
The Relational Context of Mental Health for Carers: A Qualitative Study

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Carers, Family, Mental Health, Recovery, Qualitative Research, Interviews

Abstract

The aim of this study was to explore how carers view and describe positive mental health. We interviewed 11 persons with lived experiences of caring for a close relative with a severe mental illness. A thematic analysis of the transcribed data material resulted in the following three themes: 1) Mental health as a relational phenomenon; 2) Dealing with excruciating hopelessness; and 3) Coping strategies for the carer. We discuss our results in relation to existing theory and suggest some clinical implications that follow from study findings.

Introduction

Severe mental illness (SMI) constitutes a significant burden of disease worldwide, with regard to years lived with disability and need for treatment¹. Access to treatment and care for people with SMI varies^{1,2}, and in addition to help from professionals in health care services, many of those with SMI will receive informal care from their relatives or friends. One European study found that carers spend on average 6-9 hours per day providing informal care for adults with SMI³, and findings from another study showed that 43% of carers spent more than 32 hours per week⁴. This is in line with what is found in the caregiving literature in general⁵. In Norway, a context characterized by high access to well-developed health care services, informal carers

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were also found to be heavily involved in the lives of their relatives' with SMI⁶. Informal care is considered an important contribution to recovery for persons with SMI, and it has been suggested that informal carers might even be more important to recovery than formal treatment, such as that provided by health care personnel^{7,8}.

Although caring for a relative with SMI can have many positive qualities, evidence also shows that those caring for someone with SMI have increased risk for experiencing several practical and emotional problems⁹. Among issues previously reported by carers are exhausting everyday lives in which they struggle with balancing their own needs with those of their relative, worries about their relative's future, feeling that they are living their lives on someone else's premises, and experiencing uncertainty while waiting for help from specialist health care services¹⁰. Weimand⁸ suggests that experiences of informal carers include ill health and carrying a burden. Furthermore, she notes that carers may wish to contribute, and to be included, in the care provided to their relatives, but often feel left out, and may even experience their encounters with professional health care providers as negative⁸.

The lives of carers and their relatives with SMI are closely intertwined. One longitudinal study of people with psychosis and their carers showed that levels of grief, carers' satisfaction with their own mental health, and carers' social connectedness were at least partially accounted for by their relatives' quality of functioning¹¹. To our knowledge, only a few systematic reviews and meta-analyses investigating effects of interventions for carers or relatives of persons with SMI have been published¹²⁻¹⁴. These studies indicate that family interventions and involvement of carers in the treatment of people with severe mental illnesses may contribute to enhanced clinical outcomes¹² as well to improve the carers' satisfaction with the health care services and their quality of life¹⁴. This has led Yesufu-Udechuku et al.¹⁴ to suggest that carer-focused interventions should be developed as an integral part of services provided to people with SMI. In order to tailor interventions that meet both the needs of people with a mental illness and their family carers, more knowledge is called for in order to understand what constitutes helpful treatment from carers' point of view.

There is limited experiential knowledge on the perspectives of carers of people with SMI. An interview study by Askey et al.¹⁵ that included professionals, service users and carers on the needs of relatives of people with psychosis, found that carers had difficulties believing that the service users' basic needs were being met in the mental health services and that a high level of distress and anger towards these services increased their own burden and suffering. Another interview study by Cree et al.¹⁶ similarly found that many carers experience a lack of involvement in care planning and that recognition of their role and input from professionals were scarce. These studies underscore the disempowerment that family members may experience in the face of the mental health system. Such knowledge needs, however, to be integrated with exploratory studies on carers' perspectives on what constitutes positive mental health. Davidson et al.¹⁷ describe recovery as "a process of restoring a meaningful sense of belonging to one's community and positive sense of identity apart from one's condition while rebuilding a life despite or within the limitations imposed by that condition" (p.25). This added focus on positive mental health instead of addressing only illnesses and deficits also corresponds with developments within the movement

of positive psychology¹⁸. Both provide an important framework for exploring what a good life means in a mental health context. In this study we aim to contribute to this by examining the following research questions: What are the lived experiences of carers of people with SMI? And what supports recovery and positive mental health for carers?

Methods

To explore carers' experiences of wellbeing and positive mental health, we designed a qualitative study based on a hermeneutical-phenomenological epistemology with individual interviews and thematic analysis as the practical method for collecting and analyzing data. The phenomenological quality in our approach is reflected in the exploratory and experiential focus¹⁹, and the hermeneutical viewpoint lies in recognizing that our understanding of experiences inevitably will be informed by our own preconceptions, assumptions and basic interpretations of the world²⁰.

Recruitment and Data Collection

As part of preparing this investigation, we developed a semi-structured interview guide²¹ to facilitate the exploratory focus of the study.

Table 1. Examples From Interview Guide

What is it like for you to care for someone with a severe mental illness? What does wellbeing mean to you? What has hindered positive mental health in your life? What has contributed to positive mental health in your life? If you were given the opportunity to build mental health services, what would you do to tailor them to the needs of carers? What would be different compared to how it is today? What would be the same?
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The first author conducted a pilot interview with a participant with significant experiences of living with a family member with an SMI to test the interview guide. As this interview was considered rich in information, it was transcribed and included in the data. The interview guide was subsequently refined. We used a snowball sampling technique to recruit participants through the Norwegian grassroots movement for carers in the field of mental health ('Landsforeningen for Pårørende innen Psykisk helse'). The interviews lasted from 54 to 102 minutes and were conducted at a location of each participant's choice. All were audio-recorded and transcribed verbatim by the first author.

Participants

Eleven participants, nine women, and two men were included in the study. Sample size was decided based on the stability of the findings, and we stopped recruiting when we considered that the last interview did not contribute any substantial new information. All participants were more than 18 years old, and reported being parents, siblings and/or (adult) children of people with a SMI. All were living in western parts of Norway and had a western European background. Table 2 provides an overview of sample characteristics.

Table 2. Sample Characteristics

#	Fictitious name	Sex	Age	Employment	Education	Carer relation as a
1	Arnold	M	55-60	Teacher	5	Father
2	Robert	M	55-60	Shipping	3	Father
3	Sarah	F	60-65	Teacher	6	Mother
4	Elizabeth	F	25-30	Shop assistant	0	Sister
5	Rachel	F	60-65	Linguist	5	Mother
6	Lucy	F	50-55	Economist	2	Sister
7	Maria	F	50-55	Sales assistant	2	Mother
8	Gina	F	60-65	Nursing assistant	2	Mother
9	Caroline	F	40-45	Consultant	6	Mother
10	Rebecca	F	70-75	Retired	6	Mother
11	Lisa	F	35-40	Economist	3	Child

Researchers

The first author (JAB) is a clinical psychologist and a master student in music therapy. The second and fifth authors are clinical psychologists and associate professors, CL in community psychology, and MV in clinical psychology. The third (LD) and fourth (CM) authors are professors in clinical psychology.

Data Analysis

For reflexive purposes²²⁻²⁴, the data were analyzed through a team-based,²⁵ structured approach of thematic analysis²⁶. Our main focus was to find patterned meaning across the data set, conceptualized as themes. According to Braun and Clarke²⁶, a theme is a category “that captures something important about the data in relation to the research question” (p. 82) and emerges when there is a high degree of convergence between the experiences of different participants. The detailed steps of our analysis are presented in Table 3.

Table 3. Steps of Thematic Analysis

1. Familiarization with the data	After each interview, the interviewer (JAB) wrote down his immediate reflections and discussed these impressions with the second (CL) and fifth author (MV), who constituted the analytic research team. All interviews were transcribed by the first author, and the analytic research team read and re-read the transcribed texts individually to become intimately familiar with its content.
2. Coding	The first author generated initial codes for patterns of meaning in the data material. Codes are the most basic segments of the raw data that can be assessed in a meaningful way regarding the phenomenon.
3. Searching for themes	The first author then examined the codes and searched for significant broader patterns of meaning. These were discussed with the second and fifth author.
4. Reviewing themes	The analytic research team then turned back to the overall dataset to check if the tentative themes were well grounded in the interviews, and to consider whether points of view needed to be added or scaled down.
5. Defining and naming themes	Through a consensus-based process in the analytic research team, the themes were formulated and presented to the third (LD) and fourth author (CM). The themes were thereafter defined and agreed on by all authors.

Ethics

The Regional Committee for Medical and Health Research Ethics (Western Region) considered that formal approval of this study should be made by the Norwegian Social Science Data Services because no patients were included in the study. The protocol was therefore submitted to and approved by this entity. All participants received written and oral information about the purpose of the study, and informed consent was obtained prior to participation. Because of the potentially sensitive nature of the interview topics, care was taken to attend supportively to participants in the interview situation and to approach their narratives with respect and confidentiality.

Results

In this paper we report themes that were common for the carers that we interviewed. Three general themes were identified in the data: 1) Mental health as a relational phenomenon; 2) Dealing with excruciating hopelessness; and 3) Coping strategies for the carer. These themes summarize the participants' lived experiences of caring for a relative with an SMI, and describe how they understand and experience their own mental wellbeing.

Mental Health as a Relational Phenomenon

When the participants discussed what promoted wellbeing and positive mental health in their lives, they spontaneously referred to the family as an entity. They had a good life when their family was doing well, and vice versa, a poor life when their family was struggling. Robert, for example, explained how his and his wife's efforts to support their son's mental health affected their own everyday lives as well as that of their other family members. When their son was struggling, this resulted in less time and poorer relation to other siblings:

"As parents we wanted to do something. It was hard. It was difficult. As my wife said: We did everything to save one, and [instead] we lost two. That is a huge dilemma."

Mental wellbeing was understood by the participants as a contextual and relational phenomenon, and this was evident both when the participants talked about themselves and when they discussed the challenges of living with someone with an SMI. Another participant, Arnold, who had a daughter with an SMI, described the difficulties relating to the health care system in the following way:

Arnold (A): "It is hard when people talk over your head, not including you in the conversation. We worked a lot towards collaborative meetings, to get a dialogue started between [my daughter] and the group of professionals. I wish that people could have shown more will to see that people live in networks. [That] mental illnesses does not reside inside a person's head. It is... between people."

Many of the participants spoke about how it inspired hope to meet others with similar experiences, through organized mutual support groups. Elizabeth, who had a sister with an SMI, explained: "It was the first time I had spoken about my situation to someone I did not know before, about my story."

When mental health is viewed as a relational phenomenon it also connects mental health to the people working in the health care system. One can view the whole system as a body where all parts affect each other. Rebecca, who had a child with an SMI, explained how being part of a service user panel was helpful for her to get an overview of the available services in the municipality. This made her feel safer and more secure. In the interview with Maria, a mother of a person with an SMI, she described her needs from the health care system in the following way:

I: "What provides you with wellbeing? What makes your life meaningful?"

Maria (M): There is only one word: Feeling safe. As a carer, safety, information and participation are important. I would have had a better mental health if I had been given a bit more information. Especially in my instance where the confidentiality had been repealed. And the health care professionals were encouraged to give information, but still they did not do it."

The quote illustrates how needing to be invited to be a part in the health care is a natural consequence of experiencing mental health as a relational phenomenon. Maria went on to describe how she would prefer healthcare workers who were genuine in meeting family members. To her, “to meet” was different from “helping” someone: when truly meeting someone she described that one is open and curious in that meeting. Not just being “friendly and nice,” but being helpers who looked forward to meeting her and who were curious about her experiences. However, this is a difficult balance, as other participants also highlighted negative experiences. For example, Arnold suggested that healthcare workers could be intrusive in their caring, as when they sometimes tried to relate to his family as friends when he actually needed them to be professionals.

Dealing with Excruciating Hopelessness

An important theme in our data was the participants’ experiences of hopelessness. Participants described a painful feeling of hopelessness as a salient part of being a carer for a person with an SMI, a feeling that in itself constituted a burden of suffering. One of the participants said:

Gina (G): “Today, I do not have any hope. I only see things getting worse.

I: So, you do not think that things will change?

G: I will celebrate if I am wrong, but I do not have any hope of change. Now I am filled with sorrow. [My son], that was my greatest joy, has become my greatest sorrow. To think that this man, was [in fact] my little, beautiful son, is almost not to believe.”

Many carers explained that they felt their situation was hopeless. Gina elaborated: “(...) One evening he stood there with [a tool] towards his head in the garage. I just managed to save his life, and then he said it was these voices that had told him to do it.” It can be overwhelming to take responsibility for another person’s life when he or she is struggling. Another mother, Caroline, explained how she suddenly turned the steering wheel when she was out driving to try to end her life: “Then I thought: ‘I can’t do this anymore.’ That thought was in my head all the time. I can’t do this, I can’t do this, and then I drove off the road.” Caroline explained how she managed to steer the car back onto the road and therefore did not get physically hurt in this situation.

Lisa, who had a mother with an SMI, described how she experienced her mother failing to help her brother when they were little: “(...) my brother was 4 years old and had cut himself with a knife and he was bleeding and bleeding and crying. But my mother was psychotic and did not realize that he needed to be taken to the acute unit at the hospital.” This quote illustrates how one can experience it as scary and unpleasant when a loved one is acting in an unusual manner. Lisa continued her story in the interview:

“(...) She was wearing a swimming cap and she pulled it down her forehead and yelled: “Lisa look!” She then pulled it up again and laughed fiercely. I left the room as it was very unpleasant. Then she yelled again, she was very ongoing, then I ran back in again,

and she was sitting naked in the sink, pulling the swimming cap up and down."

Coping Strategies for the Carer

As part of their task of caring for a person with an SMI, family members described using different strategies to master their own situation. We have divided this into four subthemes that we have termed: a) relational care; b) the little things; c) finding a personal space; and d) choosing to fight to maintain hope.

Relational care. A valuable coping strategy for many of the participants was to use resources provided by other people who were important to them. For example, many emphasized the importance of finding support among good friends. In the following quote, Lisa emphasized this:

I: "What do you find has helped you outside the healthcare system?"

Lise (L): Friends...

I: Friends.

L: Yes, I have always had many good friends. And also the teachers at school. I remember I was very focused on school as this was also important to my mother. I got a lot of positive feedback, and that was very nice."

Positive feedback in different social arenas was emphasized as useful by many, here illustrated by the following description provided by Lisa: "I collected all the positive feedback I could get in other places." Actively seeking positive regard and support from available social arenas when one does not receive this at home was upheld as a strategy to deal with one's situation as a carer. Many of the participants had experienced that being open and sharing their thoughts with family, at work, or in groups for carers was a good way to take care of oneself. Moreover, many participants received important practical help from their families. Lucy, a sister of person with an SMI, described this in the following manner: "My youngest son changed the ringtone on my phone so I would know that it was [my sister], who called." This helped Lucy with a practical support in setting boundaries and taking care of herself by preparing for the upcoming conversation

The little things. To be able to maintain an awareness of the inherent joys of everyday situations in life were important for many participants' work to master the hopelessness they otherwise experienced. Gina described this in the following words:

"To find meaning in the everyday life. To focus on the little things, to hike [in the mountain] tomorrow, a coffee, a friend, to go to the cinema or just a good feeling. To look forward to something. To look forward to tomorrow when I have a day off, I have worked during the weekend. To be thankful for not being ill, to cycle in the rain, today everything went well at work, I managed it. (...) Right, the little..."

Many of the participants found meaning in these little things in everyday life. A mother, Rebecca, told about the joy of reading a novel: "To have some peace and just read a book. That is great." Another mother, Lucy, described how she got into a better mood when being out in nature and got to "do the normal everyday things, to harvest crops, have animals and take care of them..." Another participant, Caroline, who had a daughter with an SMI, discussed how a trip to the southern hemisphere gave her the space she needed to be present and listen to her heart.

C: "(...) Then I sat down on the sunbed just by the hotel and I just listened to the ocean. It was dark down by the beach, pitch black. But you could hear the waves and there was a lot of wind. ... I felt happiness."

Finding a Personal Space. Many of the carers we interviewed focused on using their body and working out to get some personal space, a space where they were free of the burden that followed their role as a carer. For many of them, there was something special about being physically active that helped in their everyday lives. A mother said the following:

I: "What did you do to be physically and psychologically strong?"

Sarah (S): I have always focused on my health. To be active

I: So working out?

S: I have been running marathons, so... [laughs a little]"

Another participant, Elizabeth, highlighted similarly the importance of Yoga. In the interview, she described it as "something that was just mine, and I started doing it on my own." For her, it was as a personal space where she could take care of herself.

Many of the participants highlighted work as another resource and a central arena for mastery. Elizabeth explained: "For it is so that when someone in close family is mentally ill, it helps a lot to have a place that is just yours, your personal place." Gina also emphasized how work can be an arena where she can contribute: "Yes I have always used my workplace as a support, and I have thoroughly enjoyed it very, very much."

Choosing to Fight to Maintain Hope. To be able to hope that things will get better was the only thing that kept some of the carers going. On a day-to-day basis, many of them experienced a tension between death and life for their family members who suffered from an SMI. Many of them chose to put up a fight for their family members rights to get the best treatment and to help them in their everyday struggles. Sarah described how having faith had been a strength for her. In the following quote, Rachel similarly discussed how she fought for her child:

Rachel (R): "(...) Since that my life has really been a battle.

I: You have fought a lot!

R: A lot.

I: Yes.

R: All the time, fought and fought."

Sarah and Rachel both described having a fierce fighter-attitude, and for them this was a resource that helped them to not give up in an everyday life that could be painful and lonely. Another participant, Caroline, had considered ending her life as she experienced it to be very challenging. In the interview, she described how she eventually got to see herself as a resource for others, and therefore chose life. Many of the participants put in an extra effort when family members were struggling, and Caroline drove around in the city at night when her daughter was in extreme distress. She described: "... so I have thought that it is very traumatic for her to go to the psychiatric unit, and therefore I handle this best myself." Many of the participants described having a similar fighter-attitude. Sarah, for example, said the following: "Yes, then they said that it was a fight against the psychiatric units, but it was not a fight against the psychiatric units [for me], it was a fight for my son. To give him the best life and the best treatment."

Discussion

This study set out to explore the lived experiences of carers of people with SMI. An important overall finding is that mental health is understood and described in interpersonal terms, as presented in our first theme 'mental health as a relational phenomenon.' To our study participants, close relationships brought joy and mastery, but also hopelessness and misery, as described in our second theme 'dealing with excruciating hopelessness.' The third theme, 'coping strategies for the carer,' captures participants' efforts to find a way to handle their distress and to build a good and meaningful life. But how can we understand these findings and what are their clinical implications?

On a superordinate level, our findings emphasize the need to develop mental health services that better integrate contextual and relationally oriented knowledge. Within the recovery movement there is an increasing interest in the role of relational factors to processes of improvement²⁷⁻³². For example, connectedness to important others is underscored as pivotal to recovery both in meta-syntheses^{32,33} and in individual studies^{34,35}. One possible implication of the current study is that an individual's context of prior and possible relational connections could be beneficially integrated in the treatment setting, allowing for constructive reconnective processes starting as early as possible. Reflecting this point, family-oriented interventions such as open dialogue³⁶ are increasingly building evidence.

Still, however, studies repeatedly report that family carers do not experience being listened to and involved in mental health treatment^{15,16,37}. One possible interpretation of this is that mental health professionals are not properly trained in strategies for collaborating with family members in therapy and care. Hjärthag, Persson³⁸ highlight that it can be difficult for health care workers to feel competent and safe in a role where they meet and help carers. Another explanation may be that a medical model³⁹ continues to dominate the mental health field, as mental illnesses predominately are viewed as disorders that reside within the individual rather than as contextual phenomena. In line with the recovery literature, our study extends the focus of mental health to also include people's everyday life. As such, the focus is shifted from treating individual illnesses and disorders, to supporting the person in his or her community⁴⁰.

Two important concepts that also should be considered when interpreting the results of the present study relate to participants' experiences of hope and hopelessness. Many of the carers that we interviewed reported distinct feelings of hopelessness when caring for a person with a SMI. This finding is in concordance with earlier studies demonstrating how mothers can experience feeling powerless, without a voice, isolated, worried about the future and tired in relation to their children with severe mental illness^{10,41}. In the face of both SMI and the mental health system, carers' feelings of hopelessness and hope, as argued by Weingarten⁴², may also be seen as a relational phenomenon. It is better understood as a process rather than a state^{43,44} as it refers to practices and the things we do in our everyday lives. As such, we may argue that hoping is not something that should be left to the individual carer, but processes that need to be recognized as a responsibility that also lies on the professional. Health care workers can for example help carers uphold their hopes through sharing information, as well as by providing guidance and support when carers are dealing with painful periods of hopelessness. In doing so we may move from an authoritarian practice focused on one-directional psychoeducation where the carers receive knowledge, to a collaborative practice³⁰ where both knowledge and treatment is developed in partnership between the person with a SMI and his or her family carers as well as professionals in the mental health services.

The carers we interviewed emphasized the importance of developing their own individual ways of managing the challenges they experienced in being close to a person suffering from SMI. In the interviews, they described a multitude of strategies they used in order to handle their everyday life. Of particular importance here is the variation of these coping strategies. They seemed to focus on the small everyday things in the carers' ongoing lives. Such things have been argued to help confirm who one is as a human being^{45,46}, and, as such, being important to the person's sense of being an active agent.

Limitations

Study findings are context dependant for our participants and the setting in which the research was carried out. Nine of 11 participants were women, and six of them had a relation as a mother to their family members who suffered an SMI. The majority of them were also ethnic Norwegian, and these contexts should be considered when evaluating the transferability of the results to other contexts. Another limitation is that we included informants with a broad range of relationships to people with SMI. There is clearly a difference between having a mother or a daughter or son who is struggling with their mental health, and care needs to be taken when interpreting our findings. Furthermore, additional research is needed to explore in depth the lived experiences of such different groups of carers.

Conclusion

To be a carer can give a feeling of hopelessness towards oneself, one's family and the mental health care system. At the same time, many carers use different strategies to find ways of caring for themselves and their family. Family members are, however, not just carers. They are, in fact, also individuals with their own lives independent from their role as carer. A pivotal development in the field of mental

health will be to develop clinical interventions that meets carers' needs, both as family members and as people with resources and needs of their own.

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References

1. Whiteford, H.A., et al., *Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010*. The Lancet, 2013. **382**(9904): p. 1575-1586.
2. Demyttenaere, K., et al., *Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys*. Jama, 2004. **291**(21): p. 2581-2590.
3. Magliano, L., et al., *Burden on the families of patients with schizophrenia: results of the BIOMED I study*. Social psychiatry and psychiatric epidemiology, 1998. **33**(9): p. 405-412.
4. Roick, C., et al., *Burden on caregivers of people with schizophrenia: comparison between Germany and Britain*. The British Journal of Psychiatry, 2007. **190**(4): p. 333-338.
5. Brown, M.-A. and K. Stetz, *The labor of caregiving: a theoretical model of caregiving during potentially fatal illness*. Qualitative health research, 1999. **9**(2): p.182-197.
6. Førde, R., et al., *Next of kin's experiences of involvement during involuntary hospitalisation and coercion*. BMC medical ethics, 2016. **17**(1): p. 76.
7. Svendsen, E. *Toppmøte 2017: Fagfolk er ikke det viktigste nettverket for pasientene*. 2017; Available from: <http://www.erfaringskompetanse.no/toppmote/toppmote-2017-fagfolk-viktigste-nettverket-pasientene/>.
8. Weimand, B.M., *Experiences and nursing support of relatives of persons with severe mental illness*. 2012, Karlstads universitet.
9. Tsang, H.W., et al., *Sources of burdens on families of individuals with mental illness*. International Journal of Rehabilitation Research, 2003. **26**(2): p. 123-130.
10. Skundberg, H.K., *Everyday life of relatives of persons suffering from severe depression: Experiences of health, burden, sense of coherence and encounters with psychiatric specialist health services*. 2015, Karlstads universitet.
11. Poon, A., et al., *A longitudinal population-based study of carers of people with psychosis*. Epidemiology and psychiatric sciences, 2017. **26**(3): p. 265-275.
12. Bird, V., et al., *Early intervention services, cognitive-behavioural therapy and family intervention in early psychosis: systematic review*. The British Journal of Psychiatry, 2010. **197**(5): p. 350-356.
13. Siegenthaler, E., T. Munder, and M. Egger, *Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis*. Journal of the American Academy of Child & Adolescent Psychiatry, 2012. **51**(1): p. 8-17. e8.
14. Yesufu-Udechuku, A., et al., *Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis*. The British Journal of Psychiatry, 2015. **206**(4): p. 268-274.
15. Askey, R., et al., *What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals*. Journal of Family Therapy, 2009. **31**(3): p. 310-331.
16. Cree, L., et al., *Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services*. BMC psychiatry, 2015. **15**(1): p. 208.
17. Davidson, L., et al., *Creating a recovery-oriented system of behavioral health care: Moving from concept to reality*. Psychiatric Rehabilitation Journal, 2007. **31**(1): p. 23.
18. Slade, M., et al., *Positive Psychotherapy for Psychosis: A Clinician's Guide and Manual*. 2016: Routledge.
19. Van Manen, M., *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. 2014: Routledge.

20. Gadamer, H.-G., *Truth and method*. 1960/2004, London: Continuum.
21. Kvale, S. and S. Brinkmann, *Learning the craft of qualitative research interviewing*. Thousands Oaks: Sage Publications, 2009.
22. Veseth, M., et al., *Collaborating to stay open and aware: Service user involvement in mental health research as an aid in reflexivity*. *Nordic Psychology*, 2017: p. 1-8.
23. Alvesson, M. and K. Sköldbberg, *Reflexive methodology: New vistas for qualitative research*. 2000: Sage.
24. Finlay, L., *Through the looking glass: Intersubjectivity and hermeneutic reflection*, in *Reflexivity: A practical guide for researchers in health and social sciences*, L. Finlay and B. Gough, Editors. 2008, John Wiley & Sons. p. 105-119.
25. Binder, P.-E., H. Holgersen, and C. Moltu, *Staying close and reflexive: An explorative and reflexive approach to qualitative research on psychotherapy*. *Nordic Psychology*, 2012. **64**(2): p. 103-117.
26. Braun, V. and V. Clarke, *Using thematic analysis in psychology*. *Qualitative research in psychology*, 2006. **3**(2): p. 77-101.
27. Topor, A., et al., *Not just an individual journey: Social aspects of recovery*. *International Journal of Social Psychiatry*, 2011. **57**(1): p. 90-99.
28. Price-Robertson, R., A. Obradovic, and B. Morgan, *Relational recovery: beyond individualism in the recovery approach*. *Advances in Mental Health*, 2017. **15**(2): p. 108-120.
29. Tew, J., et al., *Social factors and recovery from mental health difficulties: a review of the evidence*. *The British Journal of Social Work*, 2012. **42**(3): p. 443-460.
30. Ness, O., et al., *"Walking alongside:" collaborative practices in mental health and substance use care*. *International journal of mental health systems*, 2014. **8**(1): p. 55.
31. Veseth, M., P.-E. Binder, and S.H. Stige, *"If there's no stability around them": experienced therapists' view on the role of patients' social world in recovery in bipolar disorder*. *International journal of mental health systems*, 2017. **11**(1): p. 55.
32. Leamy, M., et al., *Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis*. *The British Journal of Psychiatry*, 2011. **199**(6): p. 445-452.
33. Drake, R.E. and R. Whitley, *Recovery and severe mental illness: description and analysis*. *The Canadian Journal of Psychiatry*, 2014. **59**(5): p. 236-242.
34. Moltu, C., et al., *What are "good outcomes" in public mental health settings? A qualitative exploration of clients' and therapists' experiences*. *International journal of mental health systems*, 2017. **11**(1): p. 12.
35. Ware, N.C., et al., *Connectedness and citizenship: Redefining social integration*. *Psychiatric Services*, 2007. **58**(4): p. 469-474.
36. Seikkula, J., et al., *Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies*. *Psychotherapy research*, 2006. **16**(02): p. 214-228.
37. Larkin, M., M. Henwood, and A. Milne, *Carer-related research and knowledge: Findings from a scoping review*. *Health & social care in the community*, 2018.
38. Hjärthag, F., et al., *Professional views of supporting relatives of mental health clients with severe mental illness*. *International Journal of Social Psychiatry*, 2017. **63**(1): p. 63-69.
39. Wampold, B.E., *The great psychotherapy debate: Models, methods, and findings*. Vol. 9. 2013: Routledge.
40. Davidson, L. and J.S. Strauss, *Beyond the biopsychosocial model: Integrating disorder, health, and recovery*. *Psychiatry*, 1995. **58**(1): p. 44-55.
41. Copeland, D.A. and M.V. Heilemann, *Choosing "the best of the hells": Mothers face housing dilemmas for their adult children with mental illness and a history of violence*. *Qualitative health research*, 2011. **21**(4): p. 520-533.
42. Weingarten, K., *Reasonable hope: Construct, clinical applications, and supports*. *Family Process*, 2010. **49**(1): p. 5-25.
43. Sælør, K.T., O. Næss, and R. Semb, *Taking the plunge: Service users' experiences of hope within the mental health and substance use services*. *Scandinavian Psychologist*, 2015.
44. Sælør, K.T., et al., *Hope and recovery: a scoping review*. *Advances in Dual Diagnosis*, 2014. **7**(2): p. 63-72.
45. Bandura, A., *Self-efficacy: toward a unifying theory of behavioral change*. *Psychological review*, 1977. **84**(2): p. 191.
46. Davidson, L. and A. Johnson, *It's the little things that count: Rebuilding a sense of self in schizophrenia*. *Tidsskrift for psykisk helsearbeid*, 2013. **10**(3): p. 258-263.