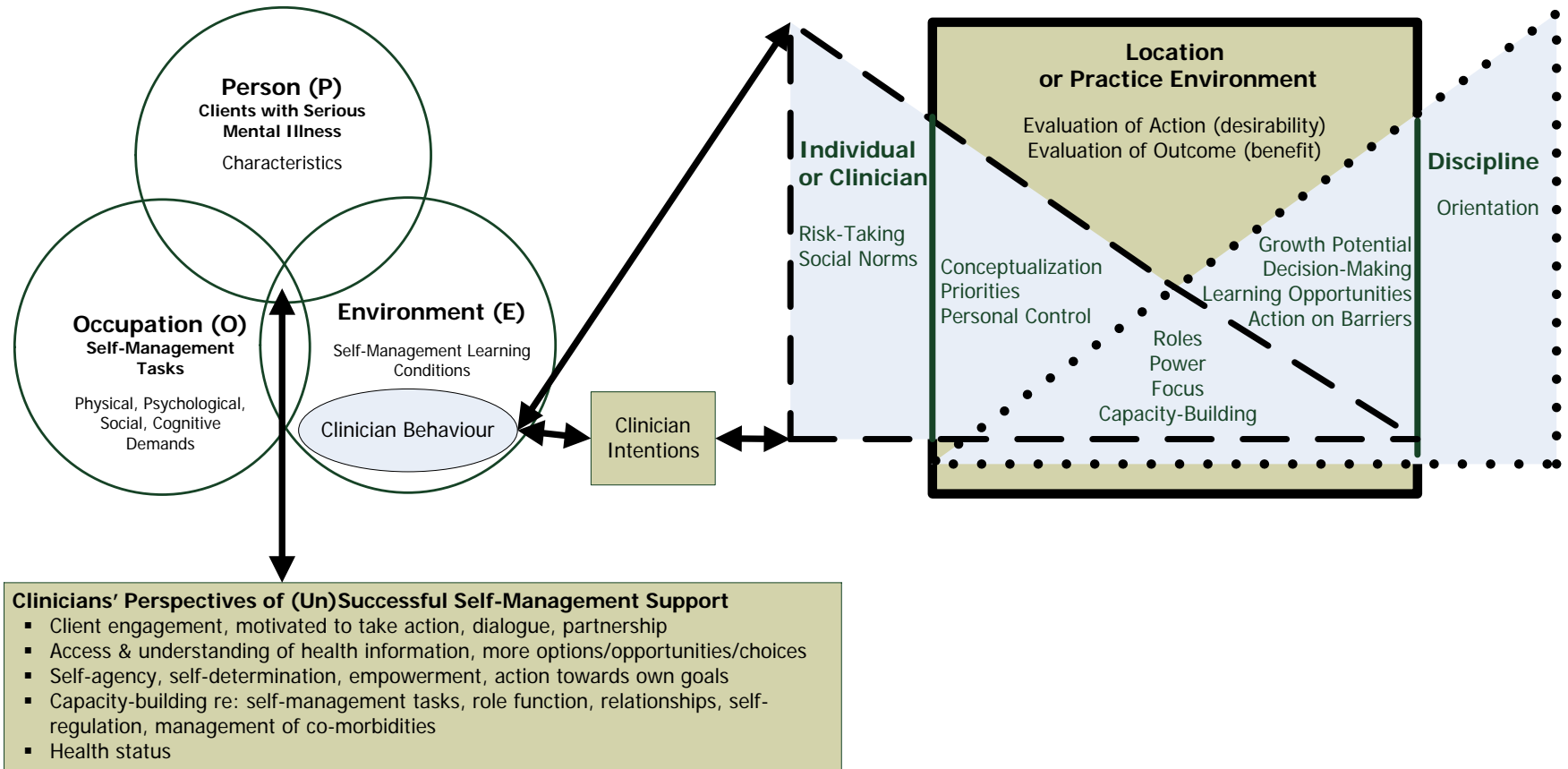
Box. Description of Data Sources	
Locations	
Inpatient Units #1-3	31, 28, 25 beds (350 visits/year)
Outpatient Programs #1-5	
Community Clinics (n=2)	First episode clinic (450 clients/year); Outpatient case management clinic (660 clients/year)
Assertive Community Treatment Teams (n=3)	Intensive outreach, treatment and support (390 clients/year)
Clinician Interviews	
Occupational therapists (n=8)	All women working 1-14 (<i>M</i> =7.1) years in field
Registered nurse (n=9)	6 men, 3 women working 6-35 (<i>M</i> =20.7) years in field
Social work (n=7)	1 man, 6 women working 3-25 (<i>M</i> =11.6) years in field
Site Manager Interviews (n=8)	
Material Reviews	
Archived materials	Program descriptions, policies & procedures
Client materials	Orientation, education, goal-setting, worksheets
Service delivery products	Referrals, communication & care planning materials
Field Notes	>400 pages

Table. Dimensions Describe Key Elements of Self-Management Support		
Clinician Lens		
1. Orientation to Health		
Bio-Medical Model	Rehabilitation Model	Socio-Ecological Model
2. Conceptualization of Self-Management Support		
Narrow	Mixed	Broad
3. Client's Growth Potential		
None/Few able to grow	Some able to grow	All able to grow
Client-Clinician Relationships		
4. Roles		
Client passive, clinician expert	Client student, clinician teacher	Client expert, clinician consultant
5. Power Relations		
Clinician unaware of power, coercion, paternalism	Clinician giving power to while holding authority over client	Negotiated partnership
Practice Emphasis		
6. Focus		
Psychiatric treatment, crisis management	Illness management	Self-management, self-management support
7. Decision-Making		
Informed consent	Cooperation-collaboration	Shared decision-making
8. Risk-Taking		
Adherence	Harm reduction	Pro-active risk planning
Integration of into Practice		
9. Learning Opportunities		
Responds to client requests	Engages as part of program procedures	Creates learning moments, opportunities
10. Capacity-Building		
Limited/None	Client only	Client and support network
11. Priorities		
Not a priority	Important addition to routine tasks	Makes it a routine priority

Table Continued. Dimensions Describe Key Elements of Self-Management Support

Intention-to-Action		
12. Action on Barriers		
Actions limited by fears/risks	Persists in face of fears/risks	Targets barriers/negative cycles
13. Evaluation of Action		
Undesirable	Mixed	Desirable
14. Evaluation of Outcomes		
Emphasized disadvantages	Mixed	Beneficial
15. Personal Control		
Disempowered	Mixed	Empowered
16. Social Norms		
Actions not supported by others	Mixed	Actions supported by others (e.g., clients, team, admin)

Figure. The Process of Enabling Self-Management. Adapted from the Person-Environment-Occupation Model (17) and Theory of Planned Behavior (18). Right half of model depicts patterns of conditions shaping clinician self-management support intentions and behaviour. Left half of model depicts client-clinician self-management support encounters.



CHAPTER FOUR

OPERATIONALIZATION OF SELF-MANAGEMENT SUPPORT

Title of Paper: “Integrating self-management support into routine specialized mental health services: A learning and embedding initiative”

Strong, S., Letts, L., Boblin, S., & Wilkins, S. (2013). Integrating self-management support into routine specialized mental health services: A learning and embedding initiative. *Under review for publication.*

This paper synthesizes and applies evidence, including findings from both the Clients Learning Self-Management Study and Clinicians Enabling Self-Management Support Study to create a self-management support innovation and implementation plan.

Abstract

Internationally, healthcare policies recommend the provision of self-management support as one strategy to improve health and address health inequalities. To implement organizational change in a specialized mental health service, a collaboration (director, eight front-line managers, researcher) adapted a tool for teaching healthcare providers a structured approach to self-management support (the 5A’s of Self-Management Support within a Recovery Framework) and planned a Learning and Embedding Initiative. The development of a theory-driven evidence-based innovation and implementation plan using an integrated knowledge translation approach involved art and science. Strategies to operationalize theory and reflections are offered to interdisciplinary teams and planners.

Despite dedication of resources for workforce development and strategies to implement new innovations into mental health workplaces, success has been limited with respect to impacting routine practices and changing clinician behaviour or client outcomes (Franx et al., 2008). Researchers examining diffusion of innovations into practice contend that focusing solely on clinicians is insufficient and suggest making organizational changes at a program level while considering program-setting interactions (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004). Organizational changes such as integrated care and changes in multidisciplinary teams and service settings have led to improved client outcomes during provision of specialized mental health services (Franx et al., 2008).

The focus of this paper is the development of an implementation strategy for an organizational change -- integration of self-management support into routine services for individuals living with serious mental illnesses. The objectives are to:

- 1) Describe the process of creating the innovation, the 5A's of Self-Management Support within a Recovery Framework, an adaptation of the 5A's Model of Self-Management Support (Glasgow, Davis, Funnell, & Beck, 2003);
- 2) Outline the development of a strategy to implement the innovation, the Learning and Embedding Initiative, and demonstrate how the Behaviour Change Wheel (Michie, van Stralen, & West, 2011) and Essential Characteristics of an Innovation (Greenhalgh et al., 2004) can be used to strategically plan a provider behaviour change intervention.

Self-Management Support

Self-management support is defined as healthcare providers enabling clients to have the tools, resources and supports they need to live ‘well’ with mental illnesses. Adams, Greiner and Corrigan (2004) suggested focusing interventions on client confidence and the behaviours necessary to perform tasks related to the management of medical regimens, role functioning and emotional changes based on studies that identified common tasks people with chronic conditions face in their day-to-day lives (Clark et al., 1991; Corbin & Strauss, 1988). A phenomenological study of individuals living with serious mental illnesses found learning self-management began at the onset of symptoms irrespective of intervention by health services (Authors, 2013a). Further, learning self-management focused on eight self-management tasks, some of which were in common with other groups: gaining knowledge of mental illness and what the illness means for me to live well; finding medications and services that work in partnership with me; trusting myself and learning different ways of thinking to manage thoughts and fears; dealing with stigma and all its effects on my life; developing a social network for an interdependent life; performing daily activities to fulfill the necessities of living and offer reassurance of control; finding meaningful occupations that fit my values, future plans, capabilities and stress management needs; and integrating management of any addictions and medical conditions with management of mental illnesses. Supporting self-management across the breadth of these tasks requires services to be integrated with rehabilitation and support services and to embrace a social-ecological model or whole systems approach (Fisher et al., 2005; Greenhalgh, 2009). Therefore, delivery of self-

management support is an example of organizational change in circumstances where mental health services have primarily focused on psychiatric treatment and clinical illness-based care.

In Australia (NHPAC, 2005), the United Kingdom (Wilson, 2001), the United States (U.S. Department of Health and Human Services, 2000) and parts of Canada (MOHLTC, 2007), policy-makers are adopting chronic disease management models which specify the provision of self-management supports. With disadvantaged groups, such as those with schizophrenia who die 25-30 years prematurely (Brown, 1997; Colton & Manderscheid, 2006), self-management support is viewed as one strategy to improve their health and address health inequities (CMHA-ON, 2009). The chronic disease management model has not been tested in the serious mental illness arena. Dissonance exists between the model's emergence from medical fields viewing mental illnesses as chronic conditions that need health promotion and disease management, and the mental health community that frames serious mental illnesses around the concept of recovery while emphasising the population-based social determinants of health (income, housing, education, employment, social inclusion) (CMHA-ON, 2008). Based on lived experiences with serious mental illnesses, self-management can be considered a personal resource for self-determination and living well (Authors, 2013a). Self-management is essentially an application of recovery i.e., the active process of engaging in self-management to diminish the effects of illness and regain a sense of control over life (Authors, 2013a).

Evidence is growing that individuals with serious mental illnesses can benefit from self-management support and from a chronic disease management philosophy. For example, studies demonstrated individuals with schizophrenia learned to recognize the early warning signs of decompensation and take preventative actions (Morriss, 2013), strategies to decrease the negative aspects of hearing voices that were not amenable to medications (Buccheri et al., 2004), and to use cognitive strategies to deal with delusions (Authors, 2013a; Martyn, 2003). Lifestyle interventions have shown behavioural changes in areas such as smoking cessation, weight management and healthy eating (Cabassa, Ezell, & Lewis-Fernandez, 2010) particularly when interventions addressed cognitive disability and limited access to resources (Cimo, Stergiopoulos, Chiachen, Bonato, & Dewa, 2012). Demonstration projects with individuals with serious mental illnesses providing practical strategies and structured self-management problem-solving suggested benefits to increased client engagement and participation in decision-making, self-management techniques, decreased relapse or hospitalization rates and improved health-specific outcomes (Anzai et al., 2002; Goldberg et al., 2013; Hasson-Ohayon, Roe, & Kravetz, 2007; Lawn et al., 2007; Roe, Hasson-Ohayon, Salyers, & Kravetz, 2009). Concerns are being uncovered of self-management support limited to illness management, being accessed by a select group, and not delivered as envisioned within a client-centred approach and client-provider partnerships (Greenhalgh, 2009; Rogers, Kennedy, Nelson, & Robinson, 2005; Stevens & Sin, 2005). This is the context within which our initiative took place.

Moving Innovations into Practice While Ensuring Sustainability

The study of implementation science, in particular implementation of self-management support is a newly emerging field. Knowledge translation interventions to change clinician practice behaviour have had only small to moderate effects (Greenhalgh et al., 2004; Sudsawad, 2007). The field has shifted from focused intensive interventions to broadening to connect efforts across levels of influence (individual, interpersonal, organizational, communities) within a socio-ecological model for greater sustainable impact (Glasgow & Emmons, 2007; Greenhalgh, 2009). Literature moving innovations into mental health practice and integrating self-management support into routine practice was examined for ‘lessons learned’. The following were key messages:

- Support and validation from funder and management is essential for success (Brooks, Pilgrim, & Rogers, 2011). For example, self-management support be communicated as a core essential service and formally recognized as part of staff duties (Challis et al., 2011).
- Local circumstances and the context within which front-line work interactions take place must be strategically addressed (Brooks et al., 2011). In the mental health context of provider obligations to safeguard clients and protect the public, Brooks and colleagues found client-centred care intended to advance client participation and community integration competed with a culture of risk avoidance. Organizational pressures of ‘routinisation’ to maintain stability tended to support the status quo. Destabilising structural elements (staff turnover, funding cuts) undermined conditions needed for implementation.

- Mental health providers need to be involved in the operationalization of an innovation at the day-to-day practice level (Challis et al., 2011; Kennedy, Gately, & Rogers, 2004). This was consistent with conditions conducive to success: project champions, project activities aligning with sites' essential functions, facilitation of teamwork (Brooks et al., 2011) and staff empowered to deliver flexible, responsive services (Challis et al., 2011).
- All individuals within a person's circle of care need to buy-in and self-management support validated, coordinated, and communicated through care plans (Williams et al., 2007).
- Stand-alone client education programs are insufficient and self-management support needs to be integrated system wide e.g., patient education, clinician behaviour change, healthcare delivery processes, community engagement (Kennedy, Rogers, & Bower, 2007).
- For sustainability, strategies to promote self-management support and client-centred practice must be embedded in clinician practices and organizational structures of routine care pathways (Rogers et al., 2005), and clinicians receive feedback of the impact on clients (Williams et al., 2007).

Theoretical Framework

The Ottawa Model of Research Use (OMRU) (Graham & Logan, 2004) (Figure 1) was designed to facilitate integration of research evidence into healthcare organizations by policymakers at the level of individual clinicians, healthcare teams and/or organizations. The OMRU frames the process or steps of an innovation's implementation

(assessment, monitoring and evaluation) and offers a contextual framework of adopters-innovation-practice environment relationships that impact adoption of the innovation.

METHODS

An integrated knowledge translation (IKT) approach was selected as the most effective way to achieve our objectives. IKT is “a collaborative participatory approach to research that is action oriented and is solution and impact focused” (Tetroe, 2011, slide 4). Researchers and knowledge users (providers delivering self-management support services) actively collaborate to exchange knowledge, co-produce knowledge products and translate knowledge into practice (Parry, Salsberg, & Macaulay, 2013). Involvement of users and their tacit knowledge was deemed essential to tailor an innovation to the social and organizational context and ensure sustainability. Engagement of knowledge users as participatory partners is a predictor of research use and impact (Gagnon, 2011). For an IKT process to work effectively, four key factors were built into the project design: a process to develop a shared understanding of the health issue; a collaboration plan with agreed upon roles, responsibilities and evaluation; team members who have competencies in developing and navigating collaborations; and a strategy for dealing with conflicts and ensuring trust is maintained (Gagnon, 2011, pp.28-29). Over the course of the collaboration, provider behaviour for enabling self-management was identified for the innovation, the 5A’s of Self-Management Support within a Recovery Framework (Figure 2).

Setting and Population Served

The setting was a specialized mental health service mandated to serve individuals with schizophrenia and related psychotic disorders living in a large Canadian city and surrounding rural regions. The individuals served have an Axis 1 diagnosis coupled with complex psychiatric, physical, psychosocial, behavioural, and legal needs. The service offers a broad continuum of services involving: three inpatient units and a diverse range of transitional and outpatient programs. All programs at different locations are administered by one public, teaching, specialized mental health service.

Development of Innovation and Implementation Plan

Development took place in an overlapping four phased process in which the evidence was further synthesized, messages refined and plans tailored to local conditions.

Phase 1 – Gathering and synthesis of knowledge to draft innovation. Two foundational studies were conducted to provide local evidence of current conditions. A phenomenological study of clients across the service described unmet self-management learning needs and identified eight self-management tasks shaped by contextual structures for framing self-management support services (Authors, 2013a). A case study with embedded units of nurse-social worker-occupational therapist triads across eight locations within the service provided an understanding of the conditions influencing clinician behaviour, and a profile of what and how self-management was/was not enabled (Authors, 2013b). Both studies provided evidence about the barriers and supports to implementing self-management support locally.

In the process, awareness was raised about self-management support amongst participants and managers. The director of service provided her full active support for integration of client self-management and self-management support into routine services. The first author and one site manager drafted “5A’s of Self-Management Support within a Recovery Framework”. The draft was further revised integrating studies’ findings and local language, practices throughout the four phases.

Phase 2 – Building trust, a shared view and obtaining manager knowledge.

Program managers across the service (n=8) were targeted to engage as project partners because this group was in the position to leverage the innovation service wide (Birken, Lee, & Werner, 2012). Middle managers as project champions who can solve problems of resistance are important contributors as a condition of successful projects (Brooks et al., 2011). Five meetings were organized with facilitated managers-researcher discussions to arrive at a shared view, build trust and obtain manager knowledge for assembling an integration plan. The focus and meeting activities are outlined in Table 1.

Phase 3 – Assessing barriers/supports, drafting implementation plan. To proactively, strategically address potential implementation barriers and build on supports, an assessment was conducted of the attributes of the innovation, the potential adopters and practice environment as guided by the OMRU (Figure 1). To assess the innovation, we used the Essential Characteristics of an Innovation (Greenhalgh et al., 2004), a list of innovation attributes demonstrated to predict successful adoption. The review found the 5A’s tool to be compatible with clinicians’ values and concepts were familiar from behaviour counselling for tobacco addiction. The tool offered a structured approach with

sufficient flexibility to allow clinicians' personal ways of working and sites to tailor to program operations. However, the 5A's would require implementation skills and expertise. The steps can be broken down into manageable parts that can be adopted incrementally. It would be important to empower providers with opportunities to trial, discuss experiences and perceptions of risk, shape the innovation process and carve out a place for use in roles and work routines (Rogers et al., 2005).

To assess the potential adopters and practice environment, we used the Behaviour Change Wheel for Behaviour Change Interventions (Michie et al., 2011). Drawing on a range of theoretical approaches to understand clinician behaviour in context, the Behaviour Change Wheel provided a strategy to consider clinicians and the practice environment according to 'capability' (psychological and physical capabilities to implement the innovation), 'opportunity' (favourable circumstances outside the individual, prompting or making implementation possible) and 'motivation' (reflections, habits, emotions that encourage or detract from implementation). In Table 2, site specific strengths and weaknesses were mapped according to these elements from managers' reflections and findings of the two local studies in phase one. The mapping facilitated consideration of targeting clinician habits and making organizational changes to support opportunities for clinicians to enact capabilities. Michie and colleagues (2011) provided a broad range of approaches to interventions and policies for shaping these behaviour elements for users to consider. Then, the Behaviour Change Wheel was used to drill down to potential behaviour change techniques that matched selected approaches

(Michie, Johnston, Francis, Hardeman, & Eccles, 2008). One example is provided in Table 3.

Phase 4 – Discussing and revising implementation plans, clarify roles, responsibilities. The researcher met with each manager individually to encourage discussion and manager input. A page of questions and initial suggestions was pre-circulated targeting issues of concern to managers (How to ensure new employees use a ‘self-management state of mind’? How to implement self-management support amongst existing staff? How will we sustain these practices?). Manager feedback was requested, disagreement invited and managers asked what they felt was essential to put in place. The response was positive with practical suggestions to help staff engage and link material to routine work.

RESULTS

Creation of the Innovation – The 5A’s of Self-Management Support within a Recovery Framework (Figure 2)

The innovation was an adaptation of the heuristic model, the Five A’s Model of Self-Management Support, used to teach clinicians steps to patient-centred self-management support for chronic medical conditions by Glasgow and colleagues (2003; 2007). Glasgow emphasized client empowerment by integrating problem-solving and goal-setting from Lorig (1999) self-management programs and employed elements he found influenced self-management success, including research on the use of 5A’s in behavioural counselling for tobacco addiction (Whitlock, Orleans, Pender, & Allan, 2002). We modified the step ‘assess’ to ‘ask’ to align with a recovery-oriented approach

in which the client's expertise is recognized (Farkas, Gagne, Anthony, & Chamberlain, 2005) and due to our inability to determine or predict who is more likely to manage effectively (Clark, 2003). Based on study findings (Authors, 2013a; 2013b), we inserted in 'advise' explicit permission to the client to partner and own self-management. Also in steps 'advise' and 'assist', conversations were structured around the eight self-management tasks in the model, Learning Self-Management when Living with Serious Mental Illnesses (Authors, 2013a). In 'agree', providers were instructed to proactively plan for dealing with risk issues to remove these as potential barriers to proceeding with the client goals. In 'arrange', the follow-up plan was expanded believing client behaviour change will be incremental over significant time periods. Sustained behaviour change requires emotional and behaviour issues be addressed in addition to knowledge and technical skills (Glasgow & Emmons, 2007). Cueing phrases were added to connect the 5A's to locally known practices (e.g., motivational interviewing).

Implementation of the Innovation - A Learning and Embedding Initiative

The final implementation plan represented a synthesis of: managers' feedback, evidence of local conditions from two earlier studies, 'lessons learned' from studies moving innovations into practice, evaluations of clinician learning initiatives (Casper, 2008; Stolee et al., 2009), the "Navigating Self-management" toolkit (Kubina & Kelly, 2007), and the barriers/supports assessment from phase three. The focus was implementation of a structured approach to self-management support that was customised to the local conditions (i.e., integration of the 5A's into routine practice). Drawing

heavily on Kennedy and colleagues (2010), two key principles guided the plan's development.

- The first principle was fostering an enabling culture of learning. An activated workforce empowered to reflect on practices and learn from each other's successes and mistakes is associated with increased readiness to creatively problem-solve and embrace innovation. This principle is supported by research about learning organizations and 'communities of practice' having positive attitudes towards change, collaboration among colleagues and uptake of complex social innovations (Wenger, 1998).
- The second principle was embedding self-management support into providers' daily work activities and ways of thinking and working. By linking learning content to routine activities, engaging providers' assistance to reflect upon and embed the innovation, there is greater likelihood of the innovation being sustained long term. Engaging providers' assistance supports investment in innovations and taps into workers' tacit knowledge. Embedding the innovation into processes of care facilitates integration of self-management support habits into clinicians' normal routines. This principle is supported by theories and research about worker habits and how complex interventions in healthcare work processes become part of normal routines (Kennedy et al., 2010; Nilsen, Roback, Brostrom, & Ellstrom, 2012).

The learning initiative was envisioned as beginning with a participatory reflective experience in which a core set of exercises would create a common understanding of self-

management support; individuals would be inspired to pursue personal learning goals and local groups to engage in development activities aligned with site-specific interests and conditions. On-going education, follow-up support and embedding self-management in organizational practices would further support implementation given short-term learning experiences are insufficient to fully integrate and sustain such a complex innovation.

Learning components. The learning implementation plan is comprised of three parts.

Part One – 3 hour all staff session

- Introduction to core concepts using case-based learning and quotations from local studies while conveying client needs and benefits of supporting self-management (30 min).
- Exercise: Reflecting on a map of care pathway (from clients' first contact to discharge), identify the opportunities and missed opportunities for clients using and practicing self-management over the course of care. Prompt discussion with known clients (60 min).
- Exercise: Integration of 5A's into daily routines. Explore and solve problems related to operationalizing and sustaining 5A's using problem-solving worksheets (60 min). Message that self-management support is part of core services and part of many current activities. The 5A's brings a structured approach to client-centred practice.

- Complete self-assessment of self-management support core competencies adapted from self-management skills audit worksheet (Kubina & Kelly, 2007). Write an intention statement of action to take towards implementing the 5A's (30 min).
- Participant evaluation of session – one page questionnaire, group discussion.

Part Two – 30 minute session during existing staff meeting

- Problem solve how to: generate list of local self-management support resources (e.g., information sources, group training and support, voluntary sector and local support), make information accessible, have resource list sustained.

Part Three – 3 hour clinical staff session

- Recap core concepts; brainstorm what is meant by 'client-centred practice' and identify how we know a client is engaged, shared decision-making is taking place and a partnership exists.
- Skills practice using demonstration and role play techniques to practice skills needed to provide motivation and support to enable client self-management. Practice implementation of 5A's with difficult case scenarios (e.g., clients who are precontemplative, crises with suicidal ideation) role playing in threes (client, provider, observer) using a reflective practice checklist. The main focus is how to:
a) hold conversations about what clients are doing, can do and need to do, b) share decisions with clients, and c) ensure clients obtain the right support.
- Introduce Stress-Vulnerability Model (Zubin & Spring, 1977) as a framework for clients to interpret experiences, demonstrate and role play use.

- Discuss operationalizing and sustaining 5A's, follow through on intention statements.
- Participant evaluation of session and requests for further education, support via one page questionnaire, group discussion.

On-going education and support. In follow-up to the three formal sessions, supplemental learning sessions are tailored to staff self-assessments of core competencies (e.g., advanced motivational interviewing, goal-setting, sustainable action planning). A range of on-going support is provided. For example, staff champions role model, mentor peers while managers provide support and recognition of learning efforts. Monthly staff meetings with the manager and researcher discuss and strategize arising issues with implementation. An electronic database of local resources is built together. The researcher provides information searching and appraisals and consultations on evidence-based practice issues.

Embedding in organizational practices. To provide the opportunities for clients and staff to exercise capabilities and further develop expertise, spaces are created for clients to use self-management and for providers to offer self-management support throughout care processes. Examples of key junctures include: hiring processes, referral-intake process, appointment setting, care planning, relationships with formal and informal self-management supports, and information sharing with health care organizations.

DISCUSSION

The development of a theory-driven, evidence-based innovation and implementation plan involved art as well as science. Although theory provided a

framework and implementation science research provided potential evidence-based options for influencing clinician behaviour, multiple nuanced decisions were made during application. Considerations included: local conditions, historical staff education experiences, organizational expectations, managers' values and tacit understanding of how best to obtain staff engagement and commitment. The process involved much more than an analysis of barriers and supports and plugging in targeted interventions as if following a recipe.

Although useful as an overall skeleton, the OMRU did not delineate details. To fill in the gaps, the Behaviour Change Wheel (Michie et al., 2011) and Essential Characteristics of an Innovation (Greenhalgh et al., 2004) were used to operationalize OMRU elements to assess the innovation, potential adopters and practice environment. They were useful tools as a synthesis of relevant evidence-based elements linked to the OMRU that prompted broad reflexive strategic planning. However, the Behaviour Change Wheel (Michie et al., 2011) and behaviour change techniques (Michie et al., 2008) were steeped in psychological and social science nomenclature representative of layers of meaning. Concepts had to be translated to the project context and often rephrased into plain language for dialogue. Potentially in the process some of the meanings were lost but the planning process was far richer for having utilized these tools. Also, we recommend the OMRU be modified by moving 'patients' from 'practice environment' to 'potential adopters' given supporting self-management requires a client-provider partnership and clients are the end knowledge users. In this way, any self-

management intervention will need to consider the client as an adopter and his/her self-management practices and environments.

The implementation plan is viewed as just the beginning of an on-going, evolving process informed by clinicians' and clients' feedback. Chart audits would give some indication of integration into practice (client voice, use in care planning). There are areas for particular attention in future. For example, each outpatient location will need a customized plan to engage and carve out a role with psychiatrists who operate in different roles depending on the program's practice model. Clients, the ultimate adopters of self-management, need to be asked what would facilitate client participation in the 5A's process. Also, organizational theories of change indicate knowledge of self-management support will need to undergo 'codification' (Denis & Lehoux, 2013), in which self-management support becomes part of all formal written documents (e.g., program descriptions, practice guidelines, performance management) and information processes used to pass knowledge from person to person (e.g., hiring practices, orientations, patient records). In the next phase, a research study inviting other local programs will formally evaluate the acceptability and feasibility of the Learning and Embedding Initiative while discovering how the intervention was experienced by clients and how the intervention influenced clinical practices. If results were promising, the foundation would be set for a controlled trial in other mental health organizations.

According to CIHR, IKT can be recognized by knowledge users and researchers working together to "shape the research questions... interpret study findings... craft messaging... move the results into practice" (Parry, Salsberg & Macaulay, 2013, p.9). The

project began responding from a ‘pull’ from knowledge-users. The director and managers were asking: “How do we design and deliver services to ensure clients have the tools and resources for self-management?” Clinicians were grappling with understanding recovery as a personal journey, something they could not do for clients, and were seeking role clarification and direction for moving beyond recovery rhetoric to the ‘meat and potatoes’ of practice. Clinicians were asking: “How do I best apply a recovery philosophy in my practice?” During the initial study, clients were asking: “What are others’ experiences of learning self-management and can others learn from my life experiences?” The managers and researcher together moved forward the study findings, labeling the meaning to current practices, crafting messaging, shaping implementation plans and together will roll out the Learning and Embedding Initiative.

In summary, this paper offers theory-driven, evidence-based strategies to customize integration of self-management support and movement of research into practice. The main contributions are knowledge translation products or tools for pursuing the integration of self-management support into routine practice (e.g., meeting activities for exchange, the 5A’s of Self-Management Support within a Recovery Framework, the Learning and Embedding Initiative plans). In the future, the implementation project will allow us to study the spread and sustainability of an innovation in a service organization, a current gap in the literature (Greenhalgh et al., 2004). However, all efforts will be for nothing, if self-management support is not implemented in partnership with a client-centred approach.

References

- Adams, K., Greiner, A., & Corrigan, J. (2004). *Report of a summit. The 1st Annual Crossing the Quality Chasm Summit-A focus on communities*. Washington, DC: National Academic Press.
- Anzai, N., Yoneda, S., Kumagai, N., Nakamura, Y., Ikebuchi, E., & Liberman, R. P. (2002). Training persons with schizophrenia in illness self-management: A randomized controlled trial in Japan. *Psychiatric Services, 53*(5), 545-547.
- Authors. (2013a). The work of learning self-management when living with serious mental illness. *Under review for publication*.
- Authors. (2013b). Unpacking the black box of conditions influencing clinician behaviour: An embedded case study of self-managment support during specialized mental health services. *Under review for publication*.
- Birken, S., Lee, S., & Werner, B. (2012). Uncovering middle managers' role in healthcare innovation implementation. *Implementation Science, 7*(28), 1-12. Retrieved from <http://www.implementationscience.com/content/7/1/28>
- Brooks, H., Pilgrim, D., & Rogers, A. (2011). Innovation in mental health services: What are the key components of success? *Implementation Science, 6*. Retrieved from <http://www.implementationscience.com/content/6/1/120>
- Brown, S. (1997). Excess mortality in schizophrenia: A meta-analysis. *British Journal of Psychiatry, 171*, 502-508.
- Buccheri, R., Trygstad, L., Dowling, G., Hopkins, R., White, K., Griffin, J. J. et al. (2004). Long-term effects of teaching behavioral strategies for managing

persistent auditory hallucinations in schizophrenia. *Journal of Psychosocial Nursing & Mental Health Services*, 42(1), 18-27.

Cabassa, L., Ezell, J., & Lewis-Fernandez, R. (2010). Lifestyle interventions for adults with serious mental illness: A systematic review. *Psychiatric Services*, 61, 774-782.

Canadian Mental Health Association [CMHA]- Ontario. (2009). *Diabetes and serious mental illness: Future directions for Ontario. A report from the March 30, 2009 think tank on diabetes and serious mental illness*. Toronto, ON: Author.

Casper, E. (2008). Using implementation intentions to teach practitioners: Changing practice behaviors via continuing education. *Psychiatric Services*, 59(7), 747-752.

Challis, D., Hughes, J., Berzins, K., Reilly, S., Abell, J., Stewart, K. et al. (2011). Implementation of case management in long-term conditions in England: Survey and case studies. *Journal of Health Services Research and Policy*, 16(1), 8-13.

Cimo, A., Stergiopoulos, E., Chiachen, C., Bonato, S., & Dewa, C. (2012). *Effective lifestyle interventions to improve type 2 diabetes self-management for those with schizophrenia or schizoaffective disorder: A systematic review*. Retrieved from <http://www.biomedcentral.com/1471-244A/12/24>

Clark, N. M. (2003). Management of chronic disease by patients. *Annual Review of Public Health*, 24, 289-313. doi:10.1146/annurev.publhealth.24.100901.141021

Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W., & Anderson, L. (1991). Self-management of chronic disease by older adults: A review and questions for research. *Journal of Aging and Health*, 3(1), 3-27.

- Colton, C., & Manderscheid, R. (2006). Congruencies in increased mortality rates, years of potential life lost and causes of death among public mental health clients in 8 states. *Prevention and Chronic Disease, 3*(2), 1-14.
- Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Denis, J., & Lehoux, P. (2013). Organizational theory. (Section 4.4 ed.). *Canadian Institute of Health Research*. Retrieved from <http://www.cihr-irsc.gc.ca>
- Farkas, M., Gagne, C., Anthony, W., & Chamberlain, J. (2005). Implementation of recovery oriented evidence based programs: Identifying the critical dimensions. *Community Mental Health Journal, 41*(2), 141-158. doi:10.1007/s10597-005-2649-6
- Fisher, E., Brownson, C., O'Toole, M., Shetty, G., Anwuri, V., & Glasgow, R. (2005, September). Ecological approaches to self-managment: The case of diabetes. *American Journal of Public Health, 95*(9), 1523-1535.
- Franx, G., Kroon, H., Grimshaw, J., Drake, R., Grol, R., & Wensing, M. (2008). Organizational change to transfer knowledge and improve quality and outcomes of care for patients with severe mental illness: A systematic overview of reviews. *Canadian Journal of Psychiatry, 53*(5), 294-305.
- Gagnon, M. (2011). Moving knowledge to action through dissemination and exchange. *Journal of Clinical Epidemiology, 64*, 25-31. doi:10.10116/j.jclinepi.2009.08.013

- Glasgow, R., Davis, C., Funnell, M., & Beck, A. (2003). Implementing practical interventions to support chronic illness self-management. *Joint Commission Journal on Quality and Safety*, 29(11), 563-574.
- Glasgow, R., & Emmons, K. (2007). How can we increase translation of research into practice? Types of evidence needed. *Annual Review of Public Health*, 28, 413-433. doi:10.1146/annurev.publhealth.28.021406.144145
- Goldberg, R. W., Weber, E., Dickerson, F., Tenhula, W., Lucksted, A., Kreyenbuhl, J. et al. (2013). Living Well: An intervention to improve self-management of medical illness for individuals with serious mental illnesses. *Psychiatric Services*, 64, 51-57. doi:10.1176/appinps.201200034
- Graham, I., & Logan, J. (2004). Translating research: Innovations in knowledge transfer and continuity of care. *Canadian Journal of Nursing Research*, 36(2), 89-103.
- Greenhalgh, T. (2009). Patient and public involvement in chronic illness: Beyond the expert patient. *British Medical Journal*, 338, 629-631.
- Greenhalgh, T., Robert, G., MacFarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Quarterly*, 82(4), 581-629.
- Hasson-Ohayon, I., Roe, D., & Kravetz, S. (2007). A randomized controlled trial of the effectiveness of the Illness Management and Recovery program. *Psychiatric Services*, 58(11), 1461-1466.
- Kennedy, A., Chew-Graham, C., Blakeman, T., Bowen, A., Gardener, C., Protheroe, J. et al. (2010). *Delivering the WISE (Whole Systems Informing Self-Management*

- Engagement) training package in primary care: Learning from formative evaluation*. Retrieved from <http://implementationscience.co/content/5/1/7>
- Kennedy, A., Gately, C., & Rogers, A. (2004, January). *Assessing the process of embedding EPP in the NHS Preliminary Survey of PCT Pilot Sites*. Retrieved from <http://www.expertpatients.co.uk>
- Kennedy, A., Rogers, A., & Bower, P. (2007). Support for self care for patients with chronic disease. *British Medical Journal*, 335, 968-970.
- Kubina, N., & Kelly, J. (2007). *Navigating self-management: A practical approach to implementation for Australian health care agencies. Resource prepared for Whitehorse Division of General Practice, Australian Government Department of Health and Aging*. Retrieved from http://som.flinders.edu.au/FUSA/CCTU/self_managment.htm
- Lawn, S., Battersby, M. W., Pols, R. G., Lawrence, J., Parry, T., & Urukalo, M. (2007). The mental health expert patient: Findings from a pilot study of a generic chronic condition self-management programme for people with mental illness. *International Journal of Social Psychiatry*, 53(1), 63-74.
doi:10.1177/0020764007075010
- Lorig, K., Gonzalez, V., & Laurent, D. (1999). *The Chronic Disease Self-Management Workshop Leaders' Manual (revised)*. Stanford, CA: Stanford Patient Education Center, Stanford University.

- Martyn, D. (2003, December). *Self-management: The experiences and views of self-management of people with a diagnosis of schizophrenia*. Retrieved from <http://www.rethink.org/publications>
- Michie, S., Johnston, M., Francis, J., Hardeman, W., & Eccles, M. (2008). From theory to intervention: Mapping theoretically derived behavioural determinants to behaviour change techniques. *Applied Psychology*, 57(4), 660-680.
doi:10.1111/j.1464-0597.2008.00341.x
- Michie, S., van Stralen, M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), 1-11.
- Ministry of Health and Long-Term Care (MOHLTC). (2007). *Preventing and managing chronic disease: Ontario's framework*. Retrieved from <http://www.health.gov.on.ca/english/providers/program/cdpm/index.html>
- Morriss, R. (2013). Training to recognize the early signs of recurrence in schizophrenia. *Cochrane Database of Systematic Reviews*, (2. Art.No: CD006147). doi:1002-14651858.CD005147.pub2
- National Health Priority Action Council (NHPAC). (2005). *National Chronic Disease Strategy*. Retrieved from Australian Government Department of Health and Aging <http://www.health.gov.au/internet/main/publishing.nsf/Content/pq-ncds>
- Nilsen, P., Roback, K., Brostrom, A., & Ellstrom, P. (2012). *Creatures of habit: Accounting for the role of habit in implementation research on clinical behavior*

change. Implementation Science. Retrieved from

<http://www.implementationscience.com/content/7/1/53>

Parry, D., Salsberg, J., & Macaulay, A. (2013). Guide to researcher and knowledge-user

collaboration in health research. *Canadian Institute of Health Research*

Knowledge Translation Portfolio. Retrieved from <http://www.cihr->

[irsc.gc.ca/e/29418.html](http://www.cihr-irsc.gc.ca/e/29418.html)

Roe, D., Hasson-Ohayon, I., Salyers, M., & Kravetz, S. (2009). A one-year follow-up of

Illness Management and Recovery: Participants' accounts of its impact and

uniqueness. *Psychiatric Rehabilitation Journal*, 32(4), 285-291.

Rogers, A., Kennedy, A., Nelson, E., & Robinson, A. (2005). Uncovering the limits of

patient-centredness: Implementing a self-management trial for chronic illness.

Qualitative Health Research, 15(2), 224-239. doi:10.1177/1049732304272048

Stevens, S., & Sin, J. (2005). Implementing a self-management model of relapse

prevention for psychosis into routine clinical practice. *Journal of Psychiatric and*

Mental Health Nursing, 12(4), 495-501.

Stolee, P., McAiney, C., Hillier, L., Harris, D., Hamilton, P., Kessler, L. et al. (2009).

Sustained transfer of knowledge to practice in long-term care: Facilitators and

barriers of a mental health learning initiative. *Gerontology and Geriatrics*

Education, 30, 1-20. doi:10.1080/02701960802690233

Sudsawad, P. (2007). *Knowledge translation: Introduction to models, strategies and*

measures. Retrieved from Southwest Educational Development Laboratory,

National Center for the Dissemination of Disability Research

<http://ncddr.org/kt/products/ktintro/ktintro.pdf>

Tetroe, J. (2011). *Integrated knowledge translation at CIHR: An update*. Presentation

Participatory Research at Lunch, McGill University, March 2, 2011.

U.S. Department of Health and Human Services. (2000). *Healthy People 2000*.

Washington, DC, Government Printing Office.

Wenger, E. (1998). *Communities of practice. Learning, meaning and identity*.

Cambridge, UK: Cambridge University Press.

Whitlock, E., Orleans, T., Pender, N., & Allan, J. (2002). Evaluating primary care

behavioral counseling interventions. *American Journal of Preventive Medicine*,

22(4), 267-284.

Williams, A., Harris, M., Daffurn, K., Davies, G., Pascoe, S., & Zwar, N. (2007). Sustaining

chronic disease management in primary care: Lessons from a demonstration project.

Australian Journal of Primary Health, 13(2), 121-128.

Wilson, P. M. (2001). A policy analysis of the Expert Patient in the United Kingdom:

Self-care as an expression of pastoral power? *Health and Social Care in the*

Community, 9(3), 134-142.

Zubin, J., & Spring, B. (1977). Vulnerability: A new view on schizophrenia. *Journal of*

Abnormal Psychology, 86, 103-126.

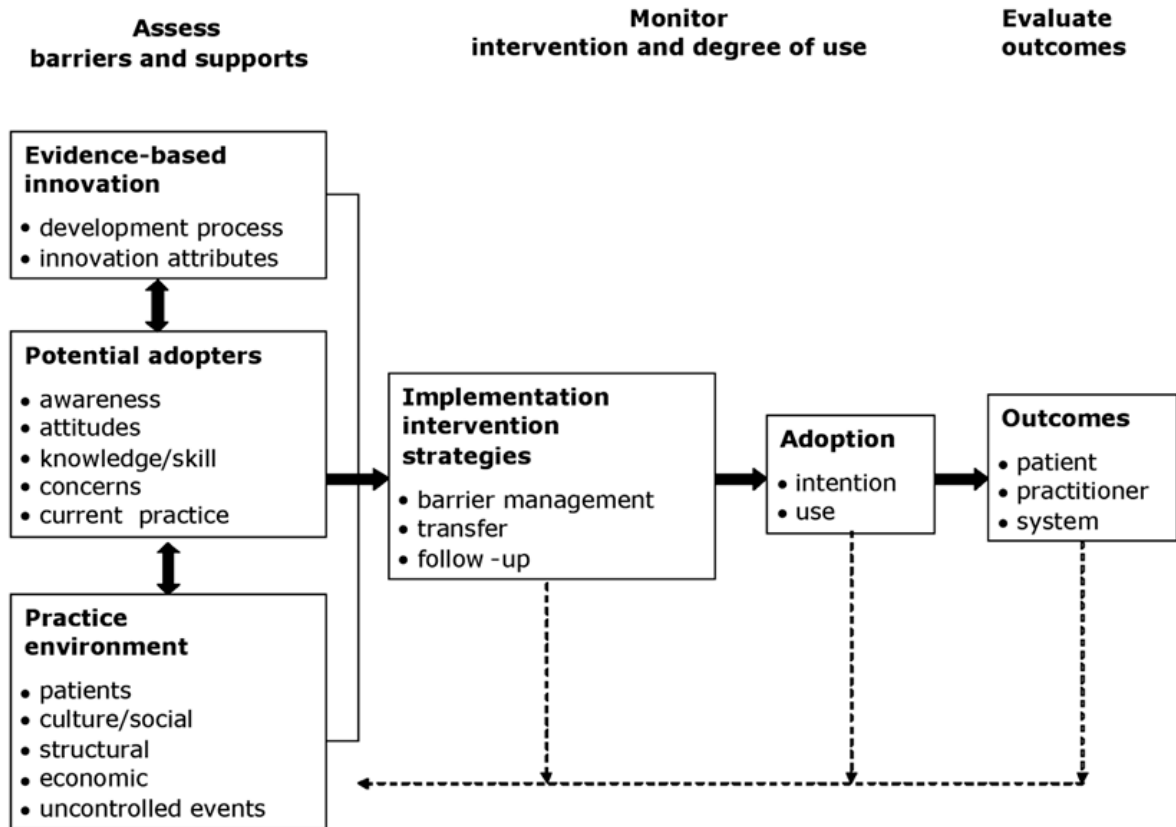


Figure 3. Ottawa Model of Research Use (OMRU) Reprinted from “Translating Research: Innovations in Knowledge Transfer and Continuity of Care,” by I. Graham and J. Logan, 2004, *Canadian Journal of Nursing Research*, 36, p.94. © 2004 by the Canadian Journal of Nursing Research. Reprinted in dissertation with permission..

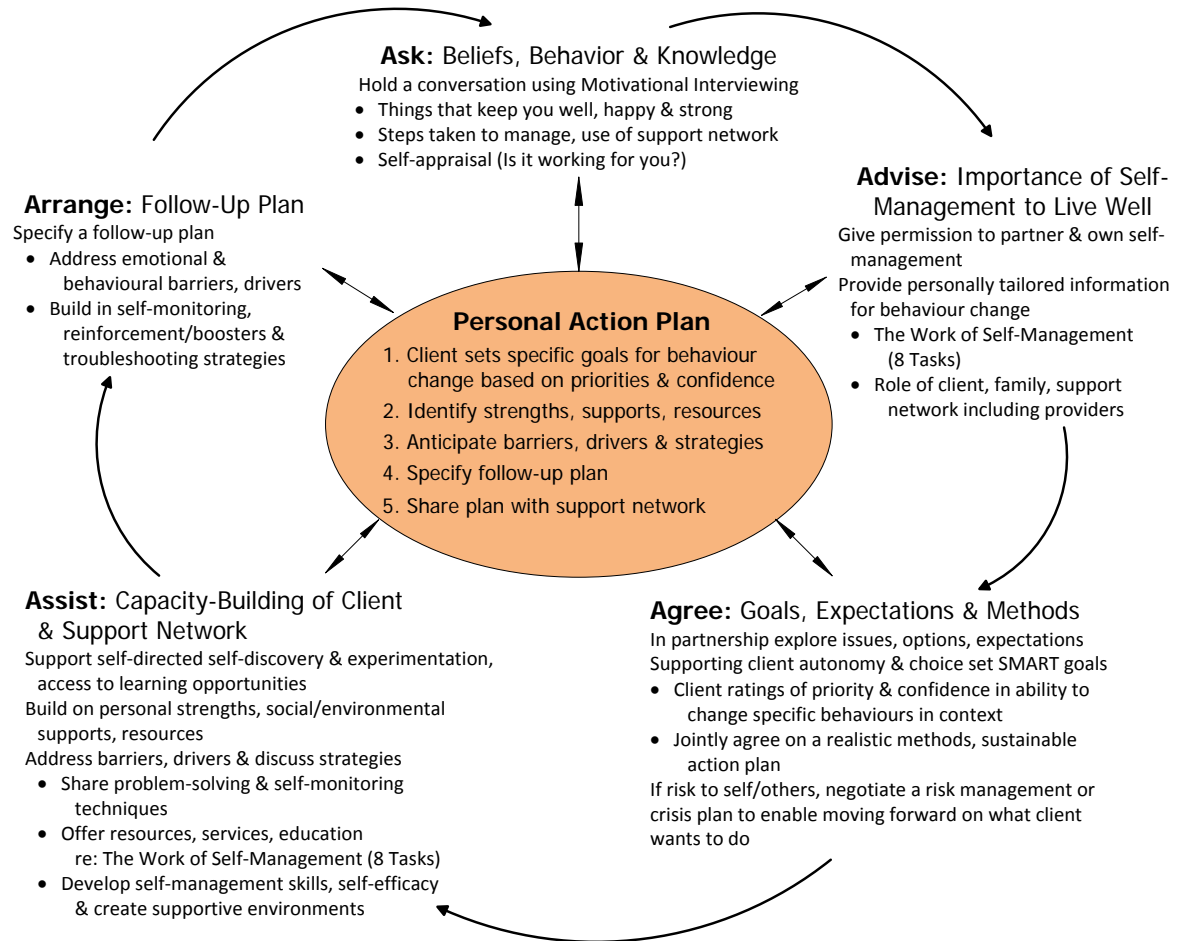


Figure 2. The 5A's of Self-Management Support within a Recovery Framework (Authors, 2013a,b; adapted from Glasgow & Emmon, 2007). Each of the 5 steps (Ask, Advise, Agree, Assist, Arrange) contributes to a personally tailored written action plan.

Table 1. *Interactive Meeting Activities*

Focus: Engage managers in project. What are clients’ experiences with self-management learning? What are clients’ self-management learning needs?

Session #1 (.5 hr)

- Pre-circulated study manuscript - “The work of learning self-management while living with serious mental illness” (Authors, 2013a)
- Managers invited to work with researcher to integrate self-management into routine practices and began negotiating managers’ needs.
- Discussion of what the concept self-management means to them and staff.

Session #2 (1 hr)

- Study presentation, discussion of findings re: clients learning self-management.
- In pairs shared examples of how see staff members support two self-management tasks (‘Trusting self and managing thought’, ‘Developing a support network’)
- Handouts: Presentation slides, figure and 2-page summary of Learning Self-Management when Living with Serious Mental Illnesses model (Authors, 2013a)
- Homework: Reflect on Self-Management Learning Model and identify what you are doing/looking at doing/hope to see in your program. Pick out 1 or 2 self-management learning tasks that are your team’s strengths to share.

Focus: How do you and staff conceptualize self-management support? What are we already doing to support self-management? Gaps?

Session #3 (1.5 hr)

- Reviewed homework and mapped areas of strength on enlarged figure of Self-Management Learning Model and visually depicted gaps.
- Discussed what integration means to routine practice and identified potential integration issues at levels of client-therapist encounters, programs and organization of services.
- Draft of a 5A’s framework was introduced as potential structured approach.

Focus: Conditions influencing self-management support practices. What do we need to do? What are our priorities?

Session #4 (1 hr)

- Study presentation re: conditions influencing clinician behaviour (Author, 2013b).
- Summary of services’ strengths and weaknesses mapped on COM-B model (Michie, van Stralen & West, 2011).
- Handouts: Presentation slides, draft of the 5A’s of Self-Management Support within Recovery Framework.
- Homework: Reflect upon how the draft 5A’s related to the work we already do.

Session #5 (1.5 hr)

- Reviewed draft 5A’s and linked examples of current practices and local resources to support implementation.
 - Exercise: Brainstormed opportunities for self-management support before, during and after client-therapist encounter/visit.
-

Table 2. *Clinician Strengths and Weaknesses mapped on the Elements of Capability (C), Opportunity (O), Motivation (M) that Influence Behaviour (B) in the COM-B system*

Psychological & Physical Capability (C) to Engage in Self-Management Support (SMS)	
Strengths	Weaknesses
<ul style="list-style-type: none"> ▶ Potential champions ▶ Build on existing concepts: <ul style="list-style-type: none"> ◦ Recovery, Client-Centred Practice, Cultural Competency, Trauma-Informed Care, Person-Environment-Occupation Fit, Adaptation ▶ Use existing skills/techniques <ul style="list-style-type: none"> ◦ Motivational Interviewing, Stages of Change ◦ Crisis Planning ◦ Teachable Moments ◦ Behaviour Change into Routines, Social Learning Theory and CBT Strategies 	<ul style="list-style-type: none"> ▶ Provider knowledge re: Health, SMS ▶ Range of provider skills with gaps <ul style="list-style-type: none"> ◦ Tailored client-directed learning ◦ Clinician self-regulation ◦ Client self-reflection, problem-solving ◦ Capacity-building of client + support network ▶ Client-provider roles <ul style="list-style-type: none"> ◦ Negotiating partnership, shared decision-making & risk planning ◦ Changing behaviour & dealing with power ◦ Breaking cycles of client disempowerment
Reflective, Habitual and Emotional Motivation (M)	
Strengths	Weaknesses
<ul style="list-style-type: none"> ▶ Matches values, mission & mandate ▶ Linked with professional identity & sense of self, job satisfaction ▶ Challenges viewed as learning experiences 	<ul style="list-style-type: none"> ▶ Beliefs acting as barriers (e.g., client growth potential, competence, time) ▶ Actions shaped by perceptions of risk/fears ▶ SMS social norms, habits not yet established
Opportunity (O) or Factors Outside the Individual Making Behaviour Possible	
Strengths	Weaknesses
<ul style="list-style-type: none"> ▶ Long standing relationships with clients ▶ Flexibility re: intensity of service delivery ▶ Existing tools, resources <ul style="list-style-type: none"> ◦ WRAP, Crisis Plans, OCAN, Client Needs Worksheet, Modules, Comfort Plans ▶ Existing care processes re: client orientation, engagement ▶ Interdisciplinary teams provide information, expertise, support 	<ul style="list-style-type: none"> ▶ Whose job is it any way? ▶ Delivery of focused self-management learning opportunities ▶ Spaces for clients to use & practice SM in all processes of care from admission to discharge ▶ Healthcare environment undermines partnerships, self-determination, health ▶ Quality initiatives, staff education primarily focuses on psychiatry versus living well

Note. Adapted from “The behaviour change wheel” by S Michie, M van Stralen & R West, 2011, *Applied Psychology*, 57(4), 660-680.

Table 3. *Targeted Behavioural Determinants Matched with Potential Behaviour Change Techniques*

Target Motivation – Weaknesses ^a	Behaviour Change Techniques ^b
Assumptions and beliefs acting as barriers:	
<ul style="list-style-type: none"> ◦ Client potential to grow/change, competence in coping with stress and making decisions, reluctance to take responsibility; ◦ Clinician lack of ability to communicate and negotiate risk with clients; ◦ Lack of support by physicians, undermining physician-patient relationship; ◦ Lack of technical support/resources; ◦ Inconsistent with perceived priorities 	<ul style="list-style-type: none"> Goal specified as behaviour/outcome Link behaviour & outcomes Persuasive communication Social encouragement, pressure, support Self-evaluation, elicit self-motivating statements Contract with self, intention statements Rewards, incentives, self-evaluation Homework, skills building (problem-solving, decision-making); Graded easy to harder tasks; Personal experiments; Experiential tasks

^a Michie et al., 2011

^b Michie, Johnston, Francis, Hardeman & Eccles, 2008

Note. Clinician capability and opportunity were also matched and only one motivation example is provided.

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

The basic premise of this dissertation is that self-management support can be provided and be beneficial within a recovery framework for individuals with serious mental illnesses. A local service was studied as an exemplar of current specialized mental health service delivery. The intent was to lay the foundation for customizing self-management to a conventional mental health service delivery environment. Evidence and recommendations were obtained from a phenomenological study of clients' perspectives and experiences learning self-management, and from a case study of conditions shaping clinicians' perspectives and experiences enabling self-management. In collaboration with a management team, the research evidence was translated into a draft protocol of customizing the integration of self-management into routine services for implementation and evaluation in the near future. In this chapter, I address the overall strengths and limitations of the dissertation. Then, this work is reviewed to summarize the contributions (discoveries, innovations, assumptions challenged) and further reflections regarding: 1) the nature and roles of context; 2) self-management and self-management support for individuals living with serious mental illnesses; 3) the conceptualization of self-management support and the CDPM framework (MOHLTC, 2007); 4) the Self-Regulation Model (Clark, 2003; Clark, Gong, & Kaciroti, 2001); 5) the Ottawa Model of Research Use (Graham & Logan, 2004a); and 6) the conceptualization of health within a socio-ecological model. Next, I consider the implications and recommendations for practice, the participating organization and mental health services, policy and research.

The chapter concludes with personal reflections concerning the impact of the PhD experience and final conclusions.

Overview of Results

The Clients Learning Self-Management study described the lived experiences of learning self-management while living with serious mental illnesses and interpreted the meaning of those experiences within each individual's recovery journey and the context of healthcare delivery. The van Manen (1997) approach of phenomenology embedded the researcher in the research process which enabled the use of an occupational therapist lens to view participants as engaging in the world as occupational beings. Findings were based on the lives of 25 participants with self-reported psychosis and diverse experiences with respect to age, illness tenure, co-morbidities, service utilization and occupational roles. The nature of learning self-management was a gradual growth process of self-discovery and experimentation interrupted by psychotic episodes, hospitalizations and medication changes. The learning process was uniquely personal with no shared timeframe or sequence. However, participants commonly described and recommended that to live well there was a need to put in place eight essentials, viewed as tasks within the work of learning self-management. Further, learning experiences were shaped by contextual structures. Results indicated clients' self-management learning needs were not being met and they were largely learning with life as the 'teacher' against a back drop of experiencing services that were predominately psychiatric management and pharmacotherapy, and crisis or risk management.

The Clients Learning Self-Management study is the first known documentation and in-depth exploration of client-defined critical events of learning what they can do to manage their condition and be more in control of their lives. Participants' voices and the drawings that mapped learning journeys can be used by health professionals and planners to raise awareness and understanding amongst clients, families, clinicians and policy-makers. For clinicians, results provided evidence of the gaps in what and how services were delivered and offered suggestions to address these gaps. A model (Learning Self-Management when Living with Serious Mental Illnesses) of self-management tasks and structures that influenced participation in learning was created that provided a framework for clinicians and planners to describe learning self-management and for planning responsive interventions. The model offers a tool to assist clinicians to consider a range of points of intervention at each of the eight tasks and seven contextual structures. Also, the model can assist planners to reflect upon whether services address the breadth of self-management needs.

The Clinicians Enabling Self-Management study used Yin's (2009) case study methodology to discover the conditions that shaped clinician perspectives and experiences with enabling self-management during specialized service delivery. Replication sampling of discipline triads (nursing-social work-occupational therapy) from eight varied service locations allowed analyses by embedded unit (individual participant, discipline, location) and the use of analytical strategies (replication, pattern matching, explanation building). Thematic analyses of multiple data sources of experiential understanding and naturalistic observation generated a rich picture of practices and

conditions in context. This is the first study to describe key dimensions of self-management support practices which can provide the basis for developing a self-reflection tool for clinicians and may be used in future research protocols to develop fidelity measures of delivering self-management support. Also, the study provided insights into behavioural and organizational processes and drivers that shaped practices. Within an emergent model of complex dynamic relationships, the practice environment was the dominant influence of clinician actions toward enabling self-management.

Results provided insights into the tensions and dilemmas faced by clinicians in the realities of routine service delivery. In principle, clinicians supported clients' right to health information, acknowledged the need for such information to manage living with mental illnesses and supported the principles of client-centred practice. However, in practice, when dealing with daily realities and working conditions, there were issues with putting principles into practice, and clinicians' beliefs and actions were shaped and sometimes swayed by practice conditions. The public organization's culture of risk minimization and standardization was a driver behind clinician struggles to deliver client-centred care, and to support client self-determination, experimentation and growth. Others have written about clinicians' good intentions being subverted by organizational cultures, processes (Townsend, 1998) and how client-centred care can be interpreted as a risk in mental health practice environments (Brooks, Pilgrim, & Rogers, 2011).

Hammell (2006) observed how occupational therapists serve two masters, the client and the healthcare system in which they work and declared "this is an area of profound conflict of interest" (p.163). Occupational therapists are accountable to clients

while being ‘agents of the state’. By rights, on the surface, there should not be a divide regarding client-centred practice since the study’s organization like many others formally incorporated client-centred practice into the organization’s policy. Disciplines such as nursing and occupational therapy actively support client-centred care (Canadian Association of Occupational Therapists, 1991, 1994; Registered Nurses of Ontario, 2006). However, there are variations in how client-centred practice is conceptualized and translated into practice. In occupational therapy, the principles most emphasized in client-centred practice are to ensure equity (care addresses individual client’s contextual differences) and democracy (a sharing of power in collaborative partnerships) (Law, 1998). Although the principles are consistent with clinicians’ and the organization’s values, and healthcare has moved to focusing on the patient experience and participation in healthcare, client-centred practice has not been operationalized and embedded into the organization’s day-to-day routine health practices.

A mechanism both facilitating and constraining self-management support was clinicians’ self-regulation skills, in particular in the context of negotiating client-clinician partnerships and navigating risk-taking. Key dimensions of self-management support identified during analysis were risk-taking and power relations. Those clinicians who proactively planned risk-taking jointly with clients and sorted out shared responsibilities appeared to be able to remove clinicians’ fears of risk as a barrier (i.e., clinician fears were less likely to constrain clients’ experimentation to learn self-management). The study offered insights into how clinicians struggled with giving power and transferring authority to clients. Vestiges of clinicians holding authority as the expert providing

traditional health teaching and skills training were documented. The Clinicians Enabling Self-Management study confirmed the gaps in service delivery identified by the Clients Learning Self-Management study. Priority was placed on psychiatric and risk management, and enabling self-management was not a routine essential service. However, results provided examples of how some clinicians used strategies as requested by client participants to “teach us to teach ourselves” (e.g., role modelled learning, acted as a resource, shared explanatory frameworks, facilitated self-reflection, shared self-monitoring techniques, mentored/coached problem-solving and self-evaluation, and guided structured experiments).

The Operationalization of Self-Management Support study used an integrated knowledge translation (IKT) approach (Parry, Salsberg, & Macaulay, 2013) to translate research evidence and develop a plan for moving self-management support into routine practice. A collaboration (between director, eight managers and myself, the researcher) adapted a tool for teaching healthcare providers and structuring the delivery of self-management support within a recovery framework. The tool, the 5A’s of Self-Management Support within a Recovery Framework, synthesized findings from the first two studies with Glasgow and colleagues’ (2003) Five A’s Model and applied a recovery framework. Guided by the Ottawa Model of Research Use (Graham & Logan, 2004b), a situational assessment was conducted of the supports and barriers related to the innovation-potential adopters-practice environment. The assessment informed a strategic implementation plan, a Learning and Embedding Initiative. The study illustrated the use of an IKT approach and strategies to operationalize self-management support, that is,

reflective collaboration activities, application of the Essential Characteristics of an Innovation (Greenhalgh, Robert, MacFarlane, Bate, & Kyriakidou, 2004) and Behaviour Change Wheel (Michie, van Stralen, & West, 2011), and mapping potential behaviour change techniques (Michie, Johnston, Francis, Hardeman, & Eccles, 2008).

Study preparations revealed that the development of the innovation and implementation involved art and science. The result was a protocol, materials and committed collaboration -- all essential steps in preparation for implementation of self-management support for a future evaluation study. The study offered an exemplar of an IKT approach of taking research to action.

Strengths and Limitations of the Dissertation Research

The findings must be considered within the overall strengths and limitations of the dissertation research. The conclusions from clients' learning self-management and the conditions influencing clinicians' enabling self-management are based on one study each involving participants who were receiving or providing specialized services. I am unable to comment about those individuals who have not received services or left services or other sectors of mental health services. Consequently, the studies may have portrayed a more optimal picture of services received and given, and portrayed individuals living with schizophrenia with greater disabilities. Also, the dissertation did not capture the perspectives of families or other members of clients' circles of care. The studies involved client and clinician participant reports of reflections and observations with no independent direct observations (e.g., client-clinician encounters). Knowing what is

reported is not always reflective of what occurred; the studies were designed to have reflections grounded in example experiences, multiple data sources for triangulation and sufficient sampling for exploration of critical cases. The studies occurred through the eyes of an occupational therapist embedded as a researcher in the study organization which allowed me to use my understandings of meanings and often subtle nuances to prompt further reflection and clarification. The Clinician Enabling Self-Management study would be stronger if the data set was reviewed by an occupational therapist-social worker-registered nurse team. To some extent this was offset by a transparent ‘chain of evidence’ (Yin, 2009) reviewed by PhD Committee members, transcripts reviewed by my thesis supervisor, and the manager group’s participation in reviewing findings and planning implementation into practice. Also, I reviewed with professional practice leaders (key informants) if practices were considered routine as questions arose. The Operationalization of Self-Management Support has yet to be implemented and evaluated. The paper in Chapter Four highlighted areas earmarked for further development.

The strengths of this dissertation are that it dealt with real world clinical questions of particular current relevance within the changing health policy of mental health. Studies explored phenomena in situ and laden in rich context. The dissertation is theory driven and demonstrates systematic use of multifaceted theory-based strategies rather than a single strategy (Grol & Grimshaw, 2003; Sudsawad, 2007). A variety of methodologies were used with methodology-specific criteria to uphold rigour. In particular, multiple methodologies allowed for gathering several perspectives and accrual of understanding

within multi-layered contexts. The work goes beyond description to offer explanation and direction for health services. In sum, as intended, the work provides the foundation for customizing self-management to a conventional mental health service delivery environment.

Impact of Dissertation Studies

This dissertation makes several contributions to inform our thinking. The Clients Learning Self-Management study and the Clinicians Enabling Self-Management study both made discoveries that challenged prevailing assumptions, offered new perspectives and provided the evidence to envision self-management support within a recovery framework. Both studies also contributed to understanding the supports and barriers to enabling self-management in the context of specialized mental health service delivery and in the context of clients' lifeworlds. The following understandings emerged.

1. The nature and roles of context.

Context was what brought meaning to life experiences. Clients' lifeworlds were uncovered to discover the meaning of learning self-management. Meaning was derived from experiencing eight common self-management tasks within the context of recovery journeys and intersections with healthcare delivery. The meaning of experiencing client-defined critical learning events was further imbued by seven contextual structures. Similarly clinicians' routine realities were uncovered to discover the meaning of enabling self-management emerging from the context of challenges and dilemmas; this occurred

amidst the backdrop of individual clients' changing clinical (client health status), social (family support) and legal (community treatment order) circumstances.

For both clients and clinicians, contextual elements acted as markers for decision-making within their lifeworlds. As learning events were being experienced, clients' interpretations of contextual elements of learning events (seven contextual structures) influenced their decisions regarding engagement and participation. Clients described how the learning event at the time was interpreted within the contexts of past recollected experiences and anticipations of future events. Context influenced clinicians' intentions and actions toward enabling self-management. For example, context shaped clinicians' interpretations of a set of circumstances as a challenge or not a challenge. This dissertation and other studies (Brooks et al., 2011; Townsend, 1998) gave a glimpse of broader context-specific mechanisms and conditions that shaped whether and how intentions became actions; for example, the subtle oppression of risk-taking and individualization of care in the cultural context of large public organizations where the priority is safety, standardization and efficiency.

Context is one aspect used to evaluate the quality of service delivery. For instance, clients described contextual elements of client-clinician encounters that were essentially client-centred care (addressing them as a whole person rather than only symptoms or as a diagnosis, supporting client decision-making). Clients recommended this approach as the context for care. Health information provided to clients was deemed helpful when the facts were translated into the context of the client's life circumstances. From the clinician study, when clinicians were reflecting upon their actions to enable

self-management, clinicians would refer to the particular social and legal context to make evaluations. Therefore, context related to how services were experienced, what and how services were delivered and evaluated.

In sum, the dissertation studies highlight the important diverse roles of context in understanding the complexities of human living and relations within the conditions of everyday life. Context is much broader and more layered than when considering the environment. From my interpretation of van Manen's (1997) concept of lifeworld, context involves the personal dialogue we human beings have with the environment; context contains our perceptions, interpretations and the meanings we attach to the environment across our personal sense of time, space, bodily sensations and communality with the world around us. If we are to engage and support participation of clients in self-management support and clinicians in organizational change, we will need to understand the context (the people environment dialogues) within which the expected behaviours take place in order to form meaningful collaborations, and enable achievement of intended outcomes. An intimate knowledge of context is needed to embed new innovations into routine practices and processes of care for sustainable implementation of innovations. If we are to assist service planners and answer planners' questions of how do innovations or evidence-based practices work and how can we make them work better, we must study context.

2. Self-management and self-management support for individuals living with serious mental illnesses.

Client participant life stories demonstrated the considerable creative capability and resiliency of individuals with serious mental illnesses to engage in self-management practices and develop personalized ways to manage. Their journeys challenged clinicians' assumptions of clients' abilities to learn, grow and change in spite of them often contending with cognitive and social disabilities even while taking medication. Participants' declarations of living well with schizophrenia challenged the general public's negative beliefs about illness outcomes. Recovering a sense of self as a 'well' person living a life was interconnected with performing self-management tasks. At times in participants' lives, self-management was intensive, all-consuming, persistent work. Participants looked to their self-management as an indicator of recovery and "function[ing] like a normal person". Participants talked about making tradeoffs between managing their illness or health and recovery and building a life for themselves, deciding at different points in their lives to focus on restoring their health or learning to manage their illness at the expense of not attending to their careers or relationships and vice versa. Therefore, the self-management-recovery relationship was an enmeshed relationship.

Study findings indicated self-management offers persons living with serious mental illnesses the potential to live well and feel a sense of control ("I have my illness. It doesn't have me!"). Insights were provided of possible conditions under which clients can experience these outcomes. Achievement of all eight self-management tasks (Learning Self-Management when Living with Serious Mental Illnesses model) was not a

requirement; rather learning self-management was a lifelong process. However, all participants who labelled themselves as ‘successful’ were actively taking control, and engaged in self-discovery and experimentation of what worked for them and their own lives. This suggests that clinicians consider how services can facilitate clients experiencing taking control of activities that support the eight self-management tasks and foster client directed self-discovery, self-reflection, problem-solving and experimentation. Clients’ work of learning self-management required access to learning opportunities, particularly for those individuals whose illness experiences began at puberty. Also, participants experienced lack of essential resources for daily living and learning, and confronted barriers related to physical, social and policy environments. This holds particular importance for a group disproportionately negatively impacted by lacking social determinants of health (poverty, social exclusion, unemployment).

Study observations challenged clinicians, administrators and my own assumptions about the roles health services play in the treatment of mental illnesses and advancement of health. Learning self-management began out of necessity at the onset of symptoms, often at puberty, well before being involved in services or given a diagnosis. Most of the learning and all of the managing occurred outside hospitals and healthcare settings. Participants described encounters with services that often interrupted and created barriers as much as facilitating learning and self-management. Can we create spaces in service delivery for clients to use and learn self-management?

One approach to creating such spaces is the embedding of client-centred care in service delivery. A range of clinician behaviours related to client-centred practice were

described using the 16 dimensions of self-management support. Clinician practices were mapped related to client-centred practice principles of equity, defined as care addressing individual clients' contextual differences (orientation to health, client's growth potential, focus, opportunities for learning, capacity-building), and democracy, defined as a sharing of power in collaborative partnerships (conceptualization of self-management support, roles, decision-making, risk-taking, power relations). These dimensions offer one way to further understand the application of client-centred practice to routine mental health practice for the creation of spaces for client self-management and self-management support.

The clinician study contributes to understanding client-clinician relationships. A window was opened into viewing how client-clinician partnerships are dynamic, negotiated enterprises derived from a complex interplay of interrelated conditions and shifting meanings. Findings from the client and clinician studies support observations of Woltmann and Whitley (2010) that mental health clients tended to focus on the client-clinician relationship, in particular the relationship's affective quality, and the limitations of the client's own decision-making, whereas clinicians and the academic literature tended to focus on the deliberation process, the sharing of information. For clients, collaborative decision-making is all about "who has the control over the decision... focus is placed on *who*, not *how*, the decision is made" (Woltmann & Whitley, 2010, p.33). With this in mind, the dimension regarding decision-making should be revised from "shared" to "client" decision-making. This recognition of client's authority aligns with an

advisory report making recommendations to the Ontario 10-Year Mental Health and Addiction Strategy to focus on “person-directed services” (MOHLTC, 2010, p.31).

Client participants emphasized learning to follow medical and psychiatric regiments were insufficient to live well with serious mental illnesses. The model, Learning Self-Management when Living with Serious Mental Illnesses, identifies how these regiments only involved three of the eight essential tasks and contributes to understanding what else needs to be learned to live well. Findings highlighted the sophisticated level of expertise required to make daily living decisions and manage the impact of illness tailored to ever changing circumstances in such a way that clients can do what is important to them. This suggests clients need more than information and a toolkit of strategies to use. Conceptual frameworks offer ways to understand and interpret experiences to make these decisions (e.g., stress-vulnerability model). Participants spoke of needing to learn ways to think differently and often described implementing self-monitoring strategies. Clark’s (2003) work on self-regulation processes in disease prevention and management suggests assisting clients’ self-regulation by clients learning self-regulation skills (self-observation, self-judgement, making appropriate reactions) and by modifying the environment to enable self-regulation.

In addition to what clients needed to learn, the dissertation informs our thinking of how clients learn self-management. Client participants described a lengthy learning process of self-discovery and experimentation. Can we somehow facilitate a more effective learning process? Traditionally didactic health teaching has been used inconsistently to relay a curriculum of self-care material limited to illness management at

time of diagnosis or shortly afterwards. Directed by participants' concerns or problems, standardized self-management support groups, some groups co-led/led by peer facilitators, have shifted to use interactive, structured teaching approaches to teach skills and develop confidence regarding problem-solving, coping strategies and utilization of local resources/supports. Dissertation findings support these groups' emphasis on client-directed problem-solving and building self-efficacy. As discussed in Chapter Two more fully, findings inform the use of condition-specific versus generic interventions. Although several of the self-management tasks that emerged hold commonalities with tasks identified by groups with long-standing diseases (Clark et al., 1991) regarding focus, the context for learning and managing diverges and by extension the particular knowledge and skills for self-management can be exceptionally different between various diagnoses. A program specifically for individuals living with serious mental illnesses may be particularly helpful when two tasks in particular are learning priorities 'trusting self and managing thoughts' and 'dealing with stigma' or when individuals are early in the recovery process. For individuals further along in recovery or who do not view those with mental illnesses as peers, generic programs may be helpful. All eight tasks could be used to inform condition-specific programs and the seven contextual structures may be relevant to all programs to better understand the learning context for individuals with serious mental illnesses.

A key concern is that these self-management support groups are stand-alone programs not integrated into mental health service delivery and provide limited access to small groups of people for short periods of time. Given client participants described

lifelong learning and recommended “teach clients to teach themselves”, I ask: to what extent do standardized self-management support groups within a prescribed period of time facilitate learning by self-discovery and self-experimentation? Self-management programs have been criticized for not serving those individuals who would most benefit (e.g., low socioeconomic backgrounds, ethnic groups), and in doing so, may be further contributing to health inequalities (Rogers et al., 2008). Perhaps clinicians providing specialized mental health services can build upon their expertise with working with marginalized individuals living in poverty and apply existing flexible service structures to deliver responsive self-management support. Studies of self-management support expressed concerns that services are not being delivered as envisioned within a client-centred approach (Greenhalgh, 2009; Rogers, Kennedy, Nelson, & Robinson, 2005; Stevens & Sin, 2005). This further speaks to the need to embed client-centred care in service delivery and be vigilant for the subversion of partnerships.

Potentially self-management studies of individuals living with serious mental illnesses can contribute to better self-management supports for individuals with all long-standing conditions. For example, the concept of recovery, recovering a sense of self and taking charge of one’s life even when still experiencing symptoms, could be applied to anyone who experiences a life altering chronic condition and must integrate a new reality into a new sense of self. Recovery is considered both a process of personal transformation and growth, the expression of self-determination and self-management, and an outcome related to re-establishing meaningful social and occupational roles and relationships

within the community. Perhaps the most often quoted definition of recovery, Anthony (1993) identified recovery as:

a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (p.17)

Recovery-oriented programs integrate recovery values through the principles of: being oriented to each individual as a person with strengths, interests, talents and limitations rather than as a case or disease (person orientation); meaningfully involving the person in the planning, delivery and evaluation of care (person involvement); the right to self-determination and choice in all aspects of care (self-determination/choice); and a focus on building capacity and hope for the future regardless of the person's illness status (growth potential) (Farkas, Gagne, Anthony, & Chamberlain, 2005). These principles could be applied to any self-management support service.

Also, all individuals with life altering conditions must manage the emotional tasks that go along with experiencing a range of emotions (sense of loss, shame, guilt, anger) accompanying disability and coping with social stereotyping and marginalization. Individuals living with serious mental illnesses such as those individuals in the client study could provide a critical exemplar of what can be done to manage emotionally, to regain a sense of control and could inspire hope in others. Similarly individuals who moved beyond the limitations imposed by other chronic conditions could provide

inspiration and living strategies for individuals living with mental illnesses. In the client study, individuals with co-morbidities utilized strategies learned from one chronic condition to deal with another. Many of the mental strategies reported in Chapter Two could be used by others. The emphasis on self-reflection, self-discovery and experimentation to learn about one's own abilities and get on with living may be helpful too. There was an appreciation for the participation in meaningful activity in sometimes the simplest form as contributing to sense of self and health, perhaps in particular due to occupational deprivation, for many client participants over several years. This could remind others of the importance of re-engaging in meaningful activity.

3. The conceptualization of self-management support and the CDPM framework (MOHLTC, 2007).

Self-management support is presented in the policy of the Ontario Chronic Disease Prevention and Management (CDPM) framework (MOHLTC, 2007). A key argument against such policy being applied in the mental health sector is that mental illnesses are different than chronic physical illnesses (CMHA-ON, 2008b). While not the same, the question is how different are mental illnesses with respect to decreasing disability and improving health and well-being. The Client Learning Self-Management study found many of the self-management tasks had a focus common to tasks identified by other groups (Clark et al., 1991). However, the context for learning and managing diverged and consequently the knowledge sets and skills to manage tasks can be different. Context predominated in two tasks in particular: 'trusting self and managing thoughts' related to managing psychosis and 'dealing with stigma' related to society's

responses to mental illnesses. Most clients' illnesses began at puberty and they missed the life experiences that nurture the knowledge, skills and confidence on which to build self-management. Isolation, marginalization, occupational deprivation and poverty limited clients' opportunities to learn from others and their own actions. Therefore, it is likely that this client group begins learning self-management at a different starting point than many other groups, and often with fewer resources.

The dissertation studies provide considerable rich descriptions and interpretations of the mental health context with respect to living with schizophrenia and related psychotic disorders and receiving specialized mental health services. Self-determination and personal control were imbued with meaning after hiding symptoms to evade shame, discrimination and forced hospitalization; experiencing a loss of control and altered reality in psychosis; facing protective paternalism and disempowering hospitalizations; and navigating a gauntlet of healthcare system obstacles over extended periods of time to find service providers who would work with them. In public mental health services, concepts of risk and client competence held special meaning. This suggests to fulfill policy as envisioned, services will need to address the contextual elements related to the illness and healthcare experience to remove barriers and support meaningful participation as “equal partners in their own health and full collaborators in managing their conditions” (MOHLTC, 2007, p.9). Within the bounds of the study designs, this dissertation found no evidence to preclude clients with serious mental illnesses from self-management support services. Rather, there is evidence of clients having unmet self-management needs,

wanting to engage in partnership with providers, and benefiting from self-management support.

Much of the negative reaction to self-management is in regards to historical experiences with a medical model of delivery and fears of further labelling as ‘chronically disabled’ with little hope for a life not defined by the illness (CMHA-ON, 2008b). These fears are not without merit. Evaluations of the anti-stigma campaigns in which mental illness was framed as a ‘brain disease’ found biological explanations led to public fears of unpredictability, dangerousness and social distancing based on beliefs that individuals’ actions were not in their conscious control (Canadian Foundation for Healthcare Improvement, 2012). This ‘us and them’ physical illness-mental illness dichotomy has reduced, as further discussion pointed out the co-existence and interrelationships of mental and physical illnesses (CMHA-ON, 2008a). There is recognition that the CDPM framework (MOHLTC, 2007) has the potential to address historical service inequities regarding physical health conditions amongst individuals with mental illnesses by creating new working relationships and use of integrated screening and monitoring of physical health in mental health services (CMHA-ON, 2008b). In the broader health community, concerns are voiced about self-management placing a ‘burden’ on clients. Based on this dissertation study findings that clients out of necessity are already engaged in self-management and there was evidence of needing further support in this regard, this concern appears to be a ‘red herring’ when living with mental illnesses and may be veiled paternalism.

The CMHA Ontario discussion paper (2008b) posited “consideration must also be given to whether the recovery approach, as well as the services and supports that are already in place to support people with serious mental illnesses, fit within a CDPM framework” (p.1). Neuwelt (2009) compared the recovery approach depicted in CMHA’s ‘Framework for Support’ (CMHA-ON, 2004) with the CDPM framework (MOHLTC, 2007) and concluded the CDPM framework (MOHLTC, 2007) was insufficient for addressing recovery. The Client Learning Self-Management study provided evidence linking self-management and recovery. Client participants marked their personal transformation by changes in self-management tasks. During the active process of engaging in the eight self-management tasks to diminish the effects of illness and regain a sense of control over life, participants transformed the sense of themselves and their place in the world. Therefore, I conclude self-management, in essence, is the application of recovery. I will revisit this comparison of the CMHA-ON (2004) and CDPM (MOHLTC, 2007) frameworks to conduct a reappraisal with the insights gained from the dissertation studies.

Each framework has greater detail with respect to the respective authors’ worlds (i.e., the CMHA framework has greater detail of the resources needed for daily living; the CDPM framework has more detail about health services). Each addresses a different level (i.e., CMHA is at microlevel of the individual; CDPM depicts meso and macrolevels of organizations and population). Both emphasize the individual supported by the community. In the CMHA framework (CMHA-ON, 2004), healthcare is given a smaller role and viewed as one component of the community together with family, friends, self-

help and community organizations. The CDPM framework (MOHLTC, 2007) has moved toward a more person-focused, social-ecological model of health by placement of the individual with a chronic condition centrally, and emphasizing community members' roles, supportive environments, interdependent relationships and collaboration. However, the CDPM (MOHLTC, 2007) does not directly address the recovery goals of social integration, citizenship and self-determination (i.e., control over resources). The CDPM (MOHLTC, 2007) outcomes of improved clinical, functional and population health contrast with recovery goals. Other than outcomes, no component of the 'Framework for Support' (CMHA-ON, 2004) is contrary to the CDPM (MOHLTC, 2007) or vice versa. The CDPM framework (MOHLTC, 2007) could be further strengthened to reach intended health goals if it explicitly incorporated the social determinants of health and considered how services would support individuals to access and use the resources listed in the CMHA-ON framework (2004). To truly integrate recovery into the CDPM (MOHLTC, 2007), recovery goals need to be included formally as outcomes. With these changes, the CDPM framework (MOHLTC, 2007) would be aligned with this dissertation's findings. Further, a recovery approach would be incorporated into the model for all people with chronic conditions to benefit. Such a model would facilitate mental and physical health sectors working together, learning from each other and building inclusive healthy, supportive communities.

The CMHA-ON framework (2004) uses the term 'self-help' rather than self-management which I assume, having not found anything written, is because of negative responses to the term 'manage'. To me 'self-help' diminishes the complexity of decisions

and level of expertise employed by individuals living with serious mental illnesses. The activities are much more than to assist or support as indicated by ‘help’. The etymology of ‘manage’ relates to ‘govern’ and ‘steward’ which to me connotes the authority of self-determination and is more in keeping with recovery goals. In the Client Learning Self-Management study, I posited that self-management is a personal resource for self-determination and living well shaped by physical, social and policy environments and requiring access to resources. The concept of self-management as a resource, a capacity to be developed and supported, fits within the CMHA-ON (2004) resource bases (i.e., personal, community and knowledge resource bases). My thesis concept of self-management could be adopted to provide a link between the resource bases and recovery.

4. Self-Regulation Model (Clark, 2003).

During the Clients Learning Self-Management study, participants engaged in self-regulation by using self-monitoring, reality testing, early warning symptoms, stress reduction activities, mental strategies, and help seeking of peers and providers. This suggests a self-regulation model of self-management (Clark, 2003) may be useful to further examine the process of individuals using self-management strategies to control effects of illness. Based on social cognitive theory (Bandura, 1986) and self-management of chronic diseases literature, the self-regulation model was developed with the premise that basic self-regulatory processes are the main underlying mechanism of effective disease management (Clark, 2003). Self-regulation refers to both a process of learning self-management strategies and the use of self-regulation processes (observations, judgements based on observations and reacting) to achieve personal goals during a

person's management of chronic disease (Clark, 2003). This is consistent with clients describing lifelong learning with life as the 'teacher' and using self-regulation to participate in routine activities. The model depicts continuous, reciprocal self-regulation processes (observations, judgements, reactions), intrapersonal factors (knowledge, attitudes, feelings, beliefs) and external factors (role models, technical advice and service, social support, material resources) interacting with use of management strategies and endpoints (personal goals, physiological status, functioning, healthcare use, perceptions of quality).

Clark offered a compelling argument to focus interventions on clients' self-regulation skills (related to self-regulation process of observations, judgements, reactions) and external factors (listed above) believing self-management circumstances continually change and there is no standard 'recipe' or set of self-management strategies (e.g., deep breathing, distraction techniques) that will be effective under all circumstances. During a two year longitudinal study in which parents of children with asthma were interviewed, Clark and colleagues (2001) using logistic regression modelling found self-regulation processes, external factors and confidence at baseline were differentially predictive of a range of outcomes (quality of life, severity of illness, emergency and physician visits) in the expected directions. Management strategies were not found to be predictive. However, interview questions of management strategies were limited to frequency of use of a prescribed list of strategies taught by health professionals and narrowly focused on avoidance of hospitalization or emergency visits rather than the breadth of self-management tasks. High self-efficacy predicted having external resources and less

physician and emergency visits (Clark et al., 2001). However, self-efficacy was not related to use of management strategies and the researchers suggested results were due to measurement issues related to capturing self-efficacy, a construct that is very specific to a given task (Clark et al., 2001).

The self-regulation model would allow to some extent examination of dynamic self-management strategy use in context in the sense of addressing the person's dialogue (perceptions/observations, interpretations/judgements, reactions/expectations/self-efficacy) with the environment (physical and social) and with the use of management strategies. However, although Clark et al., (2001) has placed the person central to all processes and considers a person's perceptions and judgements, there is no consideration for experience and the meanings we derive across our personal sense of time, space, bodily sensations and communality with the world around us. The person appears conceptualized as a reactive, analytical, goal-directed being rather than a creative being who also acts out of habit, routine and emotions. Given the self-regulation model is based on social cognitive theory (Bandura, 1986, 1989, 1997), the theory upon which standardized self-management support programs are based, the self-regulation model potentially could be used in the evaluation of these standardized self-management support programs. For example, programs use social cognitive learning strategies (Bandura, 1986, 1989, 1997) such as experiential mastery, modeling, peer support, linking actions and outcomes, reframing interpretations for skill acquisition and development of self-efficacy. Perhaps the self-regulation model could be used to unravel which program component is associated with self-regulation processes, use of management strategies and improved

outcomes. To apply the self-regulation model to individuals living with serious mental illnesses, my study finding of self-management enmeshed with recovery suggests the model would benefit from adding the recovery process with ‘disease control’ as a use of management strategies and include recovery goals (social integration, citizenship and self-determination) as endpoints.

5. Ottawa Model of Research Use (OMRU) (Graham & Logan, 2004a).

The OMRU (Graham & Logan, 2004a) was selected as a framework to guide the facilitation of integrating research evidence into a health care organization. In Chapter 1, I outlined the model, its development and rationale for selection. When the last version of the OMRU was published in 2004, it was novel as a move from past theories of passive organizational change to a theory of planned change for administrators to strategically effect change at organizational and systems levels (National Collaborating Centre for Methods and Tools, 2010). The model represented one of the first attempts to describe a dynamic process of different individuals relating to the practice environment and the innovation, of interconnected decisions and a process that was not linear (Logan & Graham, 1998). The OMRU offered a framework for identifying and controlling factors that would likely influence the implementation and uptake of an innovation. Steps for implementing the OMRU as a tool (National Collaborating Centre for Methods and Tools, 2010) appeared to be conceptualized with a quality assurance lens of iteratively, systematically selecting and implementing strategies to deal with barriers, monitoring adoption, evaluating outcomes and returning to assessment of barriers when results were not fully realized. Users of the OMRU cited how the OMRU was helpful for project

management with respect to communicating the project to stakeholders, maintaining a focus on what is important and supporting a comprehensive approach (Graham & Logan, 2004b). To my knowledge, there was no further formal evaluation since 2004.

The OMRU authors recognized the importance of understanding context for successful implementation in the form of assessing attributes of the innovation, adopters and practice environment. At the time, mismatches between these attributes were viewed as potential barriers to uptake. The use of context was limited to identify gaps such as those between practices and recommended changes, need for skills training or resources. What was not recognized was the need for adopters to dialogue with the innovation: to place the innovation within the context of their own work and their own sense of self, to attach meaning and sense of commitment to the innovation. The Person-Environment-Occupation (PEO) Model (Law et al., 1996) could be used to understand the adopter (person)-workplace (environment)-occupation (use of innovation) transactions. If context was viewed as the person-occupation and person-environment interfaces, the dialogue of adopters engaging with innovations in given workplaces over time could be explored.

The view of adopters in the OMRU appears as individuals to be influenced to produce practice behaviours as envisioned by innovation planners. Clients were viewed as key players (Graham & Logan, 2004a). However, the role of clients was recognized in so far as clients' receptivity to an innovation was seen to influence clinicians' uptake of an innovation and as a political driver of issues for policymakers. Clients and clinicians in this dissertation's studies have demonstrated how their knowledge and expertise can make invaluable contributions to the development of an innovation and implementation

plan. The movement of the field to an integrated knowledge translation (IKT) approach is in part a response to benefit from the innovation users' insights. There does not appear to be anything in the OMRU to preclude using an IKT approach; no aspect of the OMRU's structure presents as a barrier to researchers and users co-producing an innovation and jointly translating and integrating the innovation into routine practice. In fact the OMRU provides little direction or specification regarding process. The developers of the OMRU do not give specific direction for knowledge translation strategies. At the time of its initial development, there was not the evidence to advocate one strategy over another (Logan & Graham, 1998). Later when research indicated active rather than passive dissemination strategies (Grimshaw et al., 2001; Lavis et al., 2003) and interventions tailored to specific groups and workplaces (Grol & Grimshaw, 2003), Graham and Logan (2004) recommended supplementing interactional education sessions with the use of audit, feedback and reminders.

The OMRU's focus was largely on changing clinician behaviour. Those involved in the diffusion of innovations field now recognize that focusing solely on clinicians is insufficient and directs making organizational changes at program levels and to consider program-setting interactions (Franx et al., 2008; Greenhalgh et al., 2004). In the OMRU, the innovation implementation site is acknowledged as an open system. The assessment of attributes of the innovation-adapters-practice environment relationships provides useful information for making such organizational changes. I suggest a broader assessment lens to consider strengths and resources beyond barriers with a view to capacity-building would strengthen the model. Also, I recommend an expanded

conceptualization of implementation to include capacity-building of the program and embedding the innovation rather than strictly barrier management. Also, I suggest replacing “transfer” with “linkage and exchange” (Bullock, Watson, & Goering, 2010).

My work with the manager collaboration and further study of the knowledge translation literature has highlighted the tremendous preparation required before implementation can take place. The OMRU was intended only for the implementation phase. None the less, the initial steps for implementing the OMRU are missing from the figure, that is, ‘set the stage’ (identify individuals of authority, available resources, agents of change) and ‘specify the innovation’ (define and describe what implementation will involve) (National Collaborating Centre for Methods and Tools, 2010). I suggest ‘setting the stage’ be expanded to support stakeholders as partners in the knowledge translation initiative. In sum, the OMRU needs to be updated to reflect the advancements in the implementation science field.

6. Conceptualization of health within a socio-ecological model.

On several occasions across this dissertation I have indicated the need to conceptualize health within a socio-ecological model. A social ecology model, often called a whole systems model, “see chronic illness as arising from the interplay of influences within a complex system (from the genome to the macro-environment) and acting dynamically through time” (Greenhalgh, 2009, p.338). This is consistent with the current understanding of mental illness resulting from a genetic susceptibility interacting with life experiences and range of environmental factors (Canadian Foundation for Healthcare Improvement, 2012).

Greenhalgh (2009) argued for a wider approach to self-management than a traditional bio-medical model that focused on creating expert patients compliant with following a self-management plan limited to disease management. Similarly in my studies, client participants speaking from life experiences remarked how medications were essential but not enough and went on to describe the common eight self-management tasks which engage with a broader lifeworld of relationships with family, friends, organizations and communities. Meaning was derived from experiencing these tasks shaped by contextual structures and each model element aligns with a socio-ecological model. Findings directed clinicians to focus on building capacity beyond the individual to include support networks.

A social ecological model encompasses the social determinants of health. The CMHA's 'Framework for Support' (CMHA-ON, 2004) contended policy needed to address the individual as a whole and recommended actions to readdress the social determinants of health to support recovery. The 'community resource base', one of the Three Pillars of Recovery (see figure in Chapter 1), is comprised of housing, work, education, and income (CMHA-ON, 2004). The priority outcomes of recovery relate to citizenship, relationships with the community and enacting self-determination --- all of which are tied to the social determinants of health. Essential resources for daily living and learning self-management were barriers to be overcome for the group I studied. Each self-management task required access to resources and the learning process was shaped, helped and hindered by families, community, and social and health policy. From these observations, I concluded a socio-ecological framework for planning services and setting

policy was needed to integrate the building of an individual's capability for self-management with the necessary supports and resources. The provincial government is moving in this direction. The newest advisory report for a 10-Year Mental Health and Addictions Strategy for Ontario (MOHLTC, 2010) emphasizes taking a whole systems approach and targeting stigma, resilience, creation of supportive environments and integration of services. This report speaks of valuing person-directed services and working to reduce individual and social injustices.

In the United States, Fisher and colleagues (2005) developed a whole systems approach to self-management for individuals living with diabetes as part of a multi-centre Diabetes Initiative of the Robert Wood Johnson Foundation. The approach “integrates the skills and choices of individuals with the services and support they receive from (1) the social environment of family, friends, worksites, organizations and cultures; and (2) the physical and policy environments of neighborhoods, communities and governments” (Fisher et al., 2005, p.1524). The authors offered a persuasive argument that a whole systems approach held greater likelihood of being effective by improving access to resources and supports, by supporting continuity of care and by delivering services in multiple different formats and venues to reach the same ends. Such services would support client-centred services by having the flexibility to respond to diverse interests, preferences and the variety of client living contexts. Also, such an approach potentially would less likely reinforce the concerns expressed by Lawn and Pulvirenti (2011) of health services defining the rules and stereotyping a particular client self-manager.

Implications and Recommendations for Practice, the Participating Organization and Mental Health Services, Policy and Research

1. Practice.

This dissertation confirms that self-management offers persons living with serious mental illnesses the potential to live well. The active process of engaging in self-management to diminish the effects of illness and regain a sense of control over life is in essence an application of recovery. Recovery is a personal transformation journey, something clinicians cannot do for clients. Self-management support presents as an active role for clinicians by enabling clients to have the knowledge and tools they need to effectively engage in self-management to live well. Taking medication and following medical regimens (sleep routines, exercise) although essential were insufficient to live well with serious mental illnesses.

Self-management was found to be a personal resource for self-determination and living well, a capacity to be developed, resourced and supported. The findings improved our understanding of what clients with serious mental illnesses need to learn to live well and how clients have been learning self-management which can be applied to practice. Evidence is growing that individuals with serious mental illnesses can benefit from self-management support. The roles and functions of clinicians in health services situate clinicians as gatekeepers of information and stewards of creating opportunities for capacity-building clients and client support networks for management of serious mental illnesses. Drawing on the values and principles of recovery and psychosocial rehabilitation, clinicians can be leaders in implementing self-management support.

My main recommendation is for clinicians, using a client-centred approach, to hold self-management conversations with clients that address the whole person and at the depth of complexity in which clients make self-management decisions in their lifeworlds. Clients come to our practices with expertise gained from life experiences managing the effects of illness often since puberty looking for someone to work with them and who gives credibility to their own self-management work. The meaning of clients' experiences is in understanding the context of those experiences. The dissertation portrays some of the context and meaning of experiences that will need to be addressed to remove barriers to client participation. Provision of self-management support will require an understanding of the particular context in which each client engages in self-management. Findings indicated the need for clinicians to foster an accepting, empowering environment for clients and role model client-centred practices by demonstrating equity and democracy during routine care processes. Clients had unmet self-management learning needs, in part because services tended to focus on illness and crisis management. The model, Learning Self-Management when Living with Serious Mental Illnesses, can be used as a tool to help understand the breadth of client self-management learning needs and contextual structures that influence learning. I found the co-creation of learning self-management maps with clients useful to better understand client self-management experiences, the meaning of events and clients' self-management expertise.

A second recommendation was expressed in a request by a client participant: “teach us to teach ourselves”. In other words, use an approach that emphasizes self-

discovery and experimentation and provides clients with the tools (materials, problem-solving strategies, conceptual frameworks, self-monitoring) and opportunities for self-reflection and self-evaluation. Risk-taking is inherent in client-directed actions and growth experiences. Findings indicated the need to address our own fears (as clinicians) of risk-taking and how our actions may undermine client self-determination and recovery. Pro-actively planning for risk-taking with clients while ensuring moral and legal obligations are met (re: identifying risk and potential consequences of actions) will support moving forward directed by client goals.

2. Participating Organization and Mental Health Services.

Self-management support services that have become expected in other health sectors are equally important for persons living with mental illnesses. This dissertation confirms that self-management within a recovery framework offers persons living with serious mental illnesses the potential to live well. Participants' accounts of spending 15-30 years to find medications and providers that "work with them" speaks to the need to improve timely access to resources and supports for self-management. The studies lay the initial foundation to begin to address how we design and deliver services to ensure clients have the tools and resources for self-management. The organization in this dissertation, and I expect health organizations elsewhere, has the potential to significantly influence clinician beliefs and practices. The dissertation highlights the primacy of the workplace environment influencing clinicians' delivery of self-management support and many of the conditions are amenable to organizational change.

I recommend self-management support be recognized as a core service of specialized mental health services and self-management support be made available to every client. Self-management support interventions were perceived by clinicians as an add-on, something to attend to when there was time. Challis and colleagues (2011) found self-management support needed to be communicated as an essential service and formally recognized as part of mental health providers' duties. Specialized mental health services are often the only connection individuals with serious mental illnesses have with health services, and as in the case of the exemplar organization, self-management support would be an extension and standardization of existing practices to obtain supports and resources for clients' living needs. Potentially further integration of psychosocial rehabilitation into services would bring recovery and self-management supports together. Practice change initiatives that focus solely on clinicians (e.g., education) are insufficient (Greenhalgh et al., 2004) and organizational changes such as integrated care and changes in multidisciplinary teams have led to improved client outcomes during specialized mental health services (Franx et al., 2008). Integration of self-management support is an example of organizational change.

Integrating self-management support into routine service delivery will require a focused comprehensive approach in which self-management support is integrated system wide (e.g., patient education, clinician behaviour change, healthcare delivery processes, community engagement) (Kennedy, Rogers, & Bower, 2007). The 5A's of Self-Management Support within a Recovery Framework can be useful as a clinician teaching tool that provides a structured approach to providing self-management

support services (see Chapter 4). The 5A's framework directs clinicians to what actions they can take and services they can arrange while aligning client self-management needs with services, resources and supports tailored to clients' self-management circumstances (Fisher et al., 2005; Glasgow, Davis, Funnell, & Beck, 2003; Glasgow & Emmons, 2007). A protocol is being developed, the Learning and Embedding Initiative, to implement the 5A's of Self-Management Support within a Recovery Framework into routine specialized mental health services. Planning would benefit from further engaging clients and families as developers and champions of self-management support services. The model, Learning Self-Management when Living with Serious Mental Illnesses, can be used to describe clients' self-management learning needs and as a framework to plan responsive services that address the breadth of self-management needs.

Based on work by Lawn (2009) and this dissertation, clinicians may benefit from development to deliver self-management support. Anticipated workforce education needs include: understanding the illness experience and clients' lifeworlds from the client perspective; communicating and using self-regulation skills (self-observation, self-judgement, reactions); identifying clients' strengths and current capabilities; and enabling collaborative care with consumers, families and other health professionals. For example, implementation of the 5A's of Self-Management Support within a Recovery Framework will require: collaborative goal-setting and care planning skills; knowledge of community support resources; and coaching and counselling skills to address motivational, behavioural and environmental issues necessary for behaviour change. Clinicians need opportunities for trialing, reflecting upon new practices and autonomy to make the

practice their own. To spread and sustain self-management support research suggests embedding the 5A's into worker habits and routine care processes (Kennedy et al., 2010; Nilsen, Roback, Brostrom, & Ellstrom, 2012).

Lastly, I recommend creating spaces for client self-management by using the workplace environment to shape and build clinician self-management support behaviour. For example, a theme throughout the dissertation is the need to further integrate client-centred or person-centred care, a foundational element to self-management support, into care processes. Principles of equity (care addresses individual client's contextual differences) and democracy (a sharing of power in collaborative partnerships) (Law, 1998) could be used to operationalize client-centred care. For sustainability, research suggests embedding these principles in routine clinician practices, care pathways and organizational structures (Rogers et al., 2005). In this way, clients are more likely to have the spaces to engage in self-management during processes of care and at healthcare locations.

3. Policy.

Self-management support is relatively new to the mental health sector and as yet generally not incorporated into policies. This dissertation asserts self-management support can be provided and be of benefit within a recovery framework for individuals with serious mental illnesses. The concept of recovery and principles of recovery-oriented services may be useful to all people who experience long-standing conditions. The dissertation offers insights into the conceptualization and understanding of self-management, recovery, self-management support and conditions influencing self-

management support practices. I suggest policy-makers consider the concept of self-management as a resource, a capacity to be developed and supported. Policy-makers can consider self-management as an application of recovery, particularly in cross sector discussions.

The discussion earlier in this chapter asserted that individuals with serious mental illnesses may benefit from being included in the CDPM framework (MOHLTC, 2007). However, the CDPM framework would be strengthened if key aspects of the recovery framework (CMHA-ON, 2004) were added. In particular, I suggested explicitly including recovery goals as outcomes, and supporting individuals to access and use the resources listed in the CMHA framework (CMHA-ON, 2004).

From this dissertation, self-management emerges as a personal resource for self-determination and living well shaped by physical, social and policy environments and requiring access to resources. This finding supports others' assertions that to address the breadth of self-management requires a shift to a social ecological or whole systems model (Fisher et al., 2005; Greenhalgh, 2009) to incorporate the social determinants of health. A socio-ecological model of health would be consistent with current views of the origins of chronic illness (Greenhalgh, 2009) and mental illness (Canadian Foundation for Healthcare Improvement, 2012). Fisher and colleagues (2005) pointed out the benefits of developing a self-management support service based on a whole systems approach included increased flexibility to respond to the diversity of clients' needs and preferences and greater continuity of care. In this way, self-management support services could address concerns that services may be further contributing to health inequalities by not

meeting the needs of the most marginalized groups (Rogers et al., 2008). Therefore, with respect to self-management support, health policy would benefit from shifting to a socio-ecological model.

4. Research.

The studies contained in this dissertation have provided evidence and insights for additional papers yet to be written such as: the use of concept maps as a knowledge translation tool; the application of contextual structures from the Learning Self-Management when Living with Serious Mental Illnesses model for the creation of supportive learning environments; the conceptualization and practices of negotiated partnerships; the self-management support practices of social workers, registered nurses and occupational therapists viewed through the Person-Environment-Occupation model (Law et al., 1996). The dissertation has made contributions to research methods. For example, the study in chapter two is the first known enfolding of an occupational therapist lens into van Manen's (1997) approach to phenomenology. The study in chapter three demonstrated how a Yin (2009) case study with embedded units can be used to understand practice in context and open the 'blackbox' to offer explanations of underlying processes, such as drivers and mechanisms of issues. I was a researcher embedded in an organization and my role was an example of what others have described in theory as a "boundary spanner" (Greenhalgh et al., 2004) to foster knowledge translation. During the study in chapter four, I applied theoretical strategies to a real world planning initiative.

A key research priority is the collection of evidence to support the integration of self-management support into the delivery of routine specialized mental health services. This dissertation uncovered clients' unmet self-management needs and highlighted the conditions for enabling self-management in this context. Evidence was presented to support the basic premise that self-management support can be provided and be beneficial within a recovery framework for individuals with serious mental illnesses. Many questions remain unanswered surrounding the most beneficial ways to implement and deliver self-management support services. In particular, better understanding of the diversity of self-management learning paths, and the conditions and mechanisms shaping clients' intentions and actions toward self-management would inform how to design such services. The concept of 'equifinality', that there are multiple alternative paths to reach a particular end point (George & Bennet, 2005), is now being applied in the self-management services literature to assess the optimal continuum and breadth of services in a whole systems client-centred approach (Fisher et al., 2005). Equifinality has been studied in social and physical sciences in modeling and assessing complex pathways and transactional relationships using sophisticated case study methods for theory development (George & Bennet, 2005). Pursuit of inquiry using an equifinality lens would offer value by countering a focus on one 'right' path, align services with the diversity of human lifeworlds and open up opportunities for engaging the breadth of client support networks and accompanying resources to design a sustainable client-centred delivery system.

The dissertation generated knowledge translation products for integration of self-management support that have yet to be implemented and evaluated in the context of

routine specialized mental health services. The model, Learning Self-Management when Living with Serious Mental Illnesses, requires further development: Does the model capture the core domains of self-management while living with serious mental illnesses? Does the model assist others to understand clients' lifeworlds, and plan interventions and services? Regarding the 5A's of Self-Management Support within a Recovery Framework, and the Learning and Embedding Initiative, the implementation process needs to be examined regarding client and clinician engagement, and the 5A's acceptability, feasibility and potential for modification from clients' and clinicians' perspectives. A mixed methods study can explore and assess initial impact regarding clients' lives and relationships with clinicians, clinical practices and ways of working, and organizational processes. The potential deliverable is a protocol for replication of self-management support at other specialized mental health service locations – a foundational element for future controlled trials.

Implementation of the 5A's of Self-Management Support within a Recovery Framework, and the Learning and Embedding Initiative offers the opportunity to study the spread and sustainability of an innovation in a service organization, another key research priority (Greenhalgh et al., 2004). The work could provide: exemplars of the push-pull mechanisms, what accounts for initiatives' successes and shortfalls, and further our understanding of program-setting interactions (Greenhalgh et al., 2004) and the 'codification' of knowledge (Denis & Lehoux, 2013). A case study using social learning theory (Bandura, 1986) and organizational change theories (Denis & Lehoux, 2013)

would be suitable to consider how and why contextual elements support and undermine the spread and continued employment of specific innovations.

Once self-management support is routinely delivered with fidelity it will be important to link self-management support mechanisms to outcomes (i.e., self-management support leads to informed, activated clients and outcomes of improved healthcare utilization, recovery and resilience). More RCT's are needed with integrated self-management support programs, conducting real-world intention-to-treat analysis and capturing primary outcomes (healthcare utilization, recovery and resilience). A qualitative narrative study (Roe, Hasson-Ohayon, Salyers, & Kravetz, 2009) of the Illness Management and Recovery program (Mueser et al., 2006) after one year identified how the self-management support was unique to other rehabilitation intervention experiences but due to methodological constraints was unable to establish these unique elements as mechanisms for outcomes. In any study, self-management support will need to be defined, study designs will need to address other elements contributing to the outcomes and in the case of RCT's, the fidelity of self-management support must be established. As mentioned earlier, this dissertation's 16 dimensions of self-management support can be used to develop indicators and to create tools for clinician self-reflection, both useful for program development and laying the foundation for research.

Personal Reflections

Laying the foundation for self-management support within a recovery framework has impacted me as an individual, an occupational therapist and a researcher. From past

clinical work and my master's ethnographic study of individuals with serious mental illnesses working at an affirmative business, I began this dissertation knowing that for many clients life was a daily battle and active engagement in work was a powerful influence to clients' self-concept and self-efficacy. However, I did not really understand the work of self-management; I did not fully appreciate the complexity of daily decisions, the level of expertise to master self-management tasks and the focused persistent energy required. Now I have another level of admiration and respect for clients living well. My views have progressed from knowing clients faced discrimination and marginalization in their communities and the healthcare system, to understanding some of the ways we as health professionals fight against as well as contribute to the inequities in service delivery by enabling and hindering clients' self-determination and self-management. Now I ask myself and others: "During every client-provider encounter and every contact the client has with services, how do our own actions and inactions foster supportive spaces for self-management?" My thoughts of the role each of us play in the healthcare system have solidified. We, each of us, are the 'system'. To empower clients, we need to empower ourselves; we need to shake off stereotypes, test assumptions and take action against those things that constrain us from being the best we can in our service to clients. To that end, research has been shown to bring people together, nudge self-reflection, offer another perspective, deepen understanding and suggest direction to further improve services.

Conclusions

Self-management support can be provided and be beneficial within a recovery framework for individuals living with serious mental illnesses. When engaged in self-management and sustained by their support network, including mental health services, individuals can live well with serious mental illnesses. Self-management support was found enmeshed with recovery and can be considered an application of recovery. A recovery framework brings attention to the emotional, psychological, social and occupational tasks and necessary resources to live well. The studies in this dissertation provide direction for what and how specialized mental health services can advance self-management support in the context of a conventional mental health service delivery environment. Given the commonalities shared amongst people who need to transform a sense of self and build a life with chronic or long-standing conditions, self-management support for all client groups may be strengthened when provided within a recovery framework.

References for Chapters One and Five

- Adams, K., Greiner, A., & Corrigan, J. (2004). *Report of a summit. The 1st annual Crossing the Quality Chasm Summit-A focus on communities*. Washington, DC: National Academic Press.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (DSM-IV-TR)* (4th ed.). Washington, DC: Author.
- Anthony, W. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16, 11-23.
- Anzai, N., Yoneda, S., Kumagai, N., Nakamura, Y., Ikebuchi, E., & Liberman, R. P. (2002). Training persons with schizophrenia in illness self-management: A randomized controlled trial in Japan. *Psychiatric Services*, 53(5), 545-547.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood, N.J.: Prentice-Hall.
- Bandura, A. (1989). Social Cognitive Theory. In R.Vasta (Ed.), *Annals of Child Development. Vol. 6. Six theories of child development* (6 ed., pp. 1-60). Greenwich, CT: JAI Press.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W.H. Freeman.
- Battersby, M. W., Ah Kit, J., Prideaux, C., Harvey, P., Collins, J., & Mills, P. (2008). Implementing the Flinders Model of Self-Managment Support with Aboriginal People who have diabetes: Findings from a pilot study. *Australian Journal of Primary Health*, 14(1), 66-74.

- Battersby, M. W., Harvey, P., Mills, P., Kalucy, E., Pols, R. G., Frith, P. et al. (2007). SA HealthPlus: A controlled trial of a statewide application of a generic model of chronic illness care. *The Milbank Quarterly*, 85(1), 37-67.
- Battersby, M. W., Von Korff, M., Schaefer, J., Davis, C., Ludman, E., Greene, S. et al. (2010). Twelve evidence-based principles for implementing self-management support in primary care. *The Joint Commission Journal on Quality and Patient Safety*, 36(12), 561-570.
- Bodenheimer, T., Lorig, K., & Holman, H. (2002). Patient self-management of chronic disease in primary care. *The Journal of the American Medical Association*, 288(19), 2469-2475. doi:10.1001/jama.288.19.2469
- Brooks, A., & Penn, P. (2003). Comparing treatments for dual diagnosis: Twelve-Step and Self-Management and Recovery Training. *The American Journal of Drug and Alcohol Abuse*, 29(2), 359-383.
- Brooks, H., Pilgrim, D., & Rogers, A. (2011). Innovation in mental health services: What are the key components of success? *Implementation Science*, 6. Retrieved from <http://www.implementationscience.com/content/6/1/120>
- Brown, S. (1997). Excess mortality in schizophrenia: A meta-analysis. *British Journal of Psychiatry*, 171, 502-508.
- Buccheri, R., Trygstad, L., Dowling, G., Hopkins, R., White, K., Griffin, J. J. et al. (2004). Long-term effects of teaching behavioral strategies for managing persistent auditory hallucinations in schizophrenia. *Journal of Psychosocial Nursing & Mental Health Services*, 42(1), 18-27.

- Bullock, H., Watson, A., & Goering, G. (2010). Building for success: Mental health research with an integrated knowledge translation approach. *Canadian Journal of Community Mental Health, 49*(S5), 9-21.
- Cabassa, L., Ezell, J., & Lewis-Fernandez, R. (2010). Lifestyle interventions for adults with serious mental illness: A systematic review. *Psychiatric Services, 61*, 774-782.
- Canadian Association of Occupational Therapists. (1991). *Occupational therapy guidelines for client-centred practice*. Toronto, ON: CAOT Publications ACE.
- Canadian Association of Occupational Therapists. (1994). *Occupational therapy guidelines for client-centred mental health practice*. Toronto, ON, Canada: CAOT Publications ACE.
- Canadian Association of Occupational Therapists. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation*. Ottawa, ON: CAOT Publications ACE.
- Canadian Diabetes Association. (2008). Clinical practice guidelines for the prevention and management of diabetes in Canada. *Canadian Journal of Diabetes, 32*(suppl 1), S1-S201.
- Canadian Foundation for Healthcare Improvement. (2012). *Myth: Reframing mental illness as a 'brain disease' reduced stigma*. Retrieved from <http://www.cfhi-fcass.ca/Libraries/Mythbusters/Myth-mental-Health-E.sflb.ashx>

Canadian Health Services Research Foundation. (2007). *Self-management education to optimize health and reduce hospital admissions for chronically ill patients.*

Ottawa, ON: Author.

Canadian Mental Health Association [CMHA] - Ontario. (2004). *A framework for support* (3rd ed.). Retrieved from

http://www.cmha.ca/BINS/content_page.asp?cid=7-13-981

Canadian Mental Health Association [CMHA]. (2005). *Discussion guide on recovery.*

Back to basics: Enhancing our capacity to promote consumer participation and inclusion. Retrieved from <http://www.cmha.ca>

Canadian Mental Health Association [CMHA]-Ontario. (2008). *What is the fit between mental health, mental illness and Ontario's approach to chronic disease prevention and management?* Toronto, ON: Author.

Canadian Mental Health Association - Ontario. (2008a). *Recommendations for preventing and managing co-existing chronic physical conditions and mental illnesses.*

Toronto, ON: Author.

Canadian Mental Health Association - Ontario. (2008b). *The relationship between mental health, mental illness and chronic physical conditions.* Toronto, ON: Author.

Retrieved from www.ontario.cmha.ca

Canadian Mental Health Association [CMHA]- Ontario. (2009). *Diabetes and serious mental illness: Future directions for Ontario. A report from the March 30, 2009 think tank on diabetes and serious mental illness.* Toronto, ON: Author.

- Canadian Psychiatric Association. (2005). Clinical practice guidelines - Treatment of schizophrenia. *Canadian Journal of Psychiatry, 50*(13), 1S-57S.
- Challis, D., Hughes, J., Berzins, K., Reilly, S., Abell, J., Stewart, K. et al. (2011). Implementation of case management in long-term conditions in England: Survey and case studies. *Journal of Health Services Research and Policy, 16*(1), 8-13.
- Cheng, R. (2010). Where is the recovery in chronic disease management? *Cross Currents. The Journal of Addiction and Mental Health, 14*(1), 20-20. Retrieved from <http://www.camhcrosscurrents.net>
- Cimo, A., Stergiopoulos, E., Chiachen, C., Bonato, S., & Dewa, C. (2012). *Effective lifestyle interventions to improve type 2 diabetes self-management for those with schizophrenia or schizoaffective disorder: A systematic review*. Retrieved from <http://www.biomedcentral.com/1471-244A/12/24>
- Clark, N. M. (2003). Management of chronic disease by patients. *Annual Review of Public Health, 24*, 289-313. doi:10.1146/annurev.publhealth.24.100901.141021
- Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W., & Anderson, L. (1991). Self-management of chronic disease by older adults: A review and questions for research. *Journal of Aging and Health, 3*(1), 3-27.
- Clark, N. M., Gong, M., & Kaciroti, N. (2001). A model of self-regulation for control of chronic disease. *Health Education and Behavior, 32*(2), 572-575.
- Colton, & Manderscheid. (2006). Congruencies in increased mortality rates, years of potential life lost and casues of death among public mental health clients in 8 states. *Prevention and Chronic Disease, 3*(2), 1-14.

- Coulter, A., & Ellins, J. (2006). *Patient-focused interventions: A review of the evidence*. London, U.K.: The Health Foundation and Picker Institute Europe.
- Coulter, A., Parsons, S., & Askham, J. (2008). *Where are the patients in decision-making about their own care?* Policy Brief written for the WHO European Ministerial Conference on Health Systems, 25-27 June 2008, Tallinn, Estonia: World Health Organization ISSN 1997-8073. Retrieved from <http://www.euro.who.int>
- Curkendall. (2004). Cardiovascular disease in patients with schizophrenia in Saskatchewan, Canada. *Journal of Clinical Psychiatry*, 65(5), 715-720.
- Davidson, L., Harding, C., & Spaniol, L. (2005). *Recovery from severe mental illness: Research evidence and implications for practice*. Boston: Boston University Center for Psychiatric Rehabilitation.
- Davis, D., O'Brien, M., Freemantle, N., Wolf, M., Mazmanian, P., & Taylor-Vaisey, A. (1999). Impact of formal continuing medical education: Do conferences, workshops, rounds and other traditional continuing education activities change physician behavior or health care outcomes? *American Medical Association*, 282, 867-874.
- Denis, J., & Lehoux, P. (2013). Organizational theory. (Section 4.4 ed.). *Canadian Institute of Health Research*. Retrieved from <http://www.cihr-irsc.gc.ca>
- Department of Human Services. (2007). *Self-management mapping state-wide report*. *Self-management support - a state-wide view 2006-07* Retrieved from <http://www.health.vic.gov.au/communityhealth/cdm/index.htm>

Druss, B.G., Zhao, L., von Esenwein, S., Bona, J., Fricks, L., Jenkins-Tucker, S., ...

Lorig, K. (2010). The Health and Recovery Peer (HARP) Program: A peer-led intervention to improve medical self-management for persons with serious mental illness. *Schizophrenia Research, 118*, 264-270.

El-Mallakh, P. (2006). Evolving self-care in individuals with schizophrenia and diabetes mellitus. *Archives of Psychiatric Nursing, 20*(2), 55-64.

El-Mallakh, P. (2007). Doing my best: Poverty and self-care among individuals with schizophrenia and diabetes mellitus. *Archives of Psychiatric Nursing, 21*(1), 49-60.

Epping-Jordan, J., Pruit, S., Bengoa, R., & Wagner, E. (2004). Improving the quality of health care for chronic conditions. *Quality and Safety in Health Care, 13*, 299-305. doi:10.1136/qshc.2004.010744

Fardig, R., Lewander, T., Melin, L., Folke, F., & Fredriksson, A. (2011) A randomized controlled trial of the Illness Management and Recovery program for persons with schizophrenia. *Psychiatric Services, 62*(6), 606-612.

Farkas, M., Gagne, C., Anthony, W., & Chamberlin, J. (2005). Implementing recovery oriented evidence based programs: Identifying the critical dimensions. *Community Mental Health Journal, 41*(2), 141-158.

Fisher, E., Brownson, C., O'Toole, M., Shetty, G., Anwuri, V., & Glasgow, R. (2005, September). Ecological approaches to self-managment: The case of diabetes. *American Journal of Public Health, 95*(9), 1523-1535.

- Franx, G., Kroon, H., Grimshaw, J., Drake, R., Grol, R., & Wensing, M. (2008). Organizational change to transfer knowledge and improve quality and outcomes of care for patients with severe mental illness: A systematic overview of reviews. *Canadian Journal of Psychiatry, 53*(5), 294-305.
- Gauntlett, A. (2005). Evaluation of a postgraduate training programme for community mental health practitioners. *Journal of Psychiatric and Mental Health Nursing, 12*, 223-230.
- George, A., & Bennet, A. (2005). *Case studies and theory development in the social sciences*. Cambridge, MA: Belfer Center for Science and International Affairs, Harvard University.
- Glasgow, R., Davis, C., Funnell, M., & Beck, A. (2003). Implementing practical interventions to support chronic illness self-management. *Joint Commission Journal on Quality and Safety, 29*(11), 563-574.
- Glasgow, R., & Emmons, K. (2007). How can we increase translation of research into practice? Types of evidence needed. *Annual Review of Public Health, 28*, 413-433. doi:10.1146/annurev.publhealth.28.021406.144145
- Goff, D., Cather, C., Evins, A., Henderson, D., Freudenreich, O., Copeland, P. et al. (2005). Medical morbidity and mortality in schizophrenia: Guidelines for psychiatrists. *Journal of Clinical Psychiatry, 66*(2), 183-194.
- Goldberg, R. W., Weber, E., Dickerson, F., Tenhula, W., Lucksted, A., Kreyenbuhl, J. et al. (2013). Living Well: An intervention to improve self-managment of medical

- illness for individuals with serious mental illnesses. *Psychiatric Services*, 64, 51-57. doi:10.1176/appinps.201200034
- Graham, I., & Logan, J. (2004a). Translating research: Innovations in knowledge transfer and continuity of care. *Canadian Journal of Nursing Research*, 36(2), 89-103.
- Graham, K., & Logan, J. (2004b). Using the Ottawa Model of Research Use to implement a skin care program. *Journal of Nursing Care Quality*, 19(1), 18-24.
- Green, M. (2006). Cognitive impairment and functional outcome in schizophrenia and bipolar disorder. *Journal of Clinical Psychiatry*, 67(suppl 9), 3-8.
- Green, M., Kern, R., Braff, D., & Mintz, J. (2000). Neurocognitive deficits and functional outcomes in schizophrenia: Are we measuring the right stuff? *Schizophrenia Bulletin*, 26, 117-136.
- Greenhalgh, T. (2009). Patient and public involvement in chronic illness: Beyond the expert patient. *British Medical Journal*, 338, 629-631.
- Greenhalgh, T., Robert, G., MacFarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Quarterly*, 82(4), 581-629.
- Grimshaw, J., Shirran, L., Thomas, R., Mowatt, G., Fraser, C., Bero, L. et al. (2001). Changing provider behavior. An overview of systematic reviews of interventions. *Medical Care*, 39(8,S2), II-2-II-45.
- Grol, R., & Grimshaw, J. (2003). From best evidence to best practice: effective implementation of change in patients' care. *The Lancet*, 362, 1225-1230.

- Hafner, H., & an der Heiden, W. (1997). Epidemiology of schizophrenia. *Canadian Journal of Psychiatry*, 42, 139-151.
- Hammell, K. W. (2006). *Perspectives on disability and rehabilitation*. Philadelphia, PA, USA: Elsevier.
- Hasson-Ohayon, I., Roe, D., & Kravetz, S. (2007). A randomized controlled trial of the effectiveness of the Illness Management and Recovery program. *Psychiatric Services*, 58(11), 1461-1466.
- Haydon, E. (2006). *Chronic disease in Ontario and Canada: Determinants, risk factors and prevention priorities*. Ontario Chronic Disease Prevention Alliance and Ontario Public Health Association. Retrieved from <http://www.ocdpa.on.ca/docs/CDP-FullReport-Mar06.pdf>
- Heinrichs, R., Goldberg, J., Miles, A., & McDermid, V. (2008). Predictors of medication competence in schizophrenia patients. *Psychiatry Research*, 157(1-3), 47-52.
- Jacobson, N., Butterill, D., & Goering, P. (2003). Development of a framework for knowledge translation: Understanding user context. *Journal of Health Services Research and Policy*, 8(2), 94-99.
- Jordan, J., Briggs, A., Brand, C., & Osborne, R. (2008). Enhancing patient engagement in chronic disease self-management support initiatives in Australia: The need for an integrated approach. *Medical Journal of Australia*, 189(10), S9-S13.
- Kennedy, A., Chew-Graham, C., Blakeman, T., Bowen, A., Gardener, C., Protheroe, J. et al. (2010). Delivering the WISE (Whole Systems Informing Self-Management Engagement) training package in primary care: Learning from formative

evaluation. *Implementation Science*, 5. Retrieved from

<http://implementationscience.com/content/5/1/7>

Kennedy, A., Reeves, D., Bower, P., Lee, V., Middleton, E., Richardson, G. et al. (2007).

The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: A pragmatic randomised controlled trial. *Journal of Epidemiology and Community Health*, 61, 254-261. doi:10.1136/jech.2006.053538

Kennedy, A., Rogers, A., & Crossley, M. (2007). Participation, roles and the dynamics of

change in a group-delivered self-management course for people living with HIV. *Qualitative Health Research*, 17(6), 744-758. doi:10.1177/1049732307302754

Kennedy, A., Rogers, A., & Bower, P. (2007). Support for self care for patients with chronic disease. *British Medical Journal*, 335, 968-970.

Kisely, S., Smith, M., Lawrence, D., Cox, M., Campbell, L., & Maaten, S. (2007).

Inequitable access for mentally ill patients to some medically necessary procedures. *Canadian Medical Association Journal*, 176(6), 779-784.

Kontoghiorghes, C. (2004). Reconceptualizing the learning transfer conceptual

framework: Empirical validation of a new systemic model. *International Journal of Training and Development*, 8, 210-221.

Kubina, N., & Kelly, J. (2007). *Navigating self-management: A practical approach to*

implementation for Australian health care agencies. Resource prepared for Whitehorse Division of General Practice, Australian Government Department of

Health and Aging. Retrieved from

http://som.flinders.edu.au/FUSA/CCTU/self_managment.htm

Lavis, J. N., Robertson, D., Woodside, J., McLeod, C., Abelson, J., & and the Knowledge Transfer Study Group. (2003). How can research organizations more effectively transfer research knowledge to decision makers? *Milbank Quarterly*, 81, 221-248.

Law, M. (1998). *Client-centred occupational therapy*. Thorofare, NJ: SLACK.

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person-Environment-Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23.

Lawn, S., Battersby, M., Lindner, H., Mathews, R., Morris, S., Wells, L. et al. (2009). What skills do primary health care professionals need to provide effective self-managment support? Seeking consumer perspectives. *Australian Journal of Primary Health*, 15, 37-44.

Lawn, S., Battersby, M. W., Pols, R. G., Lawrence, J., Parry, T., & Urukalo, M. (2007). The mental health expert patient: Findings from a pilot study of a generic chronic condition self-management programme for people with mental illness. *International Journal of Social Psychiatry*, 53(1), 63-74.

doi:10.1177/0020764007075010

Lawn, S., Pols, R., & Battersby, M. (2009). Working effectively with patients with comorbid mental illness and substance abuse: a case study using a structured motivational behavioural approach. *British Medical Journal*.

doi:10.1136/bcr.08.2008.0674

- Lawn, S., & Pulvirenti, M. (2011). Chronic condition self-management: Expectations of responsibility. *Patient Education and Counseling*, *84*, e5-e8.
doi:10.1177/1075547098020002004
- Leff, H., Leff, J., Chow, C., Cichocki, B., Phillips, D., & Joseph, T. (2007). *Evidence-based workforce development strategies for evidence-based practices in mental health*. Cambridge, MA: Human Services Research Institute. Retrieved from <http://www.tecathsri.org>
- Levit, A., Mueser, K., DeGenova, J., Lorenzo, J., Bradford-Watt, D., Barbosa, A., ... Chernick, M. (2009). Randomized controlled trial of Illness Management and Recovery in multiple-unit supportive housing. *Psychiatric Services*, *60*(12), 1629-1636.
- Logan, J., & Graham, I. (1998). Toward a comprehensive interdisciplinary model of health care research use. *Science Communication*, *20*(2), 227-246.
doi:10.1177/1075547098020002004
- Lorig, K., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, *26*(1), 1-7.
- Lorig, K., Sobel, D., Gonzalez, V., McGowan, P., & LaBossiere Huebner, T. (2004). *Living a Healthy Life with Chronic Conditions: Self-Management of heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema and others* (Canadian Ed.). Boulder, CO: Bull.
- Lorig, K., Sobel, D., Stewart, A., Brown, B., Bandura, A., Ritter, P. et al. (1999). Evidence suggesting that a chronic disease self-management program can improve

health status while reducing hospitalization: A randomized trial. *Medical Care*, 37(1), 5-14.

Martyn, D. (2003). *Self-management: The experiences and views of self-management of people with a diagnosis of schizophrenia*. Surrey, UK: Rethink. Retrieved from www.rethink.org/publications

McGowan, P. (2003). *Chronic Disease Self-Management Program in Vancouver and Richmond*. Retrieved from http://www.coag.uvic.ca/cdsmp/information_cdsmp_research.htm

McGowan, P. (2005). Self-management: A background paper. *New Perspectives: International Conference on Patient Self-Management* (pp. 1-10) Victoria, BC: Centre on Aging, University of Victoria.

Mental Health Commission. (2002). *Mental health recovery competencies teaching resource kit*. Retrieved from <http://www.mhc.govt.nz>

Mental Health Commission of Canada. (2009). *Toward recovery and well-being. A framework for a mental health strategy in Canada*. Retrieved from <http://mentalhealthcommission.ca>

Michie, S., Johnston, M., Francis, J., Hardeman, W., & Eccles, M. (2008). From theory to intervention: Mapping theoretically derived behavioural determinants to behaviour change techniques. *Applied Psychology*, 57(4), 660-680.
doi:10.1111/j.1464-0597.2008.00341.x

- Michie, S., van Stralen, M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(42), 1-11.
- Millar, H. (2008). Management of physical health in schizophrenia: A stepping stone to treatment success. *European Neuropsychopharmacology*, 18, S121-S128.
doi:10.1016/j.euroneuro.2008.02.002
- Miller, W., & Rollnick, S. (2002). *Motivational interviewing: Preparing people for change* (2nd ed.). New York: Guildford Press.
- Milne, D., Gorenski, O., Westerman, C., Leck, C., & Keegan, D. (2000). What does it take to transfer training? *Psychiatric Rehabilitation Skills*, 4(2), 259-281.
- Milne, D., Woodward, K., & Hanner, S. (2003). An illustration of delivering evidence-based practice through staff training: Multi-dimensional process, outcome and organizational evaluation. *Behavioural and Cognitive Psychotherapy*, 31, 85-98.
- Ministry of Health and Long-Term Care [MOHLTC]. (2007). *Preventing and managing chronic disease: Ontario's framework*. Toronto, ON: Author. Retrieved from <http://www.health.gov.on.ca/english/providers/program/cdpm/index.html>
- Ministry of Health and Long-Term Care [MHLTC]. (2010). *Respect, recovery, resilience: Recommendations fro Ontario's Mental Health and Addiction's Strategy. Report to the Minister of Health and Long-term Care*. Retrieved from http://www.health.gov.on.ca/en/common/ministry/publications/reports/mental_health/mentalhealth_rep.pdf

- Morriss, R. (2013). Training to recognize the early signs of recurrence in schizophrenia. *Cochrane Database of Systematic Reviews*, (2. Art.No: CD006147). doi:1002-14651858.CD005147.pub2
- Mueser, K. T., Meyer, P. S., Penn, D. L., Clancy, R., Clancy, D. M., & Salyers, M. P. (2006). The Illness Management and Recovery Program: Rationale, development, and preliminary findings. *Schizophrenia Bulletin*, 32(Suppl), 1-43.
- National Collaborating Centre for Methods and Tools. (2010). *Ottawa Model of Research Use: A framework for adopting innovations*. Retrieved from <http://www.nccmt.ca/registry/view/eng/65.html>
- National Health Priority Health Council [NHPAC]. (2005). *National Chronic Disease Strategy* Canberra: Australian Government Department of Health and Aging. Retrieved from <http://www.health.gov.au/internet/main/publishing.nsf/Content/pq-ncds>
- Neuwelt, B. (2009). *Mental health, mental illness and chronic disease prevention and management in Ontario. CMHA Ontario Teleseminar* (slides 10 & 23).
- Newcomer, N., & Hennekens. (2007). Severe mental illness and risk of cardiovascular disease. *Journal of American Medical Association*, 298(15), 1794-1796.
- Nilsen, P., Roback, K., Brostrom, A., & Ellstrom, P. (2012). Creatures of habit: Accounting for the role of habit in implementation research on clinical behavior change. *Implementation Science*, 7. Retrieved from <http://www.implementationscience.com/content/7/1/53>

- Ontario Chronic Disease Prevention Alliance [OCDPA]. (2009). *Proceedings for systems think tank on mental health and chronic disease prevention: Moving forward as a system*. Retrieved from http://www.ocdpa.on.ca/rpt_proceedings_MH_CDP.htm
- Parry, D., Salsberg, J., & Macaulay, A. (2013). Guide to researcher and knowledge-user collaboration in health research. *Canadian Institute of Health Research Knowledge Translation Portfolio*. Retrieved from <http://www.cihr-irsc.gc.ca/e/29418.html>
- Pekkala, E., & Merinder, L. (2002, January 23). Psychoeducation for schizophrenia [Intervention Review]. *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD002831. doi:10.1002/14651858.CD002831
- Penn, P., & Brooks, A. (1999). *Comparing substance abuse treatments: Final report*. Rockville, MD: National Institute on Drug Abuse, Treatment Services Branch.
- Penn, P., Brooks, A., Gallagher, S., & Brooke, D. (2009). *SMART Recovery: A promising best practice for group integrated treatment* [Power Point Presentation]. The Integrating Services & Research for Co-Occurring Condition Conference, Bethesda, MD, March 2009.
- Provincial Forum of Mental Health Implementation Task Force Chairs & MOHLTC. (2002). *The time is now: Themes and recommendations for mental health reform in Ontario. Final report of the Provincial Forum of Mental Health Implementation Task Force Chairs*. Retrieved from http://www.health.gov.on.ca/english/providers/pub/mhitf/provincial_forum/provincial_forum.pdf

- Registered Nurses of Ontario. (2006). *Client-centred care. Nursing best practice guideline (revised)*. Retrieved from http://rnao.ca/sites/rnao-ca/files/Client_Centred_Care.pdf
- Roe, D., Hasson-Ohayon, I., Salyers, M., & Kravetz, S. (2009). A one-year follow-up of Illness Management and Recovery: Participants' accounts of its impact and uniqueness. *Psychiatric Rehabilitation Journal*, 32(4), 285-291.
- Rogers, A., Kennedy, A., Bower, P., Gardner, C., Gately, C., Lee, V. et al. (2008). The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *Medical Journal of Australia*, 189(10), S21-S24.
- Rogers, A., Kennedy, A., Nelson, E., & Robinson, A. (2005). Uncovering the limits of patient-centredness: Implementing a self-management trial for chronic illness. *Qualitative Health Research*, 15(2), 224-239. doi:10.1177/1049732304272048
- Salerno, A., Margolies, P., Cleek, A., Pollock, M., Gopalan, G., & Jackson, C. (2011). Wellness self-management: An adaptation of the Illness Management Recovery Program in New York state. *Psychiatric Services*, 62(5), 456-458.
- Salyers, M., McGuire, A., Rollins, A., Bond, G., Mueser, K., & Macy, V. (2010). Integrating Assertive Community Treatment and Illness Management and Recovery for consumers with severe mental illness. *Community Mental Health Journal*, 46, 319-329.
- Salyers, M., Rollins, A., Clendenning, D., McGuire, A., & Kim, E. (2011). Impact of Illness Management and Recovery Programs on hospital and emergency room use by Medicaid enrollees. *Psychiatric Services*, 62(5), 509-515.

- Smith, G., Malla, A., Williams, R., Kopala, L., Love, L., & Balshaw, R. (2006). The Canadian National Outcomes Measurement Study in Schizophrenia: Overview of the patient sample and methodology. *Acta Psychiatrica Scandinavica*, *113*(S430), 4-11.
- State Government of Victoria. (2007). *Self-Management Mapping Guide*. Melbourne, Victoria, Australia: Victorian Government, Department of Human Services. Retrieved from <http://www.health.vi.gov.au/pcps/publications/self-management.htm>
- Stevens, S., & Sin, J. (2005). Implementing a self-management model of relapse prevention for psychosis into routine clinical practice. *Journal of Psychiatric and Mental Health Nursing*, *12*(4), 495-501.
- Sudsawad, P. (2007). *Knowledge translation: Introduction to models, strategies and measures*. Retrieved from Southwest Educational Development Laboratory, National Center for the Dissemination of Disability Research. Retrieved from <http://ncddr.org/kt/products/ktintro/ktintro.pdf>
- Swerissen, H., Belfrage, J., Weeks, A., Jordan, L., Walker, C., Furler, J. et al. (2006). A randomised control trial of a self-management program for people with a chronic illness from Vietnamese, Chinese, Italian and Greek backgrounds. *Patient Education and Counseling*, *64*, 360-368.
- Townsend, E. (1998). *Good intentions overruled: A critique of empowerment in the routine organization of mental health services*. Toronto, ON: University of Toronto Press.

- U.S. Department of Health & Human Services. (2000). *Healthy People 2010*.
Washington, D.C.: U.S. Government Printing Office.
- van Manen, M. (1997). *Researching the lived experience: Human science for an action sensitive pedagogy* (2nd ed.). London, ON: Althouse Press.
- van Manen, M. (2002). *Phenomenology Online*. Retrieved from
<http://www.phenomenologyonline.com>
- VonKorff, M., Gruman, J., Schaefer, J., Curry, S., & Wagner, E. (1997). Collaborative management of chronic illness. *Annals of Internal Medicine*, 127(12), 1097-1102.
- Wagner, E., Bennett, S., Austin, B., Greene, S., Schaefer, J., & VonKorff, M. (2005). Finding common ground: Patient-centredness and evidence-based chronic illness care. *The Journal of Alternative and Complementary Medicine*, 11(S1), S7-S15.
- Wagner, E., Austin, B., & VonKorff, M. (1996). Organizing care for patients with chronic illness. *Milbank Quarterly*, 74(4), 511-544.
- Woltmann, E., & Whitley, R. (2010). Shared decision making in public mental health care: Perspectives from consumers living with severe mental illness. *Psychiatric Rehabilitation Journal*, 34(1), 29-36.
- Whitley, R., Gingerich, S., Lutz, W. J., & Mueser, K. (2009). Implementing the Illness Management and Recovery Program in community mental health settings: Facilitators and barriers. *Psychiatric Services*, 60(2), 202-209.
- Wilson, P. M. (2001). A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health and Social Care in the Community*, 9(3), 134-142.

World Health Organization. (2001). *World Health Report 2001. Mental Health - new understanding, new hope*. Geneva: Author.

World Health Organization [WHO]. (1998). *Health promotion glossary*. Geneva: Switzerland: Author. Retrieved from <http://www.who.ch/hep>

Yin, R. (2003). *Applications of case study research* (2nd ed.). Thousand Oaks, CA: Sage.

Yin, R. (2009). *Case study research: Design and methods* (4th ed.). Newbury Park, CA: Sage.

Yip, Y. B., Sit, J. W., Fung, K. K., Wong, D. Y., Chong, S. Y., Chung, L. H. et al. (2007). Effects of self-management arthritis programme with an added exercise component for osteoarthritic knee: randomized controlled trial. *Journal of Advanced Nursing*, 59(1), 20-28. doi: 10.1111/j.1365-2648.2007.04292.x

APPENDICES

Appendix A: Matrix of Six Self-Management Intervention Approaches

Feature	Stanford Chronic Disease Self-Management Program (CDSMP)	Expert Patient Programme (EPP)	Flinders Model of Chronic Condition Self-Management (CCSM)
Description Development & Context of Operation	<p>A generic group-based model arising from clinicians supporting people with chronic disease to manage life by providing knowledge, skills and confidence to deal with disease related problems, and collaborate with health care professionals.</p> <p>Clinician/Lay-led SM support designed to augment regular treatment and disease –specific education.</p> <p>Promoted & coordinated through Stanford University in partnership with Kaiser Permanent Medical Care Program.</p> <p>Managed Care Environment</p>	<p>Stanford generic approach was adapted to England’s society in response to a grassroots national public health strategy for more effective resource utilization.</p> <p>Engaged in capacity building at three levels: people living with chronic diseases; Advanced Development Programme for Clinicians & Volunteer Training/Mentorships; Service Improvement Program for service delivery level improvements.</p> <p>Lay-led SM programs tailored to meet particular groups and context needs.</p> <p>Supported and coordinated by a not-for-profit social enterprise: the Expert Patients Programme Community Interest Company.</p> <p>Public Health Environment</p>	<p>A generic consultation model stemming from health professionals-researchers responding to national government initiatives and evidence-based practices.</p> <p>Focused on providing health care providers with a generic set of tools & structured processes to assess SM behaviours, and develop collaborative care plans with clients involving problem identification, goal setting, and on-going support for behaviour change.</p> <p>Clinician-led SM support designed to be used with other SM approaches and regular treatment.</p> <p>Developed and coordinated by the Human Behaviour & Health Research Unit, Flinders University, Australia</p> <p>Mixed Public-Private Health Environment</p>
View of Person	<p>Patients with health needs to participate in day-to-day living tasks re: medical/emotional/role management</p> <p>Partner of health professionals</p> <p>Biomedical View</p>	<p>Patients as experts</p> <p>Citizens with chronic conditions who have health & social care needs</p> <p>Whole person within a community</p> <p>Recognizes socially disadvantaged groups & health inequalities</p> <p>Biomedical + Sociological Paradigm</p>	<p>Individuals coping with chronic illness and disability</p> <p>Managing the physical/emotional/social impact requires knowledge of condition; active participation in monitoring, decision making; collaborative care planning with health professionals; adoption of healthy lifestyles</p> <p>Recognizes socially disadvantaged groups & health inequalities</p> <p>Biomedical + Sociological Paradigm</p>
Theoretical & Conceptual Basis of SM Support	<p>BC’s Expanded Chronic Care Model</p> <p>Person-focused Model of Change</p> <p>Social Cognitive Theory</p> <p>Stress-vulnerability Model</p>	<p>Wagner Chronic Care Model</p> <p>Social Ecology / whole systems / multi-levels</p> <p>Peer Support & Self-Help</p> <p>Community ownership</p>	<p>Wagner Chronic Care Model</p> <p>Person-focused + Social Model of Change re: shared responsibility, client-clinician interaction & health care delivery</p> <p>Social Cognitive Theory & Cognitive</p>

		Social Cognitive Theory & Cognitive Behavioural Therapy principles Stress-vulnerability Model	Behavioural Therapy principles Stress-vulnerability Model Transtheoretical Model
Key Components of SM Support	Patient-centred Skills-based Information Training Problem-solving, decision-making Goal setting & Action planning Motivational strategies (Modeling, Building Self-efficacy) Group dynamics	Consumer/Citizen-centred Offer a tool-kit of fundamental information, action strategies and SM techniques Self-help, mutual support Integrated into a package of care embedded in mainstream health services Shared decision-making & collaborative partnerships between people with conditions & clinicians Multiple components (technology, information, skills training, support networks, peer modeling, personalised SM plans, formal services) recognizing 'one size does not fit all'	Person-centred Therapeutic alliance & shared responsibility Shared Assessment of Self-management Motivational Interviewing Problem-solving, goal setting Prospective care planning using environmental supports/structures Systematic monitoring, Follow-up & Support Improved coordination of care Healthcare delivery system change
Implementation Structure	A 15-hour group-based course for 10-15 participants of various ages, diagnoses with interested family members. Workshops given 2.5 hours/week for 6 weeks in community and health care settings. Co-led by a health professional and a peer leader or two health professionals who have completed a 4.5 day training program & licensed Interactive structured sessions according to a published scripted manual	Delivered in multiple formats by self-referral for free: <ul style="list-style-type: none"> conventional generic Stanford groups (6-wk course 2.5 hours/sessions with 12-16 people with various conditions) following Stanford course manual but delivered by 2 trained/accredited peer volunteer tutors Condition-specific courses: COPD, aphasia, asthma, diabetes, coronary heart disease, back care Co-creating Health groups vary in format by setting, delivered jointly by clinical and lay tutors, condition-specific, generic SM skills + medical information On-line SM support 	Taught by accredited health professionals to health professionals. Semi-structured, motivational, sequential process Assesses SM with an exploratory interview and builds a collaborative partnership through care planning, problem-solving, monitoring of goals and on-going support Comprehensive one-to-one SM assessment & care planning process using a number of standardized tools/form Sometimes combined with Stanford SM groups or health coaching techniques or community-based health promotion activities.
Resources/Tools/Measures	Action Plans Guidelines for problem-solving Reference book for participants Audio relaxation tape Outcome Measures reference book	Stepping Stones to Quality (Ss2Q) – quality standards Stepping Stones to Success – implementation manual	Partners in Health (PIH) Scale & Guide Cue & Response (C&R) Form & Guide Problem and Goals Assessment Self-management Care Plan Symptom Action Plan Monitoring Diary Partners in Health Handbook

			CCSM Education and Training Manual The Flinders Model DVD
<p>Anticipated Outcomes</p> <p>*=research support</p> <p>?=inconsistent or weak support</p>	<p>Self-efficacy*</p> <p>Problem-solving, decision-making skills</p> <p>SM health behaviour: diet?, exercise?, cognitive symptom management*, communication with dr*</p> <p>Health status: distress*, pain?, fatigue?, depression; Disease/health markers?</p> <p>Role Function</p> <p>Adherence to medical management plan</p> <p>Healthcare utilization?</p>	<p>SM Knowledge*, Information seeking?</p> <p>Problem-solving, decision-making skills</p> <p>Sense of control* Perceived ability to manage illness*; coping*</p> <p>Self-efficacy*</p> <p>SM health behaviour: diet?, exercise*, relaxation*</p> <p>Health status: distress*, pain?, energy*, depression</p> <p>Activity levels*, Role limitations*</p> <p>Social networks, social capital & inclusion</p> <p>Life satisfaction, well-being*</p> <p>Quality of life*</p> <p>Adherence to medical management plan*</p> <p>Healthcare utilization? Service satisfaction*</p> <p>Doctor partnerships*</p> <p>Political policy</p>	<p>Knowledge of self & condition</p> <p>Behaviour change towards improved SM (e.g., symptom monitoring, actions to manage & decision-making)</p> <p>Raise the quality of life for people living with chronic disease (increased sense of control, improved health outcomes);</p> <p>Effective use of the health care system by people with chronic conditions (e.g., access to preventative services, reduction in hospital admissions)</p> <p>Collaboration among individuals, families and health care professionals (e.g., culture of relationships, shared decision-making, staff perceptions of patients, social networks, social capital).</p>
<p>Use with Individuals Living with Serious Mental Illnesses</p>	<p>Extensive international evaluations have taken place but few with marginalized groups and none with individuals with SMI.</p> <p>Richard Goldberg (2013) and Druss et al. (2013) began a hybrid CDSMP integrating management of SMI with physical co-morbidities that show promise.</p>	<p>No published RCT studies found with SMI. Qualitative studies and process evaluations indicate issues re: skill acquisition, ability to meet intensive needs.</p> <p>Unable to properly determine as no response to e-mail correspondence inquiries.</p> <p>EPP Website Lists:</p> <ul style="list-style-type: none"> • Co-creating Health Demonstration Sites for Depression at multiple sites • EPP Supporting People Recovering from Substance Misuse 	<p>Studies indicate the approach is feasible and acceptable to people with SMI & low socioeconomic conditions. However, unable to determine if changes were solely attributable to the Flinders model.</p> <p>There are some characteristics of Flinders approach that appear very attractive for use with the SMI population.</p>

Feature	Illness Management and Recovery (IMR) Program	ADMIRE Plus	Health Coaching (2000-2011)
Description Development & Context of Operation	<p>A disease-specific group-based model arising from a collection of psychosocial evidence-based practices for helping people with SMI manage symptoms and prevent relapse as part of U.S. national healthcare initiative.</p> <p>Designed for mass dissemination as a SAMHSA toolkit internationally.</p> <p>Clinician/Lay-led SM support designed to augment regular treatment and disease –specific education.</p> <p>Recently modified to create I-IMR or Integrated Illness Management & Recovery for older adults with SMI & physical co-morbidities.</p> <p>Coordinated by Dartmouth Psychiatric Institute, MASS.</p> <p>Public Health Sector in a Managed Care Environment</p>	<p>A disease-specific group-based model embedded within a case management service arising from addictions services.</p> <p>Coupled with intensive day treatment/partial hospitalization program gram with addiction counsellors.</p> <p>Clinician/Lay-led SM support designed for people with mental illness and co-occurring substance abuse.</p> <p>Multidisciplinary teams provide Rational Emotive Behavioural Therapy groups (SMART model) combined with the traditional 12-Step substance abuse program at La Frontera, Inc., locations with access to continuum of mental health/addictions’ services.</p> <p>Non-profit Community Treatment settings in a Managed Care Environment</p>	<p>An individual or group-based approach which utilises a range of principles & techniques from the fields of psychology, counselling and coaching to assist people to make & maintain health behaviour changes</p> <p>Being applied in psychological practice re: chronic disease management, primary care, pain and disability management for Worker’s Compensation, health & wellness industry</p> <p>Mixed Public-Private Health Environment</p>
View of Person	<p>Person is working towards recovery while managing psychiatric and physical disorders</p> <p>Recognizes socially disadvantaged groups & health inequalities</p> <p>Bio-medical + Sociological View</p> <p>Mental Illness Recovery Model</p>	<p>Person needs to effectively cope with and manage psychiatric symptoms while reducing the substance abuse. The abuse is a drug dependency that persists due to ‘bad’ habits.</p> <p>Biopsychosocial View (Psych emphasis)</p> <p>Mental illness Recovery Model</p>	<p>People are motivated to make health behaviour change; they know what to do but have difficulty implementing it</p> <p>Bio-medical View</p>
Theoretical & Conceptual Basis of SM Support	<p>Social Ecological Model of Change</p> <p>Stress-vulnerability Model</p> <p>Transtheoretical Model</p> <p>Adult Education</p> <p>Social Cognitive Theory & Cognitive Behavioural Therapy principles</p>	<p>Social Ecological Model of Change (limited)</p> <p>Rational Emotive Behavioural Therapy (Albert Ellis)</p> <p>Stress-vulnerability Model</p> <p>Transtheoretical Model</p> <p>Harm reduction versus abstinence</p> <p>Self-help & Mutual Aid</p>	<p>Person-focused Model of Change</p> <p>Recognition of person-environment relationships</p> <p>Adult Education</p> <p>Social Cognitive Theory & Cognitive Behavioural Therapy principles</p> <p>Stress-vulnerability Model</p> <p>Transtheoretical Model</p>

<p>Key Components of SM Support</p>	<p>Goal setting within recovery plans Education Social Support Using meds effectively Coping Skills Training Social Skills Training Relapse Prevention Navigating mental health system <u>I-IMR</u>: Additional education, goal setting, problem-solving for SM Better coordinated services</p>	<p>Person-centred Individual Assessment & Strengths-based goal setting Enhanced Case Management Intensive Day Treatment Culturally sensitive SMART 4-Point Program: <ul style="list-style-type: none"> • Motivation to abstain • Coping with urges • Problem-solving • Lifestyle Balance ADMIRE Plus covers: <ul style="list-style-type: none"> • mental illness management • relapse prevention • substance reduction, relationship with mental health • goal setting, goal review with contingent reinforcement • survival skills • problem solving & social skills building • recreation (to promote healthy, alternatives to substance use) • weekend preparation • work and education preparation/exploration </p>	<p>Patient centred counselling Therapeutic alliance Lifestyle counselling Motivational interviewing Solution-focused coaching Self-monitoring & self-regulation</p>
<p>Implementation Structure</p>	<p>Particular attention given to organization's structure, training, support Delivered by multidisciplinary mental health professionals with on-site training, supervision & f/u Delivered once or 2X/week individually or in open IMR groups (8 people max.) with rolling admissions structured to cover written curriculum (2-4 wk/topic, ~5-10 months) depending on clients' abilities & preferences Multiple strategies (motivational, educational, cognitive-behavioral) to increase intensity of the intervention</p>	<p>Led by trained facilitators with on-site training, supervision & f/u In-take meeting of client, client's family of choice, multidisciplinary treatment team to assess need and treatment planning that would extend beyond ADMIRE Plus Day Treatment Program: Participants progress through a three phased program of progressively less ADMIRE Plus attendance & increasing community-based SM as personal goals are accomplished Open enrolment groups approach daily living topics in a concrete behavioural manner following manual's material Program length is defined as 12 months;</p>	<p>Sessions are semi-structured around identification of health issues, exploring options for lifestyle change, motivation to pursue options, assisting with goal setting/action planning. Use of worksheets and tools Can be conducted individually or in small groups and multiple venues (in person, via telephone, internet) Conducted by a range of health professionals who bring prior professional training to health coaching (e.g., GPs, nurses, psychologists, OTs, SW, dietitians) in private and public health settings</p>

	<p>Handouts, worksheets, AV, homework assignments</p> <p>Goal setting & feedback each session with attention to goal tracking</p> <p>Involve significant others</p> <p><i>I-IMR</i> adds supplemental modules to integrate mental & physical health at the client-clinician level and integrates service delivery by a case manager, community health centre working with Mental Health Specialist (provider of I-IMR).</p> <p><i>Wellness IMR</i> adds participant workbook curriculum & competencies.</p>	<p>however, participants leave & re-enter as needed to accommodate the chronic, episodic nature of illnesses</p> <p>Goal-setting and problem solving are a key focus</p> <p>Interactive reflective exercises (e.g., role playing, brainstorming, imagery, written assignments)</p> <p>Application of content using homework with personal incentives</p> <p>Formal & informal individual sessions with counsellors available & used by some/not all</p> <p>Routine program evaluation and feedback sessions by participants</p>	
Resources/ Tools/ Measures	<p>Illness Management and Recovery (IMR) Scale</p> <p>IMR Fidelity Scale</p> <p>Implementation Resource Kit (extensive)</p>	<p>SMART Recovery Coordinator's Manual</p> <p>SMART Recovery Member's Manual</p> <p>SMART Recovery A Sensible Primer</p> <p>Admire Plus (A+) Manual & Annual training</p> <p>Online meetings, information, support from professional advisors</p>	<p>Goal setting – GROW conversation format</p> <p>Action Planning – Worksheets & monitoring checklists (ANTS & PETS)</p> <p>Decision Worksheets</p> <p>CBT Worksheets</p> <p>Habit Change Diaries</p>
Anticipated Outcomes *=research support ?=inconsistent or weak support	<p>Goal Attainment?</p> <p>Self-efficacy*</p> <p>Knowledge</p> <p>SM Behaviours*: relapse prevention*, coping with symptoms*; medication adherence, stress reduction?</p> <p>Health Status: symptom severity*</p> <p>Substance abuse</p> <p>Functioning level</p> <p>Social network/support?</p> <p>Patient Satisfaction?</p> <p>Recovery?</p> <p>Engagement*</p> <p>Utilization of Services*</p> <p><i>I-IMR adds:</i> Illness self-management skills, medication adherence; quality of health care for physical illness; quality of general preventative care</p>	<p>Goal Attainment</p> <p>Coping (emotional, cognitive)</p> <p>Self-efficacy</p> <p>SM Behaviours</p> <p>Substance Use?; dependency behaviour?</p> <p>Health status (mental and physical)?</p> <p>Role function?</p> <p>Health care utilization</p> <p>Client satisfaction*</p>	<p>Goal Attainment</p> <p>Readiness for change, Self-efficacy</p> <p>Positive, constructive thinking patterns</p> <p>Healthy lifestyle behaviours</p> <p>Self-regulation skills</p> <p>Emotion management</p> <p>Self-management of lifestyle risk factors & treatment regimens re: chronic diseases</p> <p>Achievement of health-related goals</p> <p>Health status</p>

<p>Use with Individuals with Serious Mental Illnesses</p>	<p>Specifically designed for use with SMI using evidence-based practices for mental illness with extensive dissemination.</p> <p>Research has focused on the use of the total IMR package with fidelity and has just begun first evaluation of I-IMR</p> <p>Research support is emerging with 6 RCT studies albeit limited to stand alone demonstration projects. Continues to have large drop-out rates and accessed by select groups.</p> <p>A qualitative narrative study (Roe et al., 2009) identified how the self-management support was unique to other rehabilitation intervention experiences but due to methodological constraints was unable to establish these unique elements as mechanisms for outcomes.</p> <p>Self-monitoring & self-regulation remain a challenge.</p>	<p>Specifically designed for use with SMI using evidence-based practices for integrated substance abuse treatment.</p> <p>Research is limited to original SMART model, no RCT, and by the authors.</p> <p>Impressive program completion rates and anecdotal reports of improved role function for a group that tends to have high drop-out rates.</p>	<p>In Australia, health coaching is the most widely put into use model proportionally to those trained; unclear extent with SMI.</p> <p>No established evidence-base. A Melbourne-based network is formalizing structures, plan to develop accreditation and evaluation</p>
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Appendix B.

St. Joseph's Healthcare Research Ethics Board Study Approval

– Clients Learning Self-Management Study

- **Letter of Approval (February 4, 2010)**
- **Advertisement**
- **Participant Information Sheet and Consent Statement**
- **Interview Guide**



RESEARCH ETHICS BOARD



50 CHARLTON AVENUE EAST, HAMILTON, ONTARIO, CANADA L8N 4A6

Tel. (905) 522-4941 ext. 33537 Fax: (905) 521-6092

Research Ethics Board Membership

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Biostatistics
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MRCP, FRCP(C) Respiriology
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Alexander Coret, MD, Diagnostic
Imaging
Giles Scofield, J.D., M.A.
Ethicist
Catherine Clase, MB BChir, MSc,
FRCP(C), Nephrology
Kevin Smith, DPhil.
President/CEO (Ex officio)

The St. Joseph's REB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the Health Canada / ICH Good Clinical Practice: Consolidated Guidelines (E6); the Health Ethics Guide (CHAC); and the applicable laws and regulations of Ontario. The membership of this REB also complies with the membership requirements for REBs as defined in Canada's Food and Drug Regulations (Division 5: Drugs for Clinical Trials Involving Humans Subjects).

February 4, 2010

Ms. Susan Strong
St. Joseph's Healthcare Hamilton
Centre for Mountain Health Services
Schizophrenia Services

RE: R.P.#09-3277

Study Title: Learning about self-management: health information uptake by specialized mental health service clients

Local Principal Investigator: Ms. Susan Strong

Received date: 21 December, 2009

Review type: Expedited

Initial Approval: 12 January, 2010

Final Approval: 04 February, 2010

All Received Enclosures:

Protocol - Protocol ver: 1 08 December, 2009
Recruitment Ad - Recruitment Advertisement ver: 1 08 December, 2009
Telephone Script - Telephone Script ver: 1 08 December, 2009
Interview Guides - Interview Guide ver: 1 08 December, 2009
Investigator Training Program Certificate for Susan Strong dated May 26th, 2008
Chart Review Tutorial Certificate for Susan Strong dated 2008-08-14
PI Letter - Letter dated February 1, 2010 responding to conditions
Consent Form (Main) - Participant Information Sheet/Consent Form ver: 2 01 February, 2010
Application Form - Revised General Research Application (revised)

Approved Enclosures:

Protocol - Protocol ver: 1 08 December, 2009
Recruitment Ad - Recruitment Advertisement ver: 1 08 December, 2009
Telephone Script - Telephone Script ver: 1 08 December, 2009
Interview Guides - Interview Guide ver: 1 08 December, 2009
Consent Form (Main) - Participant Information Sheet/Consent Form ver: 2 01 February, 2010

Acknowledged Enclosures:

Application Form - Revised General Research Application (revised)
Investigator Training Program Certificate for Susan Strong dated May 26th, 2008
Chart Review Tutorial Certificate for Susan Strong dated 2008-08-14
PI Letter - Letter dated February 1, 2010 responding to conditions

Ms. S. Strong
RE: R.P. #09-3277

Page 2

February 4, 2010

Dear Ms. Strong:

Please be advised that a member of the Research Ethics Board's Subcommittee reviewed R.P. #09-3277 on 12 January, 2010 and approved it with some conditions. Those conditions have now been met. You have final approval to commence your research.

This approval will be for a period of 12 months ending 04 February, 2011. We will request a progress report at that time.

If your project is terminated, it is your responsibility to notify the REB. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board prior to implementation.

Please ensure that all study personnel are familiar with the REB requirements on the appended page.

Please reference R.P. #09-3277 in any future correspondence.

We wish you well in the completion of this research.

Sincerely yours,



Raelene Rathbone, MB, BS, MD, PhD
Chairperson, Research Ethics Board
RR:imm

cc: Marnie Fletcher
Append.



PARTICIPANTS NEEDED!
Learning about Self-Management Study
Call the Student Researchers at: (905) 522-1155 ext. 36237

WHO?

We are looking for people who have a psychiatric illness, understand spoken English, and receive outpatient services to participate in a study being conducted at St. Joseph's Healthcare, Hamilton.

WHAT IS THE PURPOSE OF THE RESEARCH STUDY?

- To listen to peoples' stories of learning to manage the effects of illness and feel more in control of their lives. This is what is referred to as 'self-management'.
- To find out how we can support people to use health information and pursue self-management goals.

WHAT IS INVOLVED?

If you volunteer to participate, you will meet with a student researcher for about 1 hour. The session will involve answering questions about learning to manage the effects of illness in everyday life. The researcher with your help will make a drawing of your learning experiences. You will meet a second time for 15 minutes to review the drawing.

WHAT ARE THE BENEFITS?

Participants will help us improve our services to match peoples' learning needs. Participants will be given \$10.00 and bus fare as needed.

If you are interested in participating in this research study please contact the Student Researchers at: (905) 522-1155 ext. 36237



PARTICIPANT INFORMATION SHEET

Title of Study: Learning about Self-Management: Health Information Uptake by Specialized Mental Health Service Clients

Principal Investigator: Susan Strong MSc(DME), BSc(OT), Reg. (Ont.)
Coordinator of Program Evaluation
Schizophrenia & Community Integration Service
St. Joseph's Healthcare (Hamilton)

Student Investigators: Katie Denby, Eunice Kim, Tracy Martin, Alexis Moll,
Lynda Rolleman, Carolyn Scrafield
Occupational Therapy Students
McMaster University, Hamilton

Sponsor: St Joseph's Healthcare (Hamilton)



You are being invited to participate in a research study on people learning about what they can do to manage or reduce the effects of illness and feel more in control of their lives. This is what we refer to when we use the word 'self-management'. There are six student researchers participating in this study as part of the requirements for a Master of Science degree in Occupational Therapy, McMaster University. This study is also part of the requirements for a PhD in Rehabilitation Science, McMaster University for Susan Strong.

In order to decide whether or not you want to take part in this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the study, which will be discussed with you by one of the student researchers. Once you understand the study, you will be asked to sign this form indicating that you wish to participate. Please take your time to make your decision.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to describe and understand events that are important for learning self-management from the view of people with psychiatric illnesses. We want to find out what helps and hinders learning. The information will help us support people to use health information and pursue self-management. You are being invited to participate because you have experience with a psychiatric illness.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

About 18 to 24 participants with psychiatric illnesses will participate in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this research study, we will ask you to:

- Meet with a student researcher for one session of approximately one hour, at a time and place convenient to you. During this meeting, you will be asked to talk about the events that were important to your learning about self-management. You will be asked to describe events, what you took away from those experiences and give opinions about what you learned. The meeting will be audio-taped.
- Also, during this meeting, the student researcher will make a drawing of your learning events over time. The drawing will be used to keep focused and make sure the researcher understands clearly what you are saying. You can correct what is drawn at any time.
- Meet with a student researcher at a second session for approximately 15 minutes to review the drawing of learning events. You will be asked if the drawing matches your experiences and if anything needs to be added or changed.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no known risks. You will be asked to describe personal learning experiences. Some memories of experiences may be positive, others may be emotional. Some participants may experience fatigue. If you feel tired, please let us know and a rest break will be arranged.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR SOCIETY?

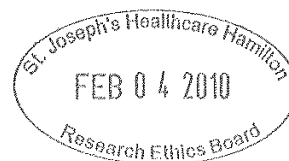
Although you will not directly benefit from participating in the study, your participation will help us to better understand self-management learning experiences. In this way, services can be designed to better meet patients' health information needs and support learning about self-management.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

No, you will not be paid to participate. However, you will be given \$10.00, an honorarium as a thank-you for the time you have given to participate in the study.

WILL THERE BE ANY COSTS TO ME IN THIS STUDY?

Participation in this study will not involve any additional costs to you. Please let us know if you need a bus ticket and we will provide one for you.



WHAT WILL HAPPEN TO MY PERSONAL INFORMATION?

Any personal information that is gathered before, during, or after your participation in this study will remain confidential and will not be disclosed without your permission.

Your data will not be shared with anyone except with the research team. All personal information such as your name will be removed from the data and will be replaced with a number. The data will be securely stored in a locked cabinet in the research office. Audiotapes of interviews will be destroyed upon being transcribed. The transcripts and any other data for this research study will be kept for 10 years.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the St. Joseph's Healthcare Hamilton Research Ethics Board may consult your research data and casebook/chart. However, no records which identify you by name or initials will be allowed to leave the hospital. By signing this consent form, you authorize such access.

If the results of the study are published or given in a presentation, your name will not be used and no information that discloses your identity will be released or published.

For the purposes of monitoring Susan Strong's PhD studies, it is possible that the PhD Supervisory Committee members may consult your data and study results. However, all personal information will be removed.

CAN PARTICIPATION END EARLY?

If you volunteer to be in this study, you may withdraw at any time. This will in no way affect the quality of care you receive at St. Joseph's Healthcare Hamilton. If you agree to participate in this study, you may refuse to answer any of the questions. If you agree to participate in this study, you may withdraw at any time, and you have the option of removing part or all your data from the study.

IF I HAVE ANY QUESTIONS, WHO SHOULD I CALL?

Susan Strong, MSc.(DME), BSc.OT Reg(Ont)
Coordinator of Program Evaluation, Schizophrenia & Community Integration Service
St Joseph's Healthcare, Hamilton, ON
Associate Clinical Professor (PT), School of Rehabilitation Science
McMaster University, Hamilton, ON
905-522-1155, extension 36237

If you have any questions concerning your rights as a research participant, you may contact the **Office of Chair of the Research Ethics Board, St. Joseph's Healthcare Hamilton, (905) 522-1155, Ext. 33537.**





CONSENT STATEMENT

SIGNATURE OF STUDY PARTICIPANT

I have read the preceding information thoroughly.
I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction.
I agree to participate in this study.
I understand that I will receive a signed copy of this form.

Name of Participant (print)

Signature of Participant

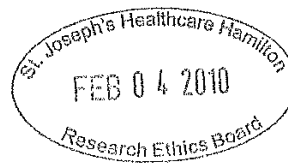
Date

CONSENT FORM ADMINISTERED AND EXPLAINED IN PERSON BY:

Name and Title (print)

Signature

Date



INTERVIEW GUIDE

Introduction

- Remind of written consent if not completed immediately before interview
- Repeat interview purpose: “For me to understand your experiences of learning what you can do to manage your condition and be more in control of your life.”
- Introduce process mapping: “As we go along I am going to put down on paper a drawing of key learning events over time that we can use to keep focused and help ensure that I understand clearly what you are saying. Feel free to correct what I put down on paper at any time if I have not understood you correctly.”
- When I say self-management learning, I mean “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”.

Closure

- Thank you very much!
- “After I have had a chance to hear the tape and tidy up the map we created today, I would like to show you a copy of the map and ask you if you think it captures the important events correctly.”
- Negotiate commitment to meet again, the time, place, and ask if a reminder or bus ticket is needed for 2nd visit. If unable to meet with student interviewer due to scheduling, offer 2nd meeting with Susan Strong, PI, at a time convenient to participant.
- Remind \$10.00 honorarium will be given at 2nd visit.

INTERVIEW QUESTIONS & PROBES

The following is a guide to hold a dialogue about key self-management learning events accompanied by drawing a process map. 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 the events that took place from the beginning to now for your learning about self-management?

- How did the process begin? Was there a key event in your life? When & where did this event take place? Who was present?
- What were important events that followed? [*Clarify link with SM learning*] When & 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's look further at each event on our map and what you took away from each event.

- Tell me about what happened, what people said, what you saw.
- What was your reaction (feelings, thoughts, actions)? What happened next?
- What did you make of it? What messages did you take away?
- How do you interpret events now?
- What were the consequences? What happened as a result?

3. Looking on the map of how things were when you began and how things are today, what has changed as a result of these experiences?

- Changes in daily activities, routines?
- Changes in how you see yourself?... your condition?... clinicians/family?
- Changes in your health?

4. Based on your life experiences, what do you believe would need to happen for yourself/others to be engaged in learning and potentially take action regarding self-management (SM)?

- What are the barriers to engaging and taking action?
- Describe what helped or hindered your learning.
- Earlier you mentioned an issue with..... How can we help people deal with this issue?
- What do you recommend staff do... family/friends/care givers do... to support people's learning?
- When and how should people be offered information?
- How can we link people with SM information?... help people use SM information?

Appendix C.

St. Joseph's Healthcare Research Ethics Board Study Approval

– Clinicians Enabling Self-Management Study

- **Letter of Approval (September 28, 2010)**
- **Participant Information Sheet and Consent Statement**
- **Interview Guide**
- **Field Note Form**
- **Amendment Approval (August 28, 2012)**



RESEARCH ETHICS BOARD



50 CHARLTON AVENUE EAST, HAMILTON, ONTARIO, CANADA L8N 4A6

Tel. (905) 522-4941 ext. 33537 Fax: (905) 521-6092

Research Ethics Board Membership

Raelene Rathbone, MB, BS, MD,
PhD, Chairperson
Peter Bieling, , PhD, CPsych. –
Psychology, Vice Chair
Christine Wallace, BScPhm,
Pharmacy
Susan Goodman, BA, MA
Community
Marie Townsend, BA, MBA
Research Administration,
McMaster University
Lehana Thabane, BSc, MSc, PhD
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Andrew Spurgeon, BA, MA, LLB
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Internal Medicine/Critical
Care
Mary Jane Sayles, RN, CCRC
Research Officer, Privacy
Margherita Cadeddu, MD, FRCSC,
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Neuropsychology, Ethics
Mary-Lou Martin, RN, BScN,
MScN, MEd - Clinical Nurse
Specialist
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Biostatistics
Helen Ramsdale, MA, BM BCh,
MRCP, FRCPC Respiriology
Debbie Macnamara, BA,
Community
Alexander Coret, MD, Diagnostic
Imaging
Giles Scofield, J.D., M.A.
Ethicist
Catherine Clase, MB BChir, MSc,
FRCPC Nephrology
Michael Kiang, MD, PhD, FRCPC
Psychiatry
David Higgins, MB, BCh, MRCPI,
FRCPC President (Ex officio)

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September 28, 2010

Ms. Susan Strong
St. Joseph's Healthcare Hamilton
Centre for Mountain Health Services
Schizophrenia Services - E-223f

RE: R.P.#10-3389

Study Title: Enabling the health literacy of clients: Clinicians' experiences and perspectives

Local Principal Investigator: Ms. Susan Strong

Received date: 26 August, 2010

Review type: Expedited

Initial Approval: 20 September, 2010

Final Approval: 28 September, 2010

All Received Enclosures:

Protocol - Study Protocol ver: 1 30 August, 2010

Consent Form (Main) - Provider Participant Information Sheet/Consent Form ver: 1 30 August, 2010

Application Form - Revised General Research Application

PI Letter - Letter dated September 23, 2010 responding to conditions

Other - Investigator Training Program Certificate for Susan Strong dated May 26th, 2008

Other - Chart Review Tutorial Certificate for Susan strong dated 2008-08-14

Approved Enclosures:

Protocol - Study Protocol ver: 1 30 August, 2010

Consent Form (Main) - Provider Participant Information Sheet/Consent Form ver: 1 30 August, 2010

Acknowledged Enclosures:

Application Form - Revised General Research Application

PI Letter - Letter dated September 23, 2010 responding to conditions

Other - Investigator Training Program Certificate for Susan Strong dated May 26th, 2008

Other - Chart Review Tutorial Certificate for Susan strong dated 2008-08-14

Ms. S. Strong
RE: R.P. #10-3389

Page 2

September 28, 2010

Dear Ms. Strong:

Please be advised that a member of the Research Ethics Board's Subcommittee reviewed R.P. #10-3389 on 20 September, 2010 and approved it with some conditions. Those conditions have now been met. You have final approval to commence your research.

This approval will be for a period of 12 months ending 28 September, 2011. We will request a progress report at that time.

If your project is terminated, it is your responsibility to notify the REB. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board prior to implementation.

Please ensure that all study personnel are familiar with the REB requirements on the appended page.

Please reference R.P. #10-3389 in any future correspondence.

We wish you well in the completion of this research.

Sincerely yours,



Raelene Rathbone, MB, BS, MD, PhD
Chairperson, Research Ethics Board
RR:lm

cc: Marnie Fletcher
Append.



PROVIDER PARTICIPANT INFORMATION SHEET

Title of Study: **Enabling the health literacy of clients:
Clinicians' experiences & perspectives**

Principal Investigator: Susan Strong MSc(DME), BSc(OT), Reg.(Ont.) OT(C)
Coordinator of Program Evaluation, SCIS
St. Joseph's Healthcare Hamilton

Co-Investigators: Seanne Wilkins, PhD, Professor
Lori Letts, PhD, Professor
School of Rehabilitation Science, McMaster University
Kevin Brazil, Professor, CE&B, McMaster University & Director,
Health System Research Network, St Joseph's Healthcare

Sponsors: Canadian Occupational Therapy Foundation
St Joseph's Healthcare Hamilton

You are being invited to participate in a research study on supporting the health literacy of people with psychiatric illness. By health literacy, we mean people having access, understanding and being able to use health information. People need to have a working knowledge of health information to actively participate in decision-making and to manage the impact of illness on their daily lives.

This study is part of the requirements for a PhD in Rehabilitation Science, McMaster University for Susan Strong.

In order to decide whether or not you want to take part in this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the study, which will be discussed with you by one of the student researchers. Once you understand the study, you will be asked to sign this form indicating that you wish to participate. Please take your time to make your decision.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to describe and understand what is involved in enabling the health literacy of people with psychiatric illness from the view of clinicians. We want to find out what helps and hinders actions to support clients' health literacy. The information will help us support clients to use health information and pursue self-

management. You are being invited to participate because you have experience working with people with a psychiatric illness.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

About 24 participants who are occupational therapists, social workers and nurses and work at the Schizophrenia and Community Integration Service, St Joseph's Healthcare are expected to participate in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this research study, we will ask you to:

- Meet with a research assistant for approximately 1-1.5 hour, at a time and place convenient to you. During an audio-taped interview, you will be asked to share your experiences and views related to supporting the health literacy of clients with psychiatric illness.
- Meet with other participants in a focus group for about one hour to review and discuss further the findings.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no known risks. You will be asked to describe work experiences. Some people may be uncomfortable sharing views in a small focus group of peers. At any time, you can decline to answer a question and the researcher will move on to another question.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR SOCIETY?

Although you will not directly benefit from participating in the study, your participation will help us to better understand what enables and constrains the process of supporting clients' health literacy. This information will be useful for planning supportive healthcare environments and addressing health inequalities. You may enjoy meeting with peers during the focus group to share experiences and learn from each other.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

No, you will not be paid to participate. You will be invited to attend a presentation of the findings. If the study results in a publication, you will be offered a copy.

WILL THERE BE ANY COSTS TO ME IN THIS STUDY?

Participation in this study will not involve any additional costs to you. Interviews and focus groups are arranged during paid work hours at a time and place convenient to you.



WHAT WILL HAPPEN TO MY PERSONAL INFORMATION?

Any personal information that is gathered before, during, or after your participation in this study will remain confidential and will not be disclosed without your permission.

Your data will not be shared with anyone except with the research team. All personal information such as your name will be removed from the data and will be replaced with a number. The data will be securely stored in a locked cabinet in the research office. Audiotapes of interviews will be destroyed upon being transcribed. The transcripts and any other data for this research study will be kept for 10 years.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the St. Joseph's Healthcare Hamilton Research Ethics Board may consult your research data. However, no records which identify you by name or initials will be allowed to leave the hospital. By signing this consent form, you authorize such access.

If the results of the study are published or given in a presentation, your name will not be used and no information that discloses your identity will be released or published.

CAN PARTICIPATION END EARLY?

If you volunteer to be in this study, you may withdraw at any time. This will in no way affect your work at St. Joseph's Healthcare Hamilton. If you agree to participate in this study, you may refuse to answer any of the questions. If you agree to participate in this study, you may withdraw at any time, and you have the option of removing part or all your data from the study.

IF I HAVE ANY QUESTIONS, WHO SHOULD I CALL?

Susan Strong, MSc.(DME), BSc.OT Reg(Ont), OT(C)
Coordinator of Program Evaluation, Schizophrenia & Community Integration Service
St Joseph's Healthcare, Hamilton, ON
Associate Clinical Professor, School of Rehabilitation Science
McMaster University, Hamilton, ON
905-522-1155, extension 36237

If you have any questions concerning your rights as a research participant, you may contact the **Office of Chair of the Research Ethics Board, St. Joseph's Healthcare Hamilton, (905) 522-1155, Ext. 33537.**





CONSENT STATEMENT

SIGNATURE OF STUDY PARTICIPANT

I have read the preceding information thoroughly.
I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction.
I agree to participate in this study.
I understand that I will receive a signed copy of this form.

Name of Participant (print)

Signature of Participant

Date

CONSENT FORM ADMINISTERED AND EXPLAINED IN PERSON BY:

Name and Title (print)

Signature

Date



INTERVIEW GUIDE (ver1, 30-Aug-2010)

[Note: This Interview Guide will be piloted and based on feedback revised prior to study data collection]

- Confirm participant signed Consent Form & time available for interview.
- Remind: “We are meeting to talk about your experiences with supporting clients’ health literacy. By supporting health literacy I mean anything that you do to enable a client to access, understand and apply information for their mental health.”
- Ask if participant has any questions.

Generalised Intention Statements (for sensitizing clinician to the area of study & prompt clinician to consider clients’ health literacy needs in their daily practice)

Before I start the interview, I would like to ask you to consider three questions.

1. For every 10 clients you see in your practice, how many clients would you expect to need to be assessed for health literacy needs (i.e., assessed for the clients’ ability to access, understand and apply information for their mental health)?

0 1 2 3 4 5 6 7 8 9 10
Comments:

2. For every 10 clients you see in your practice, how many clients would you expect would want more health information?

0 1 2 3 4 5 6 7 8 9 10
Comments:

3. For every 10 clients you see in your practice, how many clients would you expect would want to be referred to services to support their health literacy (i.e., help them to access, understand and apply information for their mental health)?

0 1 2 3 4 5 6 7 8 9 10
Comments:

Date (dd/month/yy):

Study #:

INTERVIEW GUIDE Continued

The Experience

1. Tell me about an experience you had with supporting a client's health literacy.

Describe for me what unfolded from beginning to the end.

- Preceding events
- Who was involved?
- When & where did this take place?
- What was asked or expected of you?
- What took place? Who did what?
- Reactions by client/others?
- Were there any consequences or things that happened afterwards?

Reflections about the Experience (Attitudes/Beliefs)

2. What made this experience a good/positive experience or a bad/negative experience?

3. To what extent were your actions beneficial or harmful?

4. To what extent was the experience pleasant or unpleasant for you?

- Was this a typical experience, one which you frequently encounter?

Another Experience

5. Tell me about another experience you had with supporting a client's health literacy. Perhaps with a client at a different stage in working with you/team or when there were different circumstances. Describe for me what unfolded from beginning to the end.

- Preceding events
- Who was involved?
- When & where did this take place?
- What was asked or expected of you?
- What took place? Who did what?
- Reactions by client/others?
- Were there any consequences or things that happened afterwards?

Reflections about the Experience (Attitudes)

6. What made this experience a good/positive experience or a bad/negative experience?

7. To what extent were your actions beneficial or harmful?

8. To what extent was the experience pleasant or unpleasant for you?

Repeat Questions 5-8 until participant unable to identify a different example of experience

INTERVIEW GUIDE Continued

(Attitudes/Beliefs Continued)

9. What do you believe are the advantages and disadvantages of taking action to support clients' health literacy?

- Positive or negative outcomes to you, client, team...
- Other things you associate with taking action to support health literacy

(Social Norms)

10. Are there any individuals or groups who would approve of you taking action to support clients' health literacy? Explain.

11. Are there any individuals or groups who would disapprove of you taking action to support clients' health literacy? Explain.

(Perceived Control & Power)

12. What sorts of things do you believe help and hinder you to take action to support clients' health literacy?

- Things that make it harder or easier to do (person, occupation, environment)

13. What sorts of things do you believe help or hinder your confidence in being able to support clients' health literacy?

- Extent & scope of experience, training

14. Is it up to you whether you decide to take action or are there factors beyond your control that determines if you try to help a client in this way?

- Things that would influence your decision to take action

(Recommendations for Change)

15. Please tell us about any suggestions you have to facilitate staff taking action to support clients' health literacy here at St Joseph's.

Thank you!

FIELD NOTE FORM

General Observations (Describe general observations of contextual elements that might have influenced the interview including setting, mood, rapport, prior local events, and participant's perceptions of researcher/study)

Participant's Pearls (List key words, meaningful phrases or metaphors that arose during interview)

Items for Follow-up (List questions to be discussed with PI or items to be pursued in the following interview)



RESEARCH ETHICS BOARD



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The St. Joseph's REB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the Health Canada / ICH Good Clinical Practice: Consolidated Guidelines (E6); the Health Ethics Guide (CHAC); and the applicable laws and regulations of Ontario. The membership of this REB also complies with the membership requirements for REBs as defined in Canada's Food and Drug Regulations (Division 5: Drugs for Clinical Trials Involving Human Subjects).

August 28, 2012

Ms. Susan Strong
St. Joseph's Healthcare Hamilton
Centre for Mountain Health Services
Schizophrenia Services - E-223f

R.P. #10-3389

Project Title: Enabling the health literacy of clients: Clinicians' experiences and perspectives

Local Principal Investigator: Ms. Susan Strong

Amendment Request received: 20 August, 2012

Document approved:

Administrative Change - Delete Co-investigator Kevin Brazil and add Sheryl Boblin

Dear Ms. Strong:

A member of the Research Ethics Board Subcommittee has reviewed the Amendment Request for R.P. #10-3389 and approved it as submitted. You have approval of the amendment.

Please reference R.P. #10-3389 in any future correspondence.

Sincerely yours,

Raelene Rathbone, MB, BS, MD, PhD
Chairperson, Research Ethics Board

RR:ah