Nosheen Akhtar / Cheryl Forchuk / Katherine McKay
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Handbook of Person-Centered Mental Health Care

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Preface

According to the US National Institute of Mental Health (NIMH), in 2017, almost one in five (46.6 million) adults lived with a mental health challenge. Of concern is the fact that young adults between the ages of 18 and 25 years have the highest prevalence, among whom over one in four experience mental health challenges (NIMH, 2019). Mental health challenges are therefore in need of further discussion toward subsequent action. Service providers have a range of modalities, approaches, and treatments available to them, and this handbook explores a range of practical tools and strategies to address such challenges.

The purpose of this handbook is to provide a hands-on guide that discusses the *how* of person-centered approaches. It can be seen as an extension to Rudnick and Roe's 2011 book *Serious Mental Illness: Person-Centered Approaches* (Rudnick & Roe, 2011), in that it builds on theoretical material presented there, to provide practical examples across clinical care, research, education, and health care leadership. This handbook is intended for service users and service providers alike. Often books on person-centered approaches have mostly addressed theory and neglected to give enough detailed advice on practicing this approach. The authors of this present work have therefore endeavored to provide concrete examples, techniques, tools, and resources to assist service users and service providers to use on their own and/or in practice. There are a variety of approaches that put the service user at the center of care, and this handbook explores a number of these approaches.

The book is divided into six chapters: foundations, clinical care, research, education, health care leadership, and a conclusion chapter. This text looks to address the main areas of mental health care. Within each of these realms, practical person-centered strategies are illustrated using detailed case vignettes within diverse service user–service provider clinical relationships. The application of tools and resources are illuminated using the information from the case vignettes in each section for the reader to gain real-life insight into using the person-centered approach. The same tools and resources are also provided as blank handouts in the Appendix, which can be printed out for personal or clinical use.

The case examples included in the book do not report real cases or use the names of real persons, but they are based on the experiences of the authors in their clinical work.

The clinical care chapter (Chapter 2) is further divided into: clinical relationships, clinical communication, cultural care, family-centered care, co-occurring (concurrent) disorders, adolescents, dual diagnosis, forensic care, and older adults. These sections were chosen because they represent some of the most common areas for exploration in the therapeutic realm. These topics were discussed in Rudnick and Roe (2011) and this book will delve into them in greater detail.

The research chapter (Chapter 3) is divided into: research relationships, collaboration in research, planning and implementation of research, and research communication, as

these sections mirror person-centered approaches to these areas. The chapter starts with relationships as a basis and moves to collaboration as a concept that reflects a less hierarchical concept. Planning and implementing of research are traditional phases, and communication reflects the final phase of the research process so that others are aware of the results.

The education chapter (Chapter 4) is divided into: shared decision making, family education, education of health professionals, and public education. The rationale to include these sections is the vast nature of the topic area of education. When thinking about education pertaining to person-centered care (PCC), one can conceptualize the need to engage with those making the decision (the service user involved in shared decision making), the possible extended support systems that exist (e.g., family), those providing information for the service user to make decisions (most often service providers), and the broader population who require information to make informed decisions (e.g., the public).

The health care leadership chapter (Chapter 5) is divided into: person-centered leadership, becoming a reflective leader, developing and leading service user–centered teams, emotional intelligence, generative relationships, collaboration leading change, project methodology, change models, and system change. This chapter recognizes the present challenges to health care delivery and the need for a person-centered approach to much-needed health care transformation. The chapter leads the reader through a collaborative administrative process, providing a selection of tools that may be utilized to enable successful, strength-based aspirations and results.

Although much of the knowledge about person-centered mental health care addresses serious mental health challenges, it also applies more generally to all mental health challenges; this book addresses a wide range of mental health challenges.

The authors of this book have varied educational backgrounds as well as clinical and nonclinical experiences in health care. The information provided in this handbook draws on the experiences of what has contributed toward effective health care, research, education, and health care leadership.

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Contents

1 Foundations

Mental Health Challenges and the Person-Centered Approach

Mental health challenges (MHCs) may be defined in different ways. The National Survey on Drug Use and Health (NSDUH) defines an MHC as "a mental, behavioral, or emotional disorder (excluding developmental and substance use disorders)" that is diagnosed within the year, meets *Diagnostic and Statistical Manual of Mental Disorders,* 5th edition (DSM-5) criteria, impedes function, and restricts day-to-day activities (Substance Abuse and Mental Health Services Administration, 2015, p. 1). There are some who view mental health challenges as the suffering that comes from pain to one's self-worth or identity (Abramson, Metalsky, & Alloy, 1989; Beck, 1967). This may include diagnoses such as schizophrenia, major depressive disorder, bipolar affective disorder, obsessive-compulsive disorder, anxiety disorders (such as panic disorder), and others.

A person-centered approach (PCA) – also referred to as client-centered care (CCC) or person-centered care (PCC) – has been a relatively modern attitude in the provision of services and care. PCAs are widely used in the care of individuals with dementia (Mitchell & Agnelli, 2015). PCAs are also used to counsel individuals experiencing depression (Sanders & Hill, 2014). For almost 20 years, the UK has incorporated PCA into legislative policies along with best practice guidelines (Department of Health, 2001, 2005, 2006, 2009). In Rudnick & Roe (2011) PCA is discussed as a multidimensional construct (which includes the PCA process), person-focused (with the service user as the primary beneficiary), person-driven (the service user makes choices on the course of care actions), person-sensitive (specific to service user needs), and person-contextualized (past and present experiences are taken into consideration).

The fundamental characteristics of PCA that service providers embody in a clinical relationship include those of understanding, compassion, authenticity or a genuine nature, acceptance, and unconditional positive regard, as well as empowerment or the supporting of the autonomy of the service users in their own lives (Rogers, 1949, 1956). Service providers embody these characteristics as a way of being to create a safe space where service users can work through their challenges. This may require service providers to cultivate themselves in a way that aligns with these qualities. The service provider has a sense of connectedness to the service user as a human being. Compassion involves getting into another person's world regarding their experience, where the service provider becomes present to the associated thoughts and feelings of the service user. Of importance, compassion

2 A Person-Centered Approach to Clinical Care Related to Mental Health Challenges

Introduction

Clinical care is an integral part of what service providers do to facilitate the recovery of service users who experience mental health challenges (MHCs). This chapter on clinical care includes sections that address different aspects of care (clinical relationships, clinical communication, cultural care, and family-centered practice) and different populations with MHCs (including those with co-occurring disorders, adolescents, those with a dual diagnosis, the forensic population, and older adults) through a lens using a person-centered approach (PCA). This approach includes building rapport with the service user and family; assessing service user MHCs; providing education and promoting insight; actively listening to service user values, preferences, and experiences; developing and supporting the service user in reaching recovery goals; and partnering with service users to pick treatment option(s).

Each section opens with a clinical case that will be used to guide the reader through the different aspects of the section (whether that is about different aspects of care or a particular client group) and to illustrate the service user's and service provider's experiences. Then, there is an introduction to the area of focus. The clinical cases are developed throughout the chapter to demonstrate how theoretical principles, models, and frameworks apply in the clinical setting. Exercises completed by the service user of the given clinical case are included throughout the sections, to provide the reader with realistic applications of the tools that service providers can use when working with service users. Alternatively, service users may complete the exercises independently to apply the learned information to their own situations. The sections are designed to focus on the particular area of interest in a concise manner. Some exercises, although placed in a particular section, may be applicable to various contexts of care.

When Wally met Sabrina for the first time, she was not as reserved as he had imagined, and had a friendly nature. She told him that he could call her Sabrina, which was not what he expected. When Sabrina met Wally for the first time, she found him to have an outgoing personality, which she did not anticipate. He was presentable and had a sense of humor.

Regardless of the approach taken to build a clinical relationship, it is important to develop a relationship where service users are able to discuss their thoughts and feelings, gain new insights about their situation, trial new behaviors in a safe space, and maintain the

Table 2.1 Catching Our Own Assumptions: Sabrina's Notes on Her Preconceived Ideas About Wally Before Meeting Him.

Ask yourself – what preconceived ideas do I have about this person? This can be based on, or in relation to:	
Name	I associate the name Wally with someone older, maybe 60+.
Age	He is a millennial. This appears to be the first episode of psychosis and may be quite unsettling for him, his partner, and his family.
History	I wonder if there is a history of psychosis in the family.
Race/ethnicity	I assume he is of European descent, specifically German.
Mental health challenge and diagnosis	His symptoms are quite typical of psychosis.
Family	It seems like he has a strong support system that will help him through this experience.
Cognitive ability	He appears to have been high functioning before this episode based on his employment and his personal relationships.
Gender	Male, may be reluctant to share his feelings.
Religion	He may have been born Christian. He may practice the religion as he is getting married earlier than is typical in this society.
Culture	I would assume that he has adapted to American society.
Lifestyle	He seems to live independently and, until recently, has been able to participate in activities that he enjoys.
Vocation	He works as an engineer, where he is likely doing well financially.
My previous relationships (personal or professional)	None, although his name reminds me of my father's friend with the same name whom I saw on occasion — he was quite a character.
Other	He may be experiencing low mood given that he is not working and on stress leave; he may be lacking meaningful activities at this time.

3 A Person-Centered Approach to Research on Mental Health Challenges

Introduction

Research is an important foundation for providing effective patient- or client-centered care (PCC or CCC, respectively). It can help us understand strategies that are more likely to be helpful and those that are less likely to be helpful, and for whom. Research can also help us understand processes and experiences related to mental health challenges (MHCs) and effective care delivery.

Traditionally, research has been seen by some as a form of "expert opinion" that may appear counter to focusing on the needs and preferences of individuals, families, or communities. However, participatory approaches to research emphasize collaboration and equal distribution of power by engaging multiple stakeholders as equal partners. Each research partner brings their own expertise and experience to a collaborative research process.

The sections in this chapter cover:

- A discussion of research problems, including how they are identified and the integral role of understanding the research problem to develop the research plan.
- A section on research relationships, which includes discussion of the various partners in the research process, their roles, and how they can be supported. The concept of *participatory action research* (PAR) is explored in this section as a form of research that relies heavily on relationships. Participatory action research is a form of research that is particularly congruent with the concept of CCC.
- Collaborative research approaches, which discusses the bringing together of those with research expertise, lived experience including service users and their families, along with those who have a vested interest including community organizations supporting service users and others who will make valuable contributions to the research effort.
- A brief overview of issues related to planning and implementing research. There are entire books written on this topic; this discussion focuses on some pragmatics related to collaborative research approaches.

4 A Person-Centered Approach to Education on Mental Health Challenges

Introduction

Education is integral to every aspect of mental health care provision. Indeed, education is ubiquitous within any system of care. It extends beyond the didactic relationship, which is traditional in (modern Western) mental health care education. There are many parties to such education, including service users (still called *patients* by some), peer supports, front-line staff, physicians, students, and administrators, as well as family members of service users. In addition to the many individuals involved in education, there are also different types of educational activities that can occur within various educational systems. With the different permeations of individuals involved and various models of education, there are many types of such educational interactions.

This chapter addresses person-centered mental health care education. In it, we will look at how education occurs through a person-centered care (PCC) lens, pertaining to people who experience mental health challenges (MHCs). The sections in this chapter will focus on key areas including service user education, family member education, health professional education (at multiple levels such as undergraduate, graduate, and continuing education), and public education. We will do this by approaching the specific areas where educational experiences occur and providing an example for each, highlighting key principles, and suggesting exercises in relation to considering these principles. These examples are provided to assist with understanding the guiding principles, as well as to provide a tool with which to engage individuals at various levels of education.

John was a 25-year-old man who was recently discharged from an inpatient hospital stay lasting 30 days. During that hospitalization he had been diagnosed with bipolar disorder, type I, and had experienced a manic episode with psychosis.

He presented to his follow-up two weeks post discharge from hospital wanting to speak about his medications. He had been discharged on lithium and risperidone. He recalled having had many discussions with the inpatient team about possible medication adverse effects. He has been feeling much better and wants to discuss training for a triathlon, as he has always been an active person and had competed in such events previously.

Box 4.4 Shared Decision Making: Questions to Inform an (Adapted) Wellness Recovery Action Plan

Some questions to consider when developing a wellness recovery action plan (WRAP) may include:

- What are you like when you are well?
- What strategies help you stay well?
- What are signs of the mental health challenge you face?
- What can we do about those signs indicating a crisis or challenge?
- How can we use a crisis plan?
- How do I engage in a WRAP?

For John, when he is well, he is active, determined, and ambitious and acts as an external source of motivation for others. He maintains a busy schedule, which he enjoys. Strategies that help him to stay well are physical exercise, which also helps with mental centering; staying connected with friends and family; and satiating his sense of curiosity by going to new places, trying new activities, events, and cuisines. A sign that he is unwell is that, just like when he is well, he has many ideas. When he is unwell, he acts on these ideas without forming a plan. He shows impulsivity and disregards other people's opinions, which is out of character for him. If these signs occur, they are indicators to himself and to his family that something needs to be done – such as to discuss any life stressors, reevaluate medication or otherwise. Attending the hospital is warranted as a safety measure if needed.

Family Education

John, who is discussed in the previous section, lives at home with his mother and 19-year-old brother. His mother works as an office manager and his brother is in college. John has been attending university but deferred his semester when he experienced his first manic episode.

John's family is worried, as he was very ill when he went into hospital. John had not slept and was speaking about starting three new businesses and had spent about $2,000 worth of his savings, allocated for schooling, in order to purchase supplies to pursue these endeavors. His mother heard him singing and talking to himself in his room, mostly about these business ideas, none of which really made sense to her. She does not really know how to explain John's MHC to the rest of the family and does not know how to approach the topic with John's dad, who lives in another state. She is not sure what bipolar disorder is. She knows John is now on medication, but she was not present for many of the discussions about what the medications do or how long John may be prescribed these medications. She is quite worried about John and wonders if he will experience challenges with his mental health again.

5 A Person-Centered Approach to Mental Health Care Leadership

A vision without a plan is just a dream.
A plan without a vision is just drudgery.
But a vision with a plan can change the world.

Old Proverb

Introduction

Defining Shared Health Care Leadership

There are enormous challenges to health care delivery at the present time. These challenges are evident at almost every transition point in our existing continuum of care. Difficulties in access to primary care, and for mental health, the availability of a platform of early intervention and community crisis services, have resulted in defaulting to inappropriate use of hospital emergency services. There is a consequent overcrowding and long waits in emergency rooms, lengthy waits for medical and surgical beds and procedures, and especially relevant to this chapter, a lack of timely access to mental health care. Often referred to as "hallway care," this has reached crisis proportions for health care funders, hospital administrators, health care providers, and our patients and families, as health care service users. Access challenges are compounded by obstacles to the flow from acute care and specialized care beds into step-down community services and long-term care facilities when needed. These challenges are further compounded by escalating health care costs coupled with necessary budgetary restraints and an aging demographic, which has increasing physical and mental health needs.

Physicians, other health care providers, and their administrative partners, as well as service users and their informal caregivers, are assets to a vision of a high-quality health care system more generally, and specifically in the delivery of excellent person-centered mental health care. In particular, they are responsible for administratively contributing to this vision as they combine their leader role with their other activities as clinicians, scholars,

John and Sally also engage champions – at least one or more in every hospital wing, among both service providers and management. This allows those who have questions to ask a peer or manager with whom they are familiar. It also builds momentum among hospital staff so that most service providers see the changes as effective, and even necessary. Further, suggestion boxes are in place to collect anonymous feedback. Service users are also encouraged to voice any proposed solutions to challenges they experience to their service provider or using an anonymous suggestion box. John and Sally make themselves available to answer any questions in person, by telephone or via e-mail.

During the change process, new wellness carts circulate around the hospital every month for staff. These carts consist of wellness items such as aromatic soaps, lotions, beverage mugs, teas, and other items that staff can use in or outside of work. Free massages by a registered massage therapist are also offered to staff by appointment, on-site. This is also an opportunity to ensure that the physical environment is optimal for both hospital staff and service users. Ergonomic challenges – for example, with desks, seating, and computer monitors – are addressed, and televisions are added to a number of the waiting rooms for service users. These changes are well-received by those involved and support the transition amid the larger changes in the hospital.

Optimizing Engagement in the Project

Isaacs (1999) proposed a four-player model which broadly assigns group membership. The innovators are the early adopters of change, who are referred to as the *movers*. The second group are the *followers*. They are the opinion leaders (they readily follow the innovators in the change process and thus become the opinion leaders) who will be valuable in implementation. Then there are the *bystanders* who bring an invaluable reflective perspective and act as a sounding board that is very influential. Finally, there are the *opposers* who resist change and are challengers to the process. The last is the most difficult group to engage and can be the naysayers and saboteurs of the project. This model is visually represented in Figure 5.2.

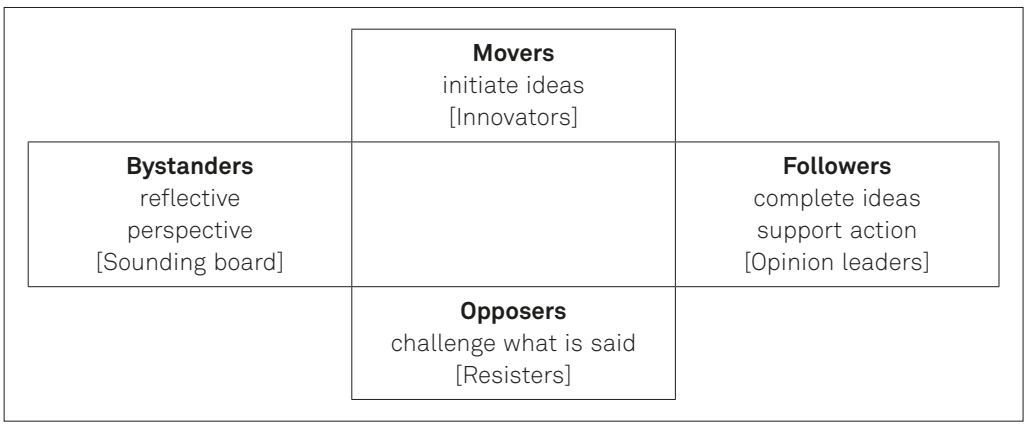

Figure 5.2 Four-player model. Adapted from Isaacs, 1999.

6 Conclusion

This handbook has explored person-centered approaches for those who experience mental health challenges (MHCs) in the realms of clinical care, research, education, and health care leadership. MHCs may include disorders which affect mental, behavioral, and emotional states, as well as one's ability to fully participate in day-to-day activities (Substance Abuse and Mental Health Services Administration, 2015). The person-centered approach is an effective means through which services and care may be provided. It is a multidimensional construct and is person-focused, person-driven, person-sensitive, and person-contextualized (Rudnick & Roe, 2011).

For each of these realms, there are a few key points that may be applied:

Clinical Care

- Service provider attitudes that are in line with person-centered approaches include compassion, genuineness, the ability to empower the service user, and unconditional positive regard
- Person-centered care in clinical care may involve, but is not limited to:
  - rapport building with the service user
  - assessment of the service user's MHCs, barriers, and goals
  - educating the service user, along with their informal supports as applicable
  - considering the service user's values, preferences, and experiences
  - supporting service users in their goals toward recovery
  - collaborating to select and implement care to meet service users' needs

Research

- Research is an important foundation for providing effective person-centered care that can elucidate the strategies that are more likely to be helpful and those less likely to be helpful, and for whom
- Research can aid in understanding the processes and experiences related to MHCs and effective care delivery

Appendix: Tools and Resources

Subject Index