ORIGINAL ARTICLE

The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities

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Abstract

Background: Resilience does not refer to a magical state of invulnerability and the capacity for resilience does not end when one is diagnosed with a prolonged disorder or disease. Despite the enduring legacy of pessimism regarding resilience in the population of people diagnosed with psychiatric disorders, a majority do recover. Aim: The present study seeks to understand how people with psychiatric disorders demonstrate the capacity for resilience in the ways they use or do not use psychiatric medications in their daily lives. Method: A qualitative method and participatory action design was used to analyze interviews with 29 people diagnosed with psychiatric disorders. Results: When discussing their use of psychiatric medications, research participants also talked about non-pharmaceutical, personal medicine. Personal medicine was found to be those activities that gave life meaning and purpose, and that served to raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization. When psychiatric medications interfered with non-pharmaceutical personal medicine, non-adherence often occurred. Conclusion: People with psychiatric disorders demonstrate resilience through the use of non-pharmaceutical, personal medicine in the recovery process. This understanding suggests that medication adherence may be improved when clinicians inquire about patients’ personal medicine and use pharmaceuticals to support, rather than interfere with, these self-assessed health resources.

Key Words: Medication adherence, non-compliance, person centered, psychiatric disability, qualitative research, resilience, recovery, strengths

Introduction

People with psychiatric disabilities are resilient. Despite the enduring legacy of pessimism regarding outcomes, worldwide longitudinal studies on recovery have consistently found that half to two-thirds of people diagnosed with schizophrenia and other major mental disorders significantly improve or recover [1]. In seven worldwide longitudinal studies on recovery from major mental disorders including schizophrenia, recovery has been found to include living and working in the community in a fashion similar to that of other community members, being free of psychiatric symptoms, using or not using psychiatric services (including psychiatric medications), having a network of friends and/or family, and living in fully integrated housing [2]. Qualitative studies [3] and contemporary first-person accounts [4] suggest that although recovery is a unique process for each person, there are common themes, challenges, and strategies used by most people.

Recovery and resilience are related. In her comprehensive review of the literature, Ridgway [5] concludes that recovery and resilience are two sides of a multi-faceted phenomenon. She notes that although there is no single, accepted operational definition of resilience, the concept refers to the capacity of people who are faced with adversity, to adapt, cope, rebound, withstand, grow, survive, and define a new sense of self through situations of adversity, including psychiatric disability. Resilience does not refer to a magical state of invulnerability. Thus the capacity for resilience does not end when one is diagnosed with a major mental disorder. Rather, those with psychiatric disabilities can be viewed as resilient even when struggling to recover from psychiatric disorder.
The concepts of recovery and resilience shift clinicians’ attention away from disease processes and onto the whole person in the life context. Clinicians become less concerned with charting pathological processes and more interested in understanding and enhancing the innate self-righting potential and resources of each person who comes for help. The focus becomes salutogenesis or the origins of health, rather than pathogenesis or the origins of sickness [6,7]. Clinicians can learn to inquire about clients’ self-assessed health resources or those qualities or strategies that are perceived to promote health [8].

In this study, I was interested in resilience among a population of people who are often perceived as victims of chronic major psychiatric disorders. Specifically, I was interested in understanding how people with psychiatric disorders demonstrated the capacity for resilience in the ways they used or did not use psychiatric medications in their daily lives. My personal experience of recovery from schizophrenia and my concern with over-prescription of psychiatric medications [9] were part of my motivation and background in approaching this research.

**Material and methods**

A qualitative research method was used because it best fit the aim of this study to create understanding of the experiential meaning of resilience in a group of people with psychiatric disabilities. A participatory action design was also incorporated so as to include research participants in the interpretation and use of the findings.

**Table I. Demographics of research participants.**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Men (10)</th>
<th>Women (19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age range</td>
<td>20–69 years</td>
<td>Median=15</td>
</tr>
<tr>
<td>No. of years in services</td>
<td>0.5–45 years</td>
<td>Median=3 admissions</td>
</tr>
<tr>
<td>No. of psychiatric hospitalizations</td>
<td>0–32 admissions</td>
<td>10 rural/frontier</td>
</tr>
<tr>
<td>Geographic</td>
<td>19 urban/suburban</td>
<td></td>
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<td>Ethnic</td>
<td>White=11</td>
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<td></td>
<td>African-American=12</td>
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<tr>
<td></td>
<td>Mexican American=1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Native American=1</td>
<td></td>
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<tr>
<td></td>
<td>Mixed Hispanic/White or Native American/White=4</td>
<td></td>
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<tr>
<td>DSM-IV diagnosis</td>
<td>Schizophrenia=10</td>
<td></td>
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<tr>
<td></td>
<td>Bipolar disorder=7</td>
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</tr>
<tr>
<td></td>
<td>Major depressive disorder=9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personality disorder=1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mixed Axis 1+2=2</td>
<td></td>
</tr>
<tr>
<td>No. of psychiatric medications simultaneously prescribed at time of interview</td>
<td>0–5 medications</td>
<td></td>
</tr>
</tbody>
</table>
The importance of personal medicine

be interviewed, comprising 29 people. Sample selection was guided by an effort to insure racial diversity as recommended in the 1999 Report of the Surgeon General [9]. Additional considerations for sample selection included an effort to interview at least two people who no longer used psychiatric medications, people representing a range of diagnoses and prescribed medications, and a rural/urban mix in this state that has a small number of densely populated urban areas, and large expanses of sparsely populated rural farmlands.

I contacted research participants by letter and distributed written descriptions of the research project and informed consent documents. During a follow-up phone call, questions about the study were answered and meeting times and places were agreed on. Research participants were paid for their work in the study.

Data were collected using individual, semi-structured interviews. After reviewing basic demographic information, participants were asked to tell me the story of how they came into mental health services and what their experience with psychiatric medications was like. Follow-up questions were aimed at clarifying the details of participants’ reports. A final question concluded the interview: “Based on your experience, what is the most important thing that mental health professionals should know in order to be helpful to people using medications?”

The one-hour interviews were conducted in settings that were identified as convenient and comfortable by the research participants. Interview settings included research participants’ homes, local libraries, or mental health consumer-operated programs. I introduced myself as both a psychologist/researcher and a former psychiatric patient who had used psychiatric medications in my recovery from schizophrenia. The purpose for this qualification was twofold: I am a nationally recognized speaker and writer on topics related to recovery from psychiatric disorders, and my name/image was already known by some of the research participants. Second, I understood that my disclosure might help to set a more trusting atmosphere for the interviews if people understood the study was being run by and for people with psychiatric disorders.

Analysis

The interviews were audiotaped and verbatim transcriptions were done. The analysis followed the phenomenological method described by Giorgi [10]. Each interview was read in its entirety to gain a contextualized understanding of the individual’s experience. In the second phase of analysis, units of meaning were identified. In the third stage, further re-reading of the meaning units revealed interrelated themes both within interviews and across them. During this stage I added commentary and reflections on the themes in parentheses, in order to strive for transparency in the analysis. Identified themes were named and all examples from the data grouped under corresponding themes. This insured that the presentation of results included quotes from the data to amplify the themes.

The results of the study were reviewed at two focus group meetings. The focus group comprised eight people from the original group of research participants as well as one additional person with a psychiatric disability. Selection of focus-group attendees was made based on their interest in the task, ability to arrange for travel to the meetings, and an effort to include people of diverse racial backgrounds. Focus-group participants were paid for their work. Discussions centered on the usefulness, accessibility, and relevance of the findings from the service users’ point of view. Notes were kept on the proceedings of the meeting and suggestions incorporated into the phrasing of the findings.

Results

A major finding was that when asked to describe their use of psychiatric medications, research participants also described “personal medicine”. Personal medicine was found to be self-initiated, non-pharmaceutical self-care activities that served to decrease symptoms, avoid undesirable outcomes such as hospitalization, and improve mood, thoughts, behaviors, and overall sense of wellbeing. Two main categories of personal medicine were identified: activities that gave meaning and purpose to life and specific self-care strategies. Research participants reported that they did not generally disclose their personal medicine to clinicians and that clinicians did not routinely inquire about these strengths. Non-adherence with prescribed psychotropics was found to occur when pharmaceuticals interfered with personal medicine resulting in a diminished quality of life.

Personal medicine

Research participants challenged conventional understandings of medication. When asked to describe their use of psychiatric medications, they described using pharmaceuticals but also spontaneously reported a variety of non-pharmaceutical
strategies that served to improve mood, outlook, thought, and behaviors. That is, when describing their use of psychiatric pharmaceuticals or “pill medicine”, research participants also described a variety of personal wellness strategies and activities that I have called “personal medicine”.

Personal medicines were non-pharmaceutical activities and strategies that served to decrease symptoms and increase personal wellness. Personal medicine was discovered by study participants in the everyday context of their lives. For instance, one research participant diagnosed with bipolar disorder found that solving mathematics problems was a powerful mood stabilizer. He said:

I think there are a lot of other things that are medication, that are not really considered medication. There’s things that you can do that changes what your body does. And it may not be medicine … I still think that one of the best mood stabilizers there is in life – maybe not for everyone but for me – is math. That stimulates your intellectual process. (Joe)

Personal medicine did not necessarily replace psychiatric medication. They were often used together successfully. For instance, one research participant who was 29 years old and diagnosed with major depression with psychotic features continued to use her psychiatric medications while also using personal medicine that included being a good mother as well as volunteering in the community:

I love being a mother. I love spending time with [my kids]. I love playing with them. I love teaching them. I love putting them to bed. Being a mom is very important to me. And being a good person in the community, like volunteering like we do. My husband and I volunteer. Doing that is very important to me. (Nancy)

Work was reported to be powerful personal medicine. For one research participant, working full time made life hectic but also filled her life with purpose, decreased her depression, and kept her out of the hospital:

If I wasn’t working my job I’d end up in a hospital or something like that. Depressed all the time. But since I’m working, I’m full time, and I’m going, going, going. I just love it you know…. It’s keep me from being in the hospital. (Nadene)

Personal medicine was not necessarily stress free. One young adult diagnosed with major depressive disorder with psychotic features made the distinction between stress and “good stress”. She reported that the stress of attending the university was bearable because it had a purpose:

(Going to university) … It’s stressful but it’s a kind of good stress. I mean there’s a purpose to it. A good purpose. And I think that’s why I still do it. It keeps me from thinking about other things and going to other sources [street drugs] to relieve my stress. (Tamika)

Personal medicine as self-care strategies

A second category of personal medicine included those self-care strategies that served to increase wellness and decrease psychiatric symptoms or unwanted outcomes such as hospitalization. There were many self-care approaches that were reported by research participants. Nearly half of the research participants mentioned that helping others in formal or informal ways had a reciprocal effect such that:

And I sung for a living for five years. And I was the lead singer…. And I like to make people happy…. And they would love us and in return I would love what I was doing you know? … I stopped taking them [neuroleptics] and I didn’t act up or anything because I was doing something I like. (Nadene)
I found by helping others, I found out how to live for myself. (Thomas)

Other self-care strategies included keeping busy, exercising, becoming involved in advocacy, spending time with loved ones, sex, fishing, doing math problems, shopping, changes in diet, having a good cry, being with “normal” people, being alone, being in nature, talking on the phone, going for a car ride, taking a day off, pushing oneself to achieve, collecting dolls, and exposure to sunlight. Although many of these activities are mundane and may be part of many people’s day, research participants specifically mentioned using these activities to alleviate various types of distress such as anxiety, confusion, lack of concentration, depression, sleeplessness, worry, suspicions, distressing voices, and racing thoughts.

Disclosure of personal medicine to healthcare providers

Some research participants reported that they did not tell their healthcare practitioners about their personal medicine. For instance, a 42-year-old woman diagnosed with major depressive disorder was prescribed an SSRI, a neuroleptic, a sedating anti-depressant, and a sleeping pill. However, she still had trouble sleeping some nights and often struggled with disabling depression. She found that watching horror movies, and playing the violent parts over and over again, helped her to fall asleep and relieved her depression, at least for a while. She was afraid to tell her psychiatrist because she feared his disapproval. Other research participants mentioned the use of alcohol, street drugs, and tobacco as self-care strategies that they purposely did not disclose to mental health practitioners. Importantly, even people who had “positive” wellness strategies and self-assessed health resources as part of psychopathology. For instance, a single working mother of three children who was diagnosed with bipolar disorder valued her energy and stamina. However, her psychiatrist interpreted these same attributes as evidence of hypomania and prescribed a neuroleptic. Not surprisingly, the research participant did not use the neuroleptic to treat what she considered to be a valuable personal strength:

I don’t really see it as mania. I see it as part of me. I just see that as an extension of me when I am full of energy. I am able to do things…. This is the me that I know but then there’s somebody else calling it a disease, a problem. Well, for me, this problem has got me through a lot! (Kim)

Additionally, some research participants reported that clinicians interpreted their valued personal strengths and self-assessed health resources as part of psychopathology. For instance, a single working mother of three children who was diagnosed with bipolar disorder valued her energy and stamina. However, her psychiatrist interpreted these same attributes as evidence of hypomania and prescribed a neuroleptic. Not surprisingly, the research participant did not use the neuroleptic to treat what she considered to be a valuable personal strength:

She’s a nurse practitioner…. She wants you to be the best person you can be so she tries to get medication for that. Not something that’s just going to, as I call it, zombify you out and get rid of the symptoms. She wants to get rid of the symptoms but also wants you to live. (Nancy)

Non-adherence: When psychiatric medicine interferes with personal medicine

Some research participants reported that there were times when psychiatric medications interfered with the things that give life meaning and purpose. Not surprisingly, when psychiatric pharmaceuticals interfered too much with personal medicine, people stopped taking the offending drug. For instance, the most important part of life for one woman was taking good care of her children. Psychotic depression prevented her from being a good mother, but so did certain psychiatric medications:

I did not feel I was a good mother because I did not have the drive to take care of my kids. I took them to daycare because I just had to sleep. I slept and slept on that medication. So I quit taking it at times. (Nancy)

Eventually she was able to find a practitioner who found a medication regimen the enhanced her personal medicine (mothering):

The study

My commitment to reflexivity in this qualitative study is grounded in an understanding that knowledge is always perspectival and situated [11]. I was not a neutral observer. My background as a person who had used psychiatric medications in recovery from psychiatric disorder positioned me in relation to the study design, the rapport that was established with research participants, the analysis of textual data, and the rapport established with the focus group. Bias and skew were minimized by disclosure of my background, as well as by the critique I welcomed from focus-group members, all of whom had psychiatric disabilities. Different researchers might have accessed different and equally valid interpretations of the data that, in
turn, would help to increase our understanding of the complex phenomena related to personal medicine and resilience.

The findings of any qualitative study are not meant to be construed as facts that can be universally applied to a population [11]. The validity of this study was established by studying the experience of people who use psychiatric medications as represented in their first-person accounts. This source of knowledge was relevant to the findings with regard to personal medicine and resilience. Alternative approaches, such as interviewing practitioners, could not have yielded these findings because, to a large extent, patients do not report such experiences and many practitioners do not inquire about personal medicine. With regards to transferability of these findings, care was taken to interview a diverse group of people and demographics have been specified. Although the research was conducted in the United States, it is conceivable that the descriptions of personal medicine and the role of patients in their own recovery is applicable to other groups in similar situations, i.e. people with major psychiatric disorders in other countries as well as people with other prolonged medical disorders. Future research efforts might continue to elaborate our understanding of personal medicine and resilience among groups of people with a variety of prolonged disorders. In addition, future research might more fully explore how patients and practitioners can use the concept of personal medicine to improve clinical outcomes, including more effective prescription of pharmaceuticals.

The significance of personal medicine for healthcare providers

Members of the focus group, who were all people with psychiatric disabilities, found the concept of personal medicine to be useful. It validated their lived experience and gave them a way to talk about the important role they play in their own recovery. Focus-group participants felt that healthcare clinicians, friends, and family often placed too much emphasis on the efficacy of psychiatric medications and too little emphasis on the role that people diagnosed with psychiatric disorders play in their own recovery. Having one’s recovery attributed to the efficacy of a pharmaceutical left focus-group members feeling disempowered. In such a construction, the role of the patient is to swallow pills faithfully. However, focus-group members stated that recovery from psychiatric disorder is not simply a matter of swallowing pills. They said their recovery is about changing their lives, not their biochemistry. Their recovery is hard work and it requires personal agency, will, vision, hope, fortitude, courage, imagination, commitment, and resilience. The concept of personal medicine helped the focus-group members talk about and feel empowered by the ways they worked to improve their lives after diagnosis with psychiatric disability.

The concept of personal medicine has practical applications for people with psychiatric disorders. It is estimated that there are over 7,467 peer support groups run by and for people with psychiatric disabilities and their families in the United States alone [12]. The concept of personal medicine might be a helpful way to share and teach recovery strategies in some of these groups. People could be taught to identify their personal medicine and to create “power statements” in order to convey the importance of personal medicine to healthcare practitioners. The concept is similar to Malterud & Hollnagel’s [13] key question speech act that invites the patient to share self-assessed resources, except that the information would be initiated by the patient instead of being elicited by the practitioner. Table II illustrates this application.

| Example 1 | Personal medicine: Being a good mother | Power statement: Being a good mom is the most important thing in my life and is vital to my recovery. I am not willing to sacrifice being a good mom to clinical depression or to medication side effects. You and I must work together to find a medication that does not interfere with my ability to be a good mother |
| Example 2 | Personal medicine: Singing in a gospel group | Power statement: Singing lifts me up and gives my life meaning. Singing is part of how I stay well. I need to sing to recover. Singing is powerful medicine for me. I want to work with you to find a medication and dosage that does not interfere with my singing |
can be so absolute that Strauss [16] reported that during interviews conducted over years, a woman diagnosed with schizophrenia finally asked him, “Why don’t you ever ask what I do to help myself?” (p. 182).

As in other studies, my findings would suggest that clinicians should routinely inquire about personal medicine and what patients are already doing to help themselves with their distress. Rapp [17] has called this way of working the Strengths Approach: “The strengths model then is about providing a new perception. It allows us to see possibilities rather than problems, options rather than constraints, wellness rather than sickness” (p. 24). In order to reinforce the importance of personal medicine, clinicians might consider having the patient list personal medicine next to prescribed pharmaceuticals as part of an overall self-care plan that patients can take home with them.

As in other studies [18,19,20], drug adherence was problematic when valued personal attributes and activities were interpreted as symptoms for which psychiatric medications were prescribed. If clinicians inquired about personal medicine prior to prescribing, and worked with the patient to establish the goal of pharmaceuticals supporting or enhancing personal medicine, then drug adherence might increase. An understanding of personal medicine may help the practitioner and patient agree on the goals of pharmacological treatment. Ideally treatment with pharmaceuticals should enhance personal medicine.

Conclusion

Personal medicine is evidence of resilience in people with psychiatric disorders. When treatment plans support the personal medicine, resilience, and self-assessed health resources of the people who come for help, then clinicians become more effective partners in the journey toward health.

Acknowledgement

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References