Psychiatr Q (2015) 86:33–48
DOI 10.1007/s11126-014-9325-3

ORIGINAL PAPER

Mental Health System Historians: Adults with Schizophrenia Describe Changes in Community Mental Health Care Over Time

Catherine H. Stein · Jaclyn E. Leith · Lawrence A. Osborn · Sarah Greenberg · Catherine E. Petrowski · Samantha Jesse · Shane W. Kraus · Michael C. May

Abstract This qualitative study examined changes in community mental health care as described by adults diagnosed with schizophrenia with long-term involvement in the mental health system to situate their experiences within the context of mental health reform movements in the United States. A sample of 14 adults with schizophrenia who had been consumers of mental health services from 12 to 40 years completed interviews about their hospital and outpatient experiences over time and factors that contributed most to their mental health. Overall, adults noted gradual changes in mental health care over time that included higher quality of care, more humane treatment, increased partnership with providers, shorter hospital stays, and better conditions in inpatient settings. Regardless of the mental health reform era in which they were hospitalized, participants described negative hospitalization experiences resulting in considerable personal distress, powerlessness, and trauma. Adults with less than 27 years involvement in the system reported relationships with friends and family as most important to their mental health, while adults with more than 27 years involvement reported mental health services and relationships with professionals as the most important factors in their mental health. The sample did not differ in self-reported use of services during their initial and most recent hospitalization experiences, but differences were found in participants' reported use of outpatient services over time. Findings underscore the importance of the lived experience of adults with schizophrenia in grounding current discourse on mental health care reform.

C. H. Stein (✉) · L. A. Osborn · S. Greenberg · C. E. Petrowski · S. Jesse
Department of Psychology, Bowling Green State University, Bowling Green, Ohio 43403, USA
e-mail: cstein@bgsu.edu

J. E. Leith
Durham North Carolina Veterans Administration Medical Center, Durham, NC 27705, USA

S. W. Kraus
New England Mental Illness Research Education and Clinical Centers, VA Connecticut Healthcare System, and Yale School of Medicine, New Haven, CT 06516, USA

M. C. May
Metropolitan Family Services, Chicago, IL 60602, USA

Keywords Schizophrenia · Mental health care reform · Consumer perspectives · Recovery-oriented services · Changes in mental health care

Introduction

The concept of recovery has become central to mental health policy and practice in the United States over the past twenty years [1, 2]. As the latest in a series of mental health reform movements, recovery-oriented care emphasizes the rights and abilities of people with mental illness to live productive and meaningful lives despite psychiatric symptoms [3]. As a significant departure from a traditional medical model of care, hallmarks of a recovery-oriented mental health system include a focus on consumer autonomy and choice and an emphasis on collaborative relationships between consumers and health care providers [4].

Historically, the recovery movement in the United States can be traced back to the mental health deinstitutionalization movement of the 1960s through its predecessors that include the Consumer/Survivor movement of the 1980s and early 1990s [5] and the Community Support Program movement of the 1970s [6]. Each of these reform movements articulated policies and practices considered to be the best and most effective form of community mental health services for people with serious mental illness. Unfortunately, previous efforts to redesign systems of mental health care have failed to meet their goals, resulting in cycles of hope and despair for adults with mental illness and their families [7]. Situating the recovery movement within a larger historical context of mental health reforms may help to avoid the mistakes of the past and offer important insights for the future [7, 8]. Yet, the historical context of community mental health care reforms is largely overlooked in the current discourse on best practices in recovery-oriented mental health care [9].

Adults with mental illness who are long-term recipients of mental health services have a unique perspective on changes in community mental health by virtue of their lived experience. In many respects, adults involved in the mental health system over many years of their lives can be viewed as informal historians of community mental health care. If recovery-oriented service delivery represents a significant departure from traditional mental health services, then consumers who have long-term involvement in the mental health system should be able to recognize significant changes in their mental health care.

The present qualitative study examines changes in mental health service delivery from the lived experience of adults diagnosed with schizophrenia who have had long-term involvement with the mental health system. Specifically, the research examines the views of these mental health consumers with regard to their psychiatric hospitalization and outpatient experiences and their general perspective on changes in the mental health system over time. To place mental health care within the larger context of individuals' lives, adults with schizophrenia shared their views about factors that they felt contributed the most to their mental health and personal well-being.

Mental Health Reform Movements Since Deinstitutionalization: A Brief Review

By the 1960s, advances in pharmacological treatment of mental illness along with harsh social criticism of conditions in state mental hospitals gave rise to the Community Mental Health Center Act (CMHCA), legislation that shifted the treatment of mental illness in the United States from state mental hospitals to local communities [10]. The deinstitutionalization movement was responsible for the discharge of over 400,000 adults from mental hospitals into communities in the period from 1955 to 1980 [11]. However, the huge influx of former inpatients into communities, a critical lack of funding, and limited numbers of trained mental health professionals contributed to the substantial gap in the provision of essential community services for people with serious mental illness [12].

The Community Support Program (CSP) was a systems-wide reform movement in the 1970s designed to address problems created by deinstitutionalization [6]. Central to CSP reforms were the goals of continuous community treatment and support services, assertive crisis and outreach services, and coordinated community care through case management. Psychosocial rehabilitation, emphasizing social skills training and community supports in areas such as independent living, employment, and education, initially emerged within the context of CSP [13]. Although research suggested that community support programs could foster positive outcomes for adults with mental illness, the costs and resource intensive nature of these programs precluded large-scale reforms from taking place.

The Consumer/Survivor Movement (CSM) developed in response to a continued lack of adequate community mental health services for adults with mental illness coupled with paternalistic views of mental health providers toward the people whom they served [5]. Reminiscent of the larger civil rights movement of the 1960s, the Consumer/Survivor Movement started with former patients and/or consumers who organized and advocated for patients' rights, protections, and voice in treatment decisions [14]. This mental health reform movement achieved a number of legal and mental health practice advances such as legislation establishing mental health planning councils and the recognition of alternatives to traditional services such as self-help and peer support [15, 16]. However, ideological tensions between consumers, psychiatric survivors, and family advocates alienated mental health professionals and tended to undermine the overall effectiveness of the movement [17].

As an outgrowth of the consumer/survivor movement, the Recovery Movement emerged by the 1990s, primarily grounded in the experiences and writings of adults with mental illness in the mental health system [18]. Central to recovery principles is the idea that people can live meaningful and personally satisfying lives without the complete elimination of psychiatric symptoms [19]. In a recovery paradigm, the role of mental health service providers is to assist individuals in pursuing their preferred futures, managing symptoms, and in overcoming the psychosocial consequences that result from mental illness [20].

By the beginning of the new millennium, the Recovery Movement had achieved prominence in shaping social policy on mental health in the United States [1]. Recovery principles were at the heart of a proposed national transformation of community mental health services to support individuals' autonomy and provide person-centered, strengths-based mental health care. The transformation of recovery-oriented mental health systems included an emphasis on consumer and family member involvement, stigma reduction initiatives, and relapse prevention and management strategies [21]. Yet, the transformation of mental health service delivery systems to a recovery orientation has faced significant challenges in the past decade that include lack of consensus in defining recovery, difficulties implementing recovery practices in community mental health settings, and limited research on factors related to recovery outcomes [22].

Consumer Perspectives on Community Mental Health Care

Given this historical context, it is not surprising that accounts of the mental health system authored by adults with mental illness appeared in scholarly discourse by the beginning of the 1980s. For example, Judi Chamberlin, organizer and activist in the survivor movement, published *On Our Own: Patient-Controlled Alternatives to the Mental Health System* in

1978 [23]. First-person accounts written by adults with schizophrenia and their families became a consistent feature in the prestigious research journal *Schizophrenia Bulletin* beginning in 1979 [9]. The views of adults with mental illness have significantly influenced scholarly definitions and processes that are thought to characterize mental health recovery [24].

More recently, researchers have solicited the views of adults with mental illness related to such issues as the implementation of recovery principles in community mental health settings [25, 26], obstacles to employment [27], and compliance with psychiatric medication [28]. Yet, there are few existing studies that have examined consumers' experiences of the mental health system over time. Some prior research has focused on adults with mental illness who were activists in the consumer/survivor movement to examine their identity transformation from "patient" to "activist" over time [29, 30]. In a recent archival study, Gumber and Stein (2013) used first-person accounts published in *Schizophrenia Bulletin* over a 30-year period to examine authors' views of the mental health system [9]. Study results suggest remarkable consistency in the narratives of adults with schizophrenia about the mental health system across the three decades of published accounts. However, the published narratives used in the research were not specifically designed to address changes in the mental health system over time as experienced by adults with schizophrenia.

Present Study

The present qualitative study examined changes in the community mental health system over time as reported by adults diagnosed with schizophrenia who have been involved in the community mental health system for between one and four decades. The study focuses on the subjective experiences and meaning that adults give to their years of engagement with the community mental health system and their perspective on how mental health care has changed across time.

The present research posed two basic research questions: To what extent do adults with schizophrenia who have long-term involvement in the mental health system view changes in their mental health care across time? What factors do these consumers identify as being most important to their mental health and personal well-being?

Sample Characteristics

The sample consisted of a total of 14 adults (7 men, 7 women) diagnosed with schizophrenia who were engaged in mental health services at a community mental health center in Northwest Ohio. To be eligible to participate in the research, adults needed to have a diagnosis of schizophrenia, have received mental health services for 10 years or more, and have been hospitalized at least twice for mental health reasons. Characteristics of the individuals in the sample can be found in Table 1.

The majority of the sample was Caucasian (85.7 %), African American (7.1 %) and Hispanic (7.1 %). and the mean age of participants was 50.6 years (*SD* = 10.16). A total of seven adults in the sample were married (50 %), five were never married (35.7 %) and two (14.3 %) were divorced. Seventy-one percent of the participants (10) reported that they are currently employed, working an average of 8.53 h per week (*SD* = 5.3). Of those adults who reported being employed, eight reported working in the custodial field (80 %). The average monthly income reported by the sample was $1,181 (*SD* = $878).

The average number of years in the mental health system reported by the present sample was 27.4 (*SD* = 9.6) with an average of 9.7 (*SD* = 8.6) psychiatric hospitalizations

Table 1 Participant characteristics

Participant[a]	Gender	Age	Income[b]	Years in system[c]	Age of onset	Total number of hospitalizations	Decade of first and most recent hospitalizations	Years since first hospitalization
Adults with less than 27 years in the mental health system								
Sandy	Female	33	$800	12	22	6	2000s/2000s	8
Beth	Female	38	$775	12	26	10	2000s/2000s	12
Joseph	Male	54	$1100	20	26	3	1980s/2000s	28
Donna	Female	56	$850	21	35	2	1990s/1990s	21
Emily	Female	35	$3800	22	13	15	1990s/2000s	22
Anna	Female	42	$1200	26	16	4	1990s/2000s	21
Bill	Male	44	$1030	26	17	3	1980s/2010s	26
Adults with more than 27 years in the mental health system								
Ruth	Female	62	$2000	28	34	10	1980s/2000s	28
Jack	Male	53	$700	30	21	7	1980s/1990s	30
Michael	Male	55	N/A	30	24	26	1980s/2000s	30
Susan	Female	56	$1100	36	20	30	1970s/2010s	36
Daniel	Male	62	$750	40	23	8	1970s/2000s	40
Roger	Male	59	$600	41	18	2	1970s/1980s	39
Connie	Female	60	$600	42	20	10	1970s/2000s	40

[a] Pseudonym

[b] Monthly income

[c] Number of years of involvement in the mental health system

reported by participants. Adults in the sample reported being an average of 22 years old (*SD* = 6.3) at age of onset or when they first experienced symptoms and participants reported an average of 27.2 (*SD* = 9.9) years since their first hospitalization. The sample was divided into two groups based on the number of years in the mental health system, with seven participants reporting less than 27 years and seven participants reporting more than 27 years in the mental health system. As expected, results of a series of one-way analysis of variance (ANOVAs) found significant differences between the two groups such that participants who had more than 27 years involvement with the mental health system were older ($M = 58.2$; $SD = 3.5$) than participants with less than 27 years involvement in the mental health system ($M = 43.1$; $SD = 8.9$; F (1, 12) = 17.01, $p < 0.01$). Results of one-way ANOVAs found no significant mean differences between participants in the two groups in terms of age of illness onset (F (1, 12) = .04, $p = 0.84$), reported monthly income ($F(1, 11) = 0.68$, $p = 0.43$), or total number of psychiatric hospitalizations (F (1, 12) = 2.55, $p = 0.14$). Chi square analysis indicated that there were no differences between participants in the two groups in terms of gender ($X^2 = 1.2, p = 0.21$) and current employment status (employed/not employed; ($X^2 = 1.4$, $p = 0.24$)) than would be expected by chance.

Method

Procedure

Approval to conduct the research was given by the Institutional Review Board at Bowling Green State University. Individuals were informed about the study through fliers and announcements made by agency staff at a community mental health center and an associated psychosocial rehabilitation clubhouse in Northwest Ohio. Informed consent was obtained from all individual participants included in this study. Eligible participants completed individual semi-structured interviews that lasted about 90 min conducted at a time and location of their choice. Interview topics for participants included demographic information, adults' reports of inpatient and outpatient experiences, their views of the mental health system over time, and the role of mental health care in their lives. Interviews were conducted by doctoral students in clinical psychology who had extensive experience with the interview protocol. Participants were given a $25 gift card at the completion of the interview as a token of appreciation for their time. All interviews were audio recorded and transcribed verbatim. Atlas.ti qualitative software was used for data management and analysis.

Measures

Qualitative Interview Protocol

A semi-structured interview was developed for the present study that asked adults with schizophrenia about their experiences regarding various aspects of their mental health care across the years of their involvement in the mental health system. Participants were first asked to provide basic demographic information and mental health services history (e.g., psychiatric diagnoses, number of psychiatric hospitalizations, medication and substance use history). Participants' reports of psychiatric hospitalizations (e.g., first hospitalization and most recent) and outpatient treatment (e.g., first outpatient treatment and current) were used as time points to help participants to reflect on their experiences with community mental health care across time. After describing their first and most recent hospitalization experiences in detail, individuals were asked to recall the types of mental health services that they received during these hospitalizations from a list of eight different types of mental health services described by interviewers. Similarly, after they described their outpatient experiences, participants were asked to recall outpatient services they received using a list of seven types of services. The list of hospitalization and outpatient mental health services included in the interview reflected basic services available in community mental health from the 1970s to the present. In the context of the interview, participants were also asked to reflect upon specific changes in the mental health system they observed over time and to share views about the role of mental health care in participants' lives.

Results

Analytic Approach

Interviews were transcribed verbatim and interview texts were examined using content analysis techniques [31]. After multiple readings of the transcripts, initial codes were generated to characterize participants' descriptions of changes in their mental health care over time and their views about factors related to their well-being. An examination of participants' narratives about their experiences receiving mental health care and their reflections on changes in the mental health system more generally were also included in the present analysis. In addition to examining common themes across all interviews, unique themes based on grouping participants' narratives according to their reported length of involvement in the mental health system (i.e., less than 27 years or more than 27 years in the mental health system) were identified. A total of 1,028 utterances from 14 participants were categorized into themes by a team of five researchers. Utterances were then re-sorted into themes by two judges working independently. Differences in the coding of utterances were resolved by review and discussion.

Quantitative analysis was conducted to examine self-reported differences in the types of mental health services participants reported receiving during their first and most recent psychiatric hospitalizations. Participants' responses to eight different types of services were classified as "yes" (reported receiving the service) or "no" (reported not receiving the service) for their first and most recent hospitalization experiences and were then summarized in separate 2 × 2 contingency tables for each service. McNemar Tests were conducted to determine if there were significant differences in the proportion of the total sample who reported receiving each of the eight services during their first and during their most recent hospitalizations. Similar contingency tables were created for each of seven different types of community mental health services participants reported receiving during their initial and current outpatient experiences. McNemar Tests were conducted to examine differences in the proportion of the total sample who reported receiving each of these outpatient services during their initial and current outpatient service experience.

Hospitalization and Outpatient Services

Table 2 summaries participants' responses to the types of services they received during their initial and latest hospitalization and outpatient experiences grouped as a function of their level of involvement in the mental health system and for the total sample. Results of

Table 2 Participants receiving hospital and community mental health services at first and current use of service

Type of service	Initial use of service			Current use of service		
	Less than 27 years[a] ($n = 7$)	More than 27 years[b] ($n = 7$)	Total ($n = 14$)	Less than 27 years[a] ($n = 7$)	More than 27 years[b] ($n = 7$)	Total ($n = 14$)
Hospital services						
Medication	7	7	14	7	7	14
Group therapy	4	4	8	6	7	13
Individual therapy	0	3	3	3	4	7
Other services (art, pet, recreational therapy)	6	3	9	6	6	12
Discharge planning	3	5	8	4	6	10
Involuntary admission	2	3	5	0	1	1
Forced medication	2	2	4	1	1	2
Restraint or seclusion	1	1	2	0	2	2
Community mental health services						
Medication	6	5	11	7	7	14
Group therapy	4	2	6	4	2	6
Individual therapy	7	4	11	3	3	6
Case management	2	2	4	6	7	13
Supported employment/housing	3	1	4	4	7	11
SSDI, food stamps, or medicaid	1	0	1	4	7	11
Financial services (e.g. payee)	2	1	3	3	2	5

[a] Less than 27 years in the mental health system

[b] More than 27 years in the mental health system

McNemar Tests found no significant differences in the proportion of sample participants who reported receiving any of the eight types of mental health services during their first and during their most recent hospitalizations.

Results of McNemar Tests that compared participants' reports of community mental health services that they currently receive with their reports of outpatient services that they initially received suggest that a significantly greater proportion of sample reported currently receiving case management services ($\chi^2 = 7.1$; $p < 0.001$), and supported employment and/or supported housing services ($\chi^2 = 4.0$; $p < 0.05$), relative to their reports of their initial outpatient services. There were no significant differences in the proportion of the sample reporting that they received medication, individual therapy, group therapy, or government entitlements during their first and current use of outpatient services.

Changes in Mental Health Care Over Time

Based on their lived experience, adults with schizophrenia offered important insights into the ways in which their mental health care had changed. Themes that characterize adults' narratives about their experiences with mental health care over time and representative quotes from participants are summarized below.

Regardless of their length of involvement in the mental health system, a majority of participants (57 %) noted overall *changes in their inpatient hospitalization experiences* across time. In their narratives, adults described *decreased length of hospitalization stays* and *greater differentiation of individuals placed on psychiatric wards* as major changes in their mental health care. For example, Emily is a 35-year-old woman who was first hospitalized in the 1990s and most recently hospitalized in the late 2000s. Emily said: "they don't keep you long in the hospital…they'll only keep you [now] for about three or five days." She also explained: "They have separate [wards] for adults and for adolescents now" and that "the seventh floor [of the psychiatric hospital] is for people that are more psychotic...and the third floor [is] where they put the people who were more depressed and not acting out as much."

It should be noted that participants in the study also described considerable personal distress and trauma associated with psychiatric hospitalization, regardless of the period of time in which they were hospitalized. A majority of participants (64 %) reported hospitalization experiences that included harsh treatment by staff members, a sense of helplessness and lack of personal control, little or no information given to them about their psychiatric condition or treatment options, and unsuccessful communications between themselves and mental health care providers. These hospitalization experiences were reported by participants across the four decades in which their hospitalizations took place. Although adults with schizophrenia in the present study did perceive some changes in inpatient care across time, many individuals' narratives centered on negative hospitalization experiences.

In terms of outpatient services, a total of 50 % of adults with schizophrenia in the sample described positive changes over time in the *overall quality of mental health care.* All of the participants who described positive changes in the quality of care had been involved with the mental health system for more than 27 years. For example, Roger, a man with 41 years involvement in the mental health system noted, "[In the past] a lot of people were worse off, like they were destitute. Services were so poor...A lot has changed." Similarly, Daniel a 62-year-old man with 40 years involvement in the system, described his current experiences: "You've got your medications, you've got your doctors, you've got your case manager, you've got your group therapies, …you've even got a payee if you need some financial support…They really try hard here to not let people fall through the cracks."

Six of the 14 participants (43 %) indicated that they have experienced *more humane treatment in the mental health system over time*. For example, Joseph is a 54-year-old man who entered the mental health system in the mid-1980s. Joseph explained that, in the past, he was not "treated very good," by mental health providers, and went on to describe a hospital experience where he was forced against his will to take medications, was placed in seclusion for a number of days, and spent a prolonged amount of time in restraints. As Anna, a 42-year-old woman who was first hospitalized in the 1990s, notes: "It's changed. It's more about the client now than anything else." Anna described a current outpatient experience where she was having debilitating symptoms and felt that her case manager and other staff went "out of their way" to help her.

A total of six of the 14 participants (43 %) felt that they currently experience more of a *partnership with their treatment providers* than they did in the past. All of these participants had been involved with the mental health systems for more than 27 years. For example, Daniel, first hospitalized in 1970s, describes his earliest experiences with outpatient services: "You were discharged from the hospital [and] you either go by their system or you just didn't exist…you fight what [they're] trying to do for you. They'd say, "There's the door. Goodbye." Michael, a man with 30 years involvement in mental health system, describes his current experience: "Now at the mental health center, they have the treatment lady that sits down with me to talk about what I want. In terms of meeting [me] halfway, the client-therapist relationship is fine."

Factors that Contribute to Mental Health and Personal Well-being

Overall, adults with schizophrenia who participated in the present study identified traditional mental health services, relationships with mental health professionals, and relationships with friends and family as the three factors that made important contributions to their sense of personal well-being. Findings suggest that the emphasis that participants placed on these factors differed as a function of their length of involvement in the mental health system.

For adults with more than 27 years in the mental health system, six of the seven (86 %) participants reported that *traditional mental health services* made the most important contributions to their sense of well-being. As a woman with 21 years in the mental health system, Donna described, "Medications…help me so I don't…hear voices. It helped with the paranoia…it takes away the fear." Jack, a man who first entered the mental health system in the 1980s, explained: "…basically mental health services have saved my life because [otherwise] I would've been a statistic…I would have definitely killed myself." He goes on to say "Mental health services are very important! It dwarfs everything else…Except maybe my family. And it's still more important than family."

Five of the seven consumers (71 %) in this group also reported that their *relationships with professionals* made important contributions to their sense of well-being. Connie, who has been involved in the mental health system for the last 42 years, explained, "My current case manager, payee, and therapist are three people that have had a really positive impact on my life."

In contrast, six of the seven adults (86 %) with less than 27 years in the mental health system felt that their *relationships with their friends and family* were the most important factor that contributed to their personal well-being. Emily, a woman with 22 years in the mental health system explained that, “Family helped by just being supportive and telling me I am going to be ok, and staying with me to prevent me from hurting myself...I have so much love for my family…they would do anything for me.” Beth, a woman who first entered the mental health system in the early 2000s, remarked, “Whenever I want to talk about symptoms I might have or my problems or my life, you know, [my family] is always there.” A woman with 12 years in the mental health system, Sandy, said, “[I] like spending time with my friends. That kind of helps me out, you know, especially like real close friends.”

Discussion

The present qualitative study examined perceived changes in community mental health care across time as reported by 14 adults diagnosed with schizophrenia who have been involved in the mental health system for the past one to four decades. Present findings indicate that the overall proportion of sample participants did not report significant differences in their use of specific mental health services between their first and most recent hospitalization experiences. Significant differences were found in the overall proportion of the sample who reported currently receiving case management and supportive services (employment, housing) relative to services they received during their initial outpatient experiences. In describing their experiences, adults with long-term involvement in the mental health system also identified a number of positive changes in their mental health care over time.

Adults with schizophrenia in the present study noted improvements in the overall quality of mental health care and felt that they had received more humane treatment across the course of their time in the mental health system. Interestingly, adults involved with community mental health care for over a quarter of a century were most likely to identify these types of positive changes. In addition, individuals also described a greater sense of partnership with mental health care providers over time, a characteristic directly related to recovery-oriented mental health care [32]. Collaboration between mental health care consumers and providers in identifying and working towards consumers’ goals is considered fundamental to a recovery orientation. Given general assumptions about the inability of adults with schizophrenia to attend to interpersonal cues, it is particularly noteworthy that individuals described greater partnerships with providers, a somewhat nuanced feature of interpersonal relationships, as an important change in mental health care. Present findings underscore that a sense of partnership in working with practitioners is recognized and appreciated by adults with schizophrenia [33].

Themes in the narratives of study participants suggest that “things are getting better” in community mental health care. In fact, none of the participants expressed that their current experiences with the mental health system were worse than in the past. Nevertheless, present findings did not exactly provide a ringing endorsement of positive progress in community mental health over the past four decades as experienced by consumers. The majority of praise for mental health services was evident in about forty to fifty percent of participants’ narratives, but a number of participants did not share this perspective. Participants also did not describe many experiences within the mental health care system that reflected key dimensions of the recovery process as articulated in current literature. Aspects of recovery, such as involvement in meaningful activities, hopefulness and purpose, and community integration, are integral to recovery-oriented service delivery in the scholarly literature [34], but these themes were not generally discussed by the present sample.

Adults with schizophrenia in the present study identified decreased length of psychiatric hospitalizations and greater differentiation of individuals placed on psychiatric wards as noticeable changes in their inpatient experiences across time. Adults' views are consistent with studies that suggest a significant trend towards shorter hospital stays in the United States for people with mental illness due to both economic and treatment-related factors [35]. In the present study, participants did not express strong views about the personal benefits or costs of shorter stays in the hospital and simply noted that more recent hospital stays were brief when compared to those that they had experienced in the past.

Overall, adults' narratives about their hospitalization experiences in the present study are consistent with an analysis of first-person accounts published in *Schizophrenia Bulletin* from 1979 to 2010 conducted by Gumber and Stein [9]. Psychiatric hospitalization was a central topic in the first-person accounts of adults with schizophrenia and negative accounts of hospitalization far exceeded accounts of positive hospitalization experiences across the three decades of publications. Similarly, in the present study, negative hospitalization experiences were described by adults with schizophrenia across their four decades of the involvement with the mental health system. Regardless of the mental health reform era in which they were hospitalized, participants recounted hospitalization experiences that made them feel unnecessarily helpless, demoralized, and traumatized. As Storm and Davidson (2010) noted, inpatient settings represent the most challenging arena to involve adults with mental illness in their own care [36]. Treatment philosophies, structural hierarchies, policies, and practices in most psychiatric hospital settings create impediments to the inclusion of patients in their own treatment [36]. Adults in the present study generally expressed the absence of any sense of control or personal choice during prior hospitalizations as particularly troubling. Present findings support the movement towards greater involvement of consumers in their own care, even in inpatient hospital settings [37].

In the present study, adults with greater length of involvement in the mental health system tended to attribute traditional mental health services as most central to their sense of well-being, while adults with relatively fewer years of involvement tended to attribute relationships with friends and family as most relevant to their overall well-being. Several interpretations of this finding are possible. It may be that adults with longer involvement in the mental health system have more debilitating symptoms and fewer informal social supports than adults with shorter involvement and therefore must rely on the mental health system as a primary source of support. Although this interpretation is certainly plausible, listening closely to the stories of participants enabled us to notice many thoughtful reflections about mental health services among those adults who had been coping schizophrenia for over a quarter century. In general, adults with a greater length of involvement felt that their lives would have been considerably more difficult without access to mental health services. These adults believed that without access to psychiatric medications, outpatient services, and even hospitalization services, they would likely not have their current supports and may not even be alive today. These adults also described the significance of their relationships with mental health professionals in providing assistance and support. Present findings do not negate client satisfaction studies that suggest that people with a serious mental illness were generally less satisfied with their mental health care than individuals who did not have a serious mental illness [38]. Rather, present results may simply be an acknowledgement that these adults have continued their involvement with mental health services and providers for decades and believe that doing so has contributed to stability and improvements in their lives.

In contrast, participants whose involvement with the mental health system began primarily in the 1990s and 2000s tended to attribute relationships with family and friends as the most important contribution to their personal well-being. Adults with relatively shorter lengths of service involvement generally acknowledged benefits of mental health services, but characterized social connectedness outside of the mental health system as "most important" to their personal well-being. This finding may indirectly reflect the influence of mental health care reforms initiated in the 1990s that recognized the value of supportive ties and encouraged adults with mental illness to cultivate and maintain social networks of family and friends [19]. It is also possible that these participants had less debilitating symptoms than adults with longer involvement and thus were better able to maintain relationships with family and friends. However, participants in this group were not significantly different to participants with longer mental health system involvement in their reports of number of psychiatric hospitalizations, employment status, and income.

There are a number of possible reasons why no significant differences were found in the present study in participants' overall reports of mental health services used during their first and most recent hospitalization experiences. It may be that no differences exist in participants' perceived use or receipt of mental health services (e.g., medication, individual and group therapy) over time. Although findings need to be interpreted cautiously, this suggests that the availability of different types of mental health services have not appreciably changed over time from the perspective of consumers. However, methodological limitations, including the number and types of mental health services listed in the qualitative interview protocol, and the reduced sample size inherent to all qualitative research, may have limited the capacity to detect differences. Additionally, participants differed in the time of their first and most recent hospitalizations, but data on the use of mental health services were aggregated across participants, possibly obscuring differences. Participants' may have also encountered difficulty recalling the types of services they received in the past, although memory impairments were not explicitly acknowledged by any participant in the present sample. Notably, significant differences were found with regard to participants' reports of initial and current outpatient services in ways that aligned with the characteristics of prior mental health care reform movements.

Study Limitations and Implications for Clinical Practice

Although the findings are intriguing, the present qualitative study is limited in a number of respects. The study used a small, non-random sample of adults diagnosed with schizophrenia who lived in a mid-western city in the United States. No claims can be made about the generalizability of participants' experiences to the larger population of adults diagnosed with schizophrenia with long-term involvement in community mental health services in different geographic locations or among adults with different ethnic, cultural, educational, or socioeconomic backgrounds. It is also not clear how the interview context (e.g. wording of interview questions, flow of interview exchanges), sample selection, or memory issues may have impacted the narratives of participants and study findings.

For the past forty years, mental health reforms in the United States have promised radical improvements and transformative practices in mental health care, with the recovery movement being a most recent example. A goal of the present study was to help ground mental health care reforms in the lived experience of adults with serious mental illness who have decades of involvement in the community mental health system. As informal historians of the mental health system, study participants reported no radical shifts in their mental health care experiences over time. Rather, consumers either did not identify changes or felt that they had experienced some gradual, positive changes in mental health care over time. Some adults' experiences are consistent with current recovery principles, including those that emphasize humane treatment, increased collaboration between professionals and consumers, and encourage social connectedness outside of the mental health system. Although encouraging, study findings also suggest that many of the dramatic changes in mental health care delivery described by the recovery movement have yet to be experienced by people with long-term involvement in the mental health system.

Despite study limitations, the present study underscores the central importance of the lived experience of adults with schizophrenia in grounding rhetoric on mental health care reforms [39]. The present study also serves as a simple reminder to clinicians, researchers, and policy makers that individuals who have lived through decades of mental health reform movements have an invaluable perspective to share as consumers of mental health services. Individuals with long-term involvement in the mental health system have intimate experience with a wide variety of "best" practices and policies, yet many of the challenges these consumers face still remain.

Acknowledgments Authors express their gratitude to individuals who participated in this study for sharing their experiences and insights.

Conflict of interest None.

References

1. President's new freedom commission on mental health. In: Achieving the promise: transforming mental health care in America. Final report. Department of Health and Human Services. DHHS pub no SMA-03—3832, Rockville, 2003. http://govinfo.library.unt.edu/mentalhealthcommission/. Accessed 19 Aug 2014.
2. Davidson L, Lawless MS, Leary F: Concepts of recovery: competing or complementary? Current Opinion in Psychiatry. 18:664–667, 2005.
3. Davidson L, Tondora J, O'Connell MJ, et al.: Creating a recovery-oriented system of behavioral health care: moving from concept to reality. Psychiatric Rehabilitation Journal 31:23–31, 2007.
4. National consensus statement on mental health recovery: Substance Abuse and Mental Health Services Administration. Rockville, MD, 2005. http://www.samhsa.gov/recoverytopractice/RTP-Contribution-Detail-For-National_Consensus_Statement_on_Mental_Health_Recovery-133.aspx. Accessed 19 Aug 2014.
5. Bachrach LL: Assessment of outcomes in community support systems: results, problems, and limitations. Schizophrenia Bulletin 8:30–61, 1982.
6. Turner JC, TenHoor WJ: The NIMH community support program: pilot approach to a needed social reform. Schizophrenia Bulletin 4:319–349, 1978.
7. Braslow JT: The manufacture of recovery. The Annual Review of Clinical Psychology 9:781–809, 2013.
8. Davidson L, Ridgway P, Wieland M, et al.: A capabilities approach to mental health transformation: a conceptual framework for the recovery era. Canadian Journal of Community Mental Health 28:35–46, 2009.
9. Gumber S, Stein CH: Consumer perspectives and mental health reform movements in the United States: 30 years of first-person accounts. Psychiatric Rehabilitation Journal, 2013. doi:10.1037/prj0000003.
10. Cutler DL, Bevilacqua J, McFarland BH: Four decades of community mental health: a symphony in four movements. Community Mental Health Journal 39:381–398, 2003.
11. Koyanagi C: Learning from history: deinstitutionalization of people with mental illness as a precursor to long-term care reform. Kaiser Commission on Medicaid and the Uninsured, 2007. http://kff.org/medicaid/report/learning-from-history-deinstitutionalization-of-people-with/. Accessed 19 Aug 2014.
12. Bachrach LL: Asylum and chronically ill psychiatric patients. American Journal of Psychiatry 141:975–978, 1984.

13. Barton R: Psychosocial rehabilitation services in community support systems: a review of outcomes and policy recommendations. Psychiatric Services 50:525–534, 1999.
14. Van Tosh L: The evolution of the consumer movement. Psychiatric Services 57:1215–1216, 2006.
15. Rissmiller DJ, Rissmiller JH: Evolution of the antipsychiatry movement into mental health consumerism. Psychiatric Services 57:863–866, 2006.
16. Swarbrick M. Historical perspective—from institution to community. Occupational Therapy in Mental Health 25:201–223, 2009.
17. McLean A: The Mental Health Consumers/Survivors Movement in the United States. In: Scheid TL, Brown TN (Eds) A Handbook for the Student of Mental Health, 2nd edn. New York, Cambridge University Press, pp. 461–477, 2010.
18. Tomes N: The patient as a policy factor: A historical case study of the consumer/survivor movement in mental health. Health Affairs 25:720–729, 2006.
19. Anthony WA: Recovery from mental illness: the guiding vision of the mental health service system in the 1990's. Psychiatric Rehabilitation Journal 16:11–23, 1993.
20. Davidson L, O'Connell M, Tondora J, et al.: Recovery in serious mental illness: a new wine or just a new bottle. Professional Psychology 36:480–487, 2005b.
21. Jacobson N, Curtis L: Recovery as policy in mental health services: strategies emerging from the states. Psychiatric Rehabilitation Journal 23:333–341, 2000.
22. Silverstein SM, Bellack AS: A scientific agenda for the concept of recovery as it applies to schizophrenia. Clinical Psychology Review, 2008. doi:10.1016/j.cpr.2008.03.004.
23. Chamberlin J: On Our Own: Patient-Controlled Alternatives to the Mental Health System. New York, Haworth, 1978.
24. Ostrow L, Adams N: Recovery in the USA: From politics to peer support. International Review of Psychiatry, 2012. doi:10.3109/09540261.2012.659659.
25. Barrett B, Young MS, Teague GB, et al.: Recovery orientation of treatment, consumer empowerment, and satisfaction with services: a meditational model. Psychiatric Rehabilitation Journal , 2010. doi:10.2975/34.2.2010.153.156.
26. Marshall SL, Oades LG, Crowe TP: Mental health consumers' perceptions of receiving recovery-focused services. Journal of Evaluation in Clinical Practice, 2009. doi:10.1111/j.1365-2753.2008.01070.x.
27. Kirsh B: Work, workers, and workplaces: a qualitative analysis of narratives of mental health consumers. Journal of Rehabilitation 66:24–30, 2000.
28. Smardon R: 'I'd rather not take Prozac': Stigma and commodification in antidepressant consumer narratives. Health 12:67–86, 2007.
29. Cohen MB: Voices from an invisible movement: mental health consumer/survivor/ex-patient activism. Reflections 10:50–61, 2004.
30. Morrison LJ: A matter of definition: acknowledging consumer/survivor experiences through narrative. Radical Psychology 5:6, 2006.
31. Miles MB, Huberman AM, Saldana J: Qualitative Data Analysis: A Methods Sourcebook. Thousand Oaks, Sage, 2014.
32. Anthony WA: Expanding the evidence base in an era of recovery. Psychiatric Rehabilitation Journal 27:1–2, 2003.
33. Mead S, Copeland ME: What recovery means to us: consumers' perspectives. Community Mental Health Journal 36:315–328, 2000.
34. Davidson L, O'Connell M, Sells D, et al.: Is there an Outside to Mental Illness? In: Davidson L (Ed) Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia. New York, New York University Press, pp. 31–60, 2003.
35. Lee S, Rothbard AB, Noll EL: Length of stay for persons with serious mental illness: effects of hospital and regional characteristics. Psychiatric Services, 2012. doi:10.1176/appi.ps.201100412.
36. Storm M, Davidson L: Inpatients' and providers' experiences with user involvement in inpatient care. Psychiatric Quarterly, 2010. doi:10.1007/s11126-009-9122-6.
37. Chinman M, Young AS, Hassell J, et al.: Toward the implementation of mental health consumer providers services. The Journal of Behavioral Health Services & Research 33:176–195, 2006.
38. Kilbourne AM, McCarthy JF, Post EP, et al.: Access to and satisfaction with care: comparing patients with and without serious mental illness. The International Journal of Psychiatry in Medicine 36:383–399, 2006.
39. Borg M, Karlsson B, Lofthus A, et al.: Hitting the wall:" lived experiences of mental health crisis. International Journal of Qualitative Studies on Health and Well-being, 2011. doi:10.3402/qhw.v6i4.7197.

Catherine H. Stein, PhD is a Professor in the Psychology Department at Bowling Green State University.

Jaclyn E. Leith, PhD is a post-doctoral fellow at the Durham North Carolina Veterans Administration Medical Center.

Lawrence A. Osborn, MA is a doctoral candidate in the clinical psychology program at Bowling Green State University.

Sarah Greenberg, MA is a doctoral candidate in the clinical psychology program at Bowling Green State University.

Catherine E. Petrowski, MA is a doctoral candidate in the clinical psychology program at Bowling Green State University.

Samantha Jesse, MA is a doctoral candidate in the clinical psychology program at Bowling Green State University.

Shane W. Kraus, PhD is a post-doctoral fellow at New England Mental Illness Research Education and Clinical Centers, VA Connecticut Healthcare System, and Yale School of Medicine.

Michael C. May, MA is a staff therapist at Metropolitan Family Services, Adult Mental Health Program, Chicago, IL.