Implementing Person-centered Care in Psychiatric Rehabilitation: What Does This Involve?

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Abstract: Background: It has been challenging to move beyond the rhetoric of “recovery” and “person-centered care” to concrete practices that embody these lofty, if also obvious, values. Method: This paper describes two examples of person-centered care: the practices of person-centered care planning from the U.S. and Open Dialogue from Finland. Results: The key strategies that these two practices involve are 1) reorientation from patient to personhood; 2) reorientation of what is considered valued knowledge and expertise, and; 3) partnership and negotiation in decision-making. Limitations: This review focused on two examples of person-centered care which appear to be promising. Preliminary findings will need to be replicated and elaborated for such practices to be considered evidence-based. Conclusion: It is possible to embody the values of person-centered care and recovery in everyday clinical and rehabilitative practice. A primary shift involved is in the role of patients and their family, friends, and peers and in the importance accorded their everyday life experiences and challenges.

Concepts like person-centered care, recovery-oriented services, and user involvement all sound at first to be obvious and self-evident. When broached about these topics, many practitioners will therefore say that they “do this already”; i.e., that their practices already embody these values and concepts (1). Yet we, and others, who have accepted these ideas as challenges have found it extremely difficult to implement them in practice. As clinicians working in mental health settings for many years, we have found ourselves caught in between two competing realities. On the one hand, our work places inevitably have humanistic and holistic-sounding vision statements that include valuing the whole person, focusing on the person rather than the illness, ensuring freedom of choice, and offering people opportunities to pursue their dreams and live their lives as valued members of their communities. On the other hand, however, we have no concrete procedures or treatment approaches that embody or operationalize these values. There is nothing we can point to specifically which demonstrates just how our practice does value the whole person or how we focus on the person rather than the illness, etc. Even those practitioners who have clear visions of what such care might involve are faced with administrative demands for efficiency and productivity that do not seem to allow the time needed for consideration of the whole person or for entertaining various options as suggested in our mission statements.

Although the empowerment of service users and the need for partnerships between users and practitioners have been prominent themes in mental health policy in most Western countries for the past decade, we suggest that there remains a gap between this rhetoric and what continues to be happening in the field. First person accounts continue to suggest that the voices of service users are still not elicited or listened to, their knowledge is generally not recognised as valuable, and what they say to practitioners may well be interpreted within a diagnostic framework as a symptom of their illness rather than as a genuine exchange of crucial information. How, then, might user involvement and person-centered care actually look different from
current approaches? In the following we would like to take one step toward answering this timely and critical question. First we will review what we have learned from participants in narrative studies of recovery (2–4) and from the broader research literature (5) concerning the justifications for and ingredients of person-centered care. Then we will describe two particularly promising approaches that appear to have moved their respective systems of care one or two steps forward in this direction. The first example is that of person-centered care planning introduced in Connecticut, U.S.A., and the second is that of Open Dialogue introduced as the treatment philosophy in Finland. We conclude by distilling from these examples three of the major shifts that appear to occur in the transformation to recovery-oriented care.

What Have We Learned Thus Far From Service Users?

As we noted above, people with serious mental illnesses continue to describe negative and dehumanizing experiences with mental health services. They describe instances of being treated as disorders or diagnoses rather than as unique individuals, as being viewed only in terms of their problems, symptoms and deficits rather than as having strengths and areas of competence, and as primarily confined within the role of mental patient inhabiting artificial mental health settings as opposed to being seen as a citizen of the broader community. As one aspect of this role, they describe being extracted from the context of their daily lives and viewed largely in terms of their compliance or cooperation with treatment rather than as the protagonist of their own life story (4).

In addition to their critiques of current care, first-person accounts draw attention to everyday life situations and how mental illness affects people’s lives in the “real world” beyond the boundaries of mental health services. In contrast to the abstract concepts and illness-related concerns that dominate professional knowledge, people with serious mental illnesses talk about work, education, God, beloved pets, and friends and lovers as much as, if not more than, their mental distress. More importantly perhaps, what they define as helpful to them in their struggles with mental illness typically differs from what one might expect from evidence-based guidelines or treatment algorithms. In addition to the quality of the interpersonal relationships they may have with practitioners – which remains paramount in their narratives in both positive and negative terms – people describe what is helpful to them in highly specific and individualized terms. And in contrast to the thrust of manual-driven treatments, they value practitioners who allow them to take the lead, set the agenda, and focus on the areas where they feel they need help. These areas quite frequently encompass everyday life concerns encountered in loving, learning, playing and belonging and are distinct from the conventional focus of treatment on issues like medication, symptoms and coping with illness. As one woman in one of our studies said: “Nobody ever asks me how my day is going or what I’m doing anymore. They’re only interested in whether or not the medication is working.” Nina, another woman in one of our studies, described what she valued about her current practitioner in the following way:

I found him so balanced in a way...he didn’t have all kinds of programs of his own we had to go through. I could talk about anything... everyday life things that were important to me, not necessarily problems...I was the one who decided what to talk about.

User experience and knowledge are rich in what we may otherwise consider to be the trivialities of everyday life; activities and things we ordinarily take for granted (6). The systematic investigation of user experiences through qualitative research represents an important vehicle for beginning to draw our collective attention to and to value this aspect of the lives of individuals with serious mental illnesses. While the customary view of serious mental illness within medical settings may have been that of a chronic debilitating disease resulting inevitably in a poor outcome, the realm of everyday life appears to be the stage for recovery (7). It is here where people appear to figure out how to manage their illness and get on with their lives. In this regard, qualitative studies have generated a few insights about how recovery evolves over time within the
Recovery refers to what the person with the mental illness needs to do to manage the illness and pursue his or her life; recovery-oriented care, in contrast, is what practitioners offer in support of the person’s own efforts (5).

Recovery is not about cure or necessarily about symptom relief, but rather about learning to live with and finding ways of overcoming barriers including but not limited to those posed by the illness itself (e.g., stigma, discrimination) (8).

Recovery is considered a dynamic and social process, incorporating individual as well as environmental perspectives and the dynamic inter-relationships between the two (9).

Recovery comes as much from identifying and building on strengths as it does from resolving problems (10).

As we noted above, while this concept of recovery, along with the notions of person-centered care and service-user involvement, have been emerging as influential visions of what mental health services should look like over the past decade and around the world (11), there remain few examples of new approaches that explicitly build on or incorporate these new concepts. Instead, there have been many efforts to subsume these concepts under established ways of doing business, with the eventual result being to transform recovery and its associated concepts into being nothing more than old wine in new bottles (8).

In the following, we hope to counterbalance these efforts to subsume recovery into the status quo by describing two new approaches to care planning and delivery that have shown initial promise of being both oriented to promoting recovery and explicitly encouraging an active role for the service user in determining the direction of his or her own life and the ways in which mental health services can assist him or her in the process of pursuing that life. As these remain in the early stages of implementation and evaluation, it will require additional empirical research to determine the effectiveness of these approaches in accomplishing those goals.

**From Patient to Person-centered Care**

Patient-centered care has become an increasingly important concept in American and European medicine and health care over the past several decades (10, 12, 13). In different health care contexts it has been described variously as “self-determined services” (14), “culturally-responsive interventions” (15), and “consumer-directed treatment” (16). Despite the proliferation of the concept, inconsistencies remain in the degree to which the principles of patient-centered care have been translated into actual clinical practices that customize care based on individual person’s needs, values and preferences (17). Mental health care in particular has traditionally assumed that patients cannot always determine what is in their own best interest due to the interference of their illness, thereby requiring practitioners to take a more directive role. Practices based on such provider-centered models run counter to the principles of patient-centered medicine, however, which is defined as: “The provision of individualized health care that is closely congruent with, and responsive to, patients’ wants, needs, and preferences” (18).

Different models have been developed for implementing person-centered care across multiple healthcare contexts. Some of the earliest and most prominent of these models were developed in the early 1980s by human service professionals committed to improving living conditions and enhancing community membership among individuals with developmental disabilities (19). These models, known as lifestyle planning (20), whole-life planning (21), the McGill Action Planning System (22), and personal futures planning (23), have been brought together under the term “person-centered planning” (24). Although each approach is somewhat unique, all share certain fundamental components, including: 1) primary direction in the planning process coming from the individual; 2) involvement of significant others and reliance on personal relationships as the primary source of support; 3) focus on capacities and assets rather than on limitations and deficits; 4) emphasis on promoting access to integrated community settings rather than settings designed for people with disabilities; and 5) acceptance of uncertainty, setbacks
and disagreements as natural elements in the path to self-determination (25). In all of these ways and more, person-centered care planning therefore reflects the fundamental values and principles of recovery-oriented care as we defined above.

Person-centered planning generally involves an ongoing series of meetings that bring together a person with a disability or health problem with his/her “circle of support” (26, 27) to reconstruct the person’s history, identify his/her gifts, preferences, and needs, discover a vision for a desirable future, and develop an action plan to achieve that vision (25). These meetings typically are organized and conducted by a “facilitative advocate” (24) whose responsibility is to support the individual in articulating his/her aspirations, hopes, and dreams and to ensure that these are not subverted by demands or doubts imposed by members of his or her circle, including professional helpers and significant others. The ultimate objective of the person-centered planning process is to assist individuals with disabilities in creating a better life – not just for themselves, but also for the people with whom they interact and the local communities in which they live (10, 12–29).

The State of Connecticut is currently in the process of implementing this approach to care planning for all adults with mental illnesses in its publicly-funded state-wide system of mental health care as part of a broader system “transformation” initiative, described elsewhere (5). In addition to training people in recovery to serve as facilitative advocates, an automated interactive software program has been developed which can be used to replace traditional treatment or service planning documents with what is now called “individualized recovery planning.” Rather than focusing narrowly on the person’s presenting complaint, symptom profile and illness history, the structure of person-centered planning processes is organized around a core set of questions that the facilitator uses to collect information to create a holistic picture of the person beyond his or her identity as a person with a mental illness. Typical inquiries include: What is the person’s history? What is your dream for the person? What is your nightmare? What are the person’s strengths, gifts and abilities? What does the person need to overcome the limitations of his or her illness? What would the person’s ideal day look like, and what must be done to make it happen? While these represent typical questions that might drive a person-centered planning meeting, such meetings are, by definition, subject to modification in structure, process and content based upon an individual’s particular preferences, values and needs.

In addition to the automated recovery planning template, facilitative advocates are trained in the use of a number of tools to help individuals identify their strengths and interests, identify those persons in their lives who could be supportive of their recovery and the various roles they could play (e.g., provide transportation, facilitate someone’s entry to a faith community, etc.), and break their longer term goals down into shorter term, feasible and accomplishable goals. As one research participant described:

“So I take it step by step. I have learned to hurry slowly and do it in stages and set partial goals when I have discovered that it makes sense… doing it by partial goals and making it manageable, then you get positive feedback that it’s going okay and then you don’t hit the wall. That’s my strategy, the strategy for success: partial goals and sensible goals and attainable goals, and that’s something I’ve learned to do in order to achieve things. When I have been able to deal with something that’s been a struggle and feel secure, I move on. Step by step, put things behind me.”

In order to be prepared for this work, facilitative advocates are also trained in motivational interventions, active and empathic listening skills, community-based asset mapping and advocacy, including the development of psychiatric advance directives.

Preliminary findings from a randomized controlled trial of person-centered care planning introduced as an augmentation of illness management and recovery training for 300 adults of African and/or Hispanic origin with psychosis are promising. Specifically, with the addition of peer facilitation of care planning, participants reported increases in their sense of the responsiveness of mental health care and the degree to which extra-treatment issues, such as employment, spirituality, social and
recreational activities, were included in the care planning process. This intervention also appeared to increase participants’ sense of control in their lives and their ability to impact change and was associated with a decrease in their sense of satisfaction with their work status, possibly due to their identifying employment as a goal but then being offered little to no assistance in getting a job. Present and future research have begun to examine the role of peers as facilitating community inclusion as well as the care planning process, so that participants will be assisted not only in identifying their hopes, dreams and aspirations, but in actively pursuing those as well. More details regarding this initial study are forthcoming (30).

**Open Dialogue as Philosophy and Practice**

The Open Dialogue approach is another example of service change focusing on person-centered care and social context. It has developed since the early 1980s in Finnish Western Lapland within the framework of the Turku project and Finnish National Schizophrenia Project (31, 32). The program represents a new comprehensive model of organizing mental health services in a geographic area for people experiencing psychosis, as well as the implementation of clinical methods emphasizing close collaboration with the person, the family and the social network (33–36). The inpatient unit in the catchment area has 30 acute-care beds, and in addition there are five mental health outpatient clinics. Both in- and outpatient clinics have mobile teams that make clinical staff accessible based on the specific needs of a given patient. At this point, about 100 members of the inpatient and outpatient staff have participated in a three-year training in family therapy education conducted as on-the-job training in cooperation with the University of Jyväskylä (37–39).

Central to the philosophy of Open Dialogue is developing helpful relationships among the person experiencing the problems, the family and the network involved, and offering support in the person’s home rather than in institutions or rehabilitation sites. The skills most valued in practitioners are those involved in the capacity to generate dialogues in joint meetings, keeping the communication open between parties, respecting the voices of all participants, being patient and not make hasty decisions, and constantly emphasizing the family situation and everyday life issues. Responsibility for the entire treatment and rehabilitation process, from crisis meetings to ongoing support, rests on the same team in both in- and outpatient settings. For further reading about the model, see (35, 37, 39).

There are three principles of communication that are central to Open Dialogue: the tolerance of uncertainty, polyphony in social network and continuity of care (36). *Tolerance of uncertainty* involves appreciating the need to listen to what the people involved are worried about and have to say without immediately disposing of this material by interpreting it according to preconceived categories. It encourages dwelling on issues, considering what is going on from a variety of perspectives, and trying to avoid coming to conclusions or resolutions too early. The service user and his/her family are invited to frequent meetings in which the participants focus on finding words and ways of understanding the crisis situation or the problems that exist. Everyday issues like how psychotic experiences and crises affect school, work, hobbies, friendships, the family situation and various activities are typical. Meetings can be held as frequently as daily, if that helps the person and/or the family to feel safe. Finding words to describe psychotic experiences can be difficult and some of the experiences and behaviors involved may also have been frightening for the persons involved. The opportunity for people to talk things through with trusted others in a safe environment, and to develop ways of communicating their psychotic experiences as well as the context of their problems, releases some of the pressure of the situation and helps the person as well as the family to carry on with their daily lives (35, 37, 38).

Practitioners faced with distressing experiences and other crises often feel compelled to do something. As a part of the emphasis on the tolerance of uncertainty, participants are trained instead to keep the dialogue open until solutions emerge from the participants themselves. Traditional interventions like giving immediate advice, providing answers and drawing conclusions are discouraged. Practitioners are encouraged to enter the meeting
without any predefined view of the problems and with a hope and trust that the dialogue itself will bring forward new ideas and helpful stories (39, 40). The problematic situation is framed as an opportunity to make and remake stories, identities, relationships, and the social world they comprise. The idea of careful and active listening is very important and given more priority than interviewing, assessing or planning. The emphasis is on keeping the questions as open as possible in order to make it safe to raise any issue that feels most urgent and relevant for those involved. The dialogues in these network meetings require participants to create a shared language that attends both to what the persons say and to the emotions and intense responses that move between them. This dialogical opening offers the participants an opportunity to create a language of suffering and as such give their suffering and despair a voice (39, 40).

*Polyphony* means “music with two or more independent melodic parts sounded together” (41). In the Open Dialogue model it refers to a team approach in which the center of attention is distributed across the experiences and perspectives of everyone involved in the situation as opposed to focusing solely on the individual experiencing difficulties (40). Each person contributes to the conversation in his or her own way, and an important rule is that everyone present has the right to make comments (39). Questions or reflections from the participants are a natural part of the polyphony; however, caution must be taken to avoid interrupting ongoing dialogues. The shift between listening and talking gives the service user and his/her family new opportunities to renegotiate their understandings and preferences. The hope is that the differences will give all voices attention and encourage a respectful exchange of views, rather than polarized right-or-wrong statements. The objective is to create a context of recognition and acceptance in which all kinds of issues can be discussed in the presence of the service user and the family (40).

The principle of *continuity of care* is by no means a novelty in rehabilitation and mental health care, but it is a principle that is difficult to implement in many places due to a fragmentation in services, a variety of practitioners, and emphasis on specialized services organized by diagnostic or functional criteria. In Western Lapland some strategic choices were made in order to ensure continuity. Both in- and outpatient clinics have Open Dialogue as their philosophy of practice, and in every unit person-centered and family-based mobile teams are available when needed. Most of the practitioners are also trained in systemic family therapy, as described above. In the Open Dialogue model diagnosis is not given any specific organizational attention and the same procedure is followed in all situations (36). If inpatient treatment for a new service user is considered necessary, a person-centered team is established either before the decision to admit for voluntary admission or the first day after a compulsory admission or as a part of the home treatment. The team takes responsibility for the entire treatment process, regardless of whether the individual stays at home or in the hospital, and regardless of how long the need for help and support is expected to last.

In order to ensure continuity of care within this service context the following values have been articulated and implemented: 1) provision of immediate help and a first meeting to be held within 24 hours of the first contact; 2) a social network perspective in which the service user, family, friends and others are invited to network meetings; 3) flexibility and mobility in terms of where the meetings are held, including in the family home or wherever it is most convenient; 4) ongoing responsibility of the team which made the first contact with a person or family in need of help; 5) tolerance of uncertainty and avoiding premature conclusions or decisions about treatment and rehabilitation; and 6) dialogue, emphasizing open communication among everyone involved. Finnish Western Lapland follow-up studies focusing particularly on first episodes of psychosis have shown that within a period of five years 82% of participants did not have any residual psychotic symptoms and 86% had returned to their studies or a full-time job. Only 14% of participants were on disability allowance, and only 17% had relapsed during the first two years and 19% during the next three years. Only 29% had used neuroleptic medication in some phase of the treatment (35–40).

In these studies, Seikkulla and colleagues stressed the importance of a first meeting with
the patient and his/her closest social network as quickly as possible after the onset of psychotic signs or symptoms. The strangeness of the psychotic stories told by the individual appears to decrease and be less frightening when there is a joint effort to understand both the content of the symptoms and the whole context of the problem from the very start (39, 40).

Discussion

There are some obvious areas of overlap between the two examples described above. When considered in light of the existing literature on person-centered care, we suggest that there are at least three critical steps involved in implementing person-centered practice in rehabilitation settings: 1) reorientation from patient to personhood; 2) reorientation of valued knowledge and expertise; and, 3) partnership and negotiations in decision-making. We will describe each of these briefly below as initial steps that systems can take in their efforts to operationalize recovery in practice.

From patient to personhood

In order to see the patient as a person practitioners go beyond diagnostic criteria and functional checklists and initiate each new relationship by getting to know the person and his/her environment. Practitioners are encouraged to be curious about the person, to ask new questions, and to emphasize keeping the dialogue going rather than on settling prematurely on immediate solutions or plans. Being person-centered involves taking into account each individual's unique values and preferences, respecting the centrality of freedom, choice and responsibility to being fully human; and appreciating the significance of reciprocity in relationships (4, 12). As experienced both in the United States and in Finland, being person-centered also involves attending to the person's social context, including family, friends, significant others and peers. An interesting finding in Connecticut was how peer facilitation of care-planning seemed to increase the service users' sense of the responsiveness of mental health care and to lead to the inclusion in care planning of such topics as employment, social and recreational activities. This is consistent with reports from service users which suggest that receiving health care and being together with ordinary, “normal” people in ordinary settings is preferred to receiving services in segregated places (2). Being part of the general life stream and being confronted with the expectations of others was experienced as a sign of respect and hope.

In moving our attention from patient to personhood, we discover that the contextual situation may be of help to or may hinder the person. Seeing the person in his/her natural context with family and social network, in the home or a familiar community setting is likely to bring forth the personal and social resources and competences that are available as well as to increase understanding of the distress and problems within a larger framework. This expansive helping context which includes family, social network and peers allows a broader perspective on the present situation as well as the emergence of more solutions in which the various parties may become involved.

Reorientation of valued knowledge and skills

User knowledge has traditionally not ranked very high on the evidence hierarchy of psychiatric knowledge. A main thrust of the user movement has been to elevate the status of this knowledge, based largely on experience, to be considered its own kind of evidence and a form of evidence which is given considerable weight in decision-making within mental health. Rather than describing user experience as “merely subjective” in comparison to an objectivist ideal of “truth” (determined through rigorous empirical/experimental methods), the user movement has argued that experience has its own validity and constitutes its own form of truth; knowledge, as Foucault (42, 43) suggested, is context-determined, value-dependent, and inextricably intertwined with relations of power. According to Foucault, ideas and understandings are historically, culturally and socially specific and serve a variety of functions for any given society. Some concepts serve such important purposes and become so widely accepted and entrenched within a society and worldview that they come to be taken as absolutely and universally true. This perspective on power and knowledge suggests that in the fields of specialized or technical knowledge, our
actions are already governed by the constituents of the power structures themselves (11, 43). In mental health, this has had the form of defining truth as what is generated by medical/psychiatric knowledge, thus allowing practitioners to retain power and control.

The recent introduction of evidence-based medicine might appear to simply be a more explicit version of this hierarchy of power/knowledge in mental health. The principles, as opposed perhaps to the practice, of evidence-based medicine, however, leave ample room for user input and choice, respecting the central role the person's own needs, preferences, values and autonomy play in the process of health care decision-making (44). When this principle is overlooked in practice, a narrow emphasis on evidence proves to be problematic as long as there remains a power imbalance between empirical science and other forms of knowledge acquisition. As currently practised, the evidence-based hierarchy places user knowledge on the bottom rung of the knowledge ladder (45). Person-centered care challenges this hierarchy and suggests that the knowledge, skills and competencies of the service user her/himself, family members, significant others and peers are appreciated as being at least equally as important as the traditional professional knowledge base. Does this mean that professional knowledge is devalued or dismissed entirely? No, that is of course not the case, but we do believe that more humility and more critical professional self-evaluation is called for given how little we actually “know” about mental illness through scientific methods alone.

Partnership and negotiations in decision-making
In mental health services where cost efficiency, standard procedures of assessment and evaluation, professional authority and instrumental planning structures have been stressed, concepts like “tolerance of uncertainty,” relational competence, or the important role of peers may seem rather odd and out of place. However, research appears to be showing that these practices produce good results. Finland has seen a reduction in hospital admissions and use of psychotropic medication since the introduction of Open Dialogue. This approach also appears to have led to an increase in the number of people returning to work and a corresponding decrease in the number seeking invalidity pension (39). Connecticut has found that having trained peers act as advocates in person-centered care planning increased participants’ sense of the responsiveness of mental health care and led to the inclusion in care planning of vital everyday life activities such as employment, spirituality, socialization and leisure.

In rehabilitation, a variety of life domains may be looked into, but often the emphasis has been on functioning, coping with deficits and adjusting to the new situation of having a psychiatric disability or handicap. As we see it, a paradigm shift is needed in order for citizens with serious mental illnesses to come into the position of being at the steering wheel in their own lives and being real partners in negotiation and shared decision-making in their care. Mental health problems can be seen and met as an integral part of people’s lives as opposed to an isolated brain disease or functional deficit. This shift entails appreciation of the so-called “trivialities” of everyday life. Much of everyday life is so taken-for-granted that it risks becoming invisible, yet it is these small bits of life that are often of critical importance in an individual’s recovery process (7, 11). Patience, avoiding hasty decisions, valuing many voices and perspectives, focusing on capacities and assets and on what a person’s perfect day would look like, and appreciating disagreements are components highlighted in person-centered practices. Nina, quoted above, described a helpful helper as someone who didn’t have all kinds of programs of his/her own that she had to go through, who would listen to her and follow her lead, who appreciated the importance of everyday life, and who understood that she was in the position to make her own decisions. This is valuable guidance for practitioners wishing to become more person-centered in their approach.

Conclusion
In the end, person-centered care for people with serious mental illnesses is no different from how we all would like to be met, treated, understood and helped. This is as it should be, given that individuals
with serious mental illnesses are at bottom no different from anyone else as well. But recognizing individuals with serious mental illnesses as fellow human beings with citizenship rights will require an approach in which each person’s basic humanity and everyday life are acknowledged as primary and of central importance within a helping relationship. In treatment and rehabilitation, practitioners will do well to pay more attention to these trivialities of everyday life, as well as to the individual’s own and his/her social network’s expertise in managing various life situations, if the promise of recovery is to be made real and enduring.

References


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