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ORIGINAL ARTICLE

Family perspectives of how their relatives with mental illness benefit from Clubhouse participation: a qualitative inquiry

Chia-Ling Chung[1], Francesca Pernice-Duca[2], David E. Biegel[1], Marissa Norden[1], and Ching-Wen Chang[3]

[1]*Jack, Joseph and Morton Mandel School of Applied Social Sciences, Case Western Reserve University, Cleveland, OH, USA,* [2]*Department of Educational Psychology, Wayne State University, Detroit, MI, USA, and* [3]*Department of Social Work, The Chinese University of Hong Kong, Hong Kong*

Abstract

Background: Although researchers have demonstrated the benefits of psychosocial Clubhouse participation on a number of clinical and psychosocial outcomes, few studies have investigated the consumer's participation from the perspectives of others.
Aim: This study aimed to investigate family members' perspectives of how Clubhouse programming has affected consumers' recovery.
Method: Twenty-four relatives of Clubhouse members were interviewed using a semi-structured protocol. Relatives were nominated by their Clubhouse members as their family member who provided them with the most social support. All interviews were transcribed and underwent content analysis yielding multilevel coding.
Results: Four main dimensions emerged from family interviews about how Clubhouses affected their relatives. These dimensions aligned with areas of clinical recovery and personal growth. Family members observed and noted changes in: (1) positive affective changes, (2) improved goal directed and challenging behaviors, (3) positive attitude changes and (4) greater social interactions.
Conclusion: As one of the first studies to document the perspectives of the relatives of Clubhouse members, this exploratory study indicates that family members recognize positive changes in their Clubhouse family members and these changes align with areas of functional recovery. Implications for practice and future studies are discussed.

Keywords

Adults with severe mental illness, clubhouse, family caregivers, qualitative research

History

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Introduction

Family caregivers are family members who provide ongoing emotional or instrumental support and constitute a significant portion of the social support networks of their relatives living with a psychiatric disability, such as schizophrenia (Biegel et al., 2013; Corrigan & Phelan, 2004). Caregivers' extensive contact with their ill relatives can result in burden of care leading to caregivers' emotional distress (Lefley, 1996). Feelings of anger, anxiety as well as depressive symptoms can permeate the relational dynamics between a caregiver and their ill relative, regardless of whether they share the same household (Stjernswärd & Östman, 2008).

Although family involvement can be helpful to clinicians and has been noted as an evidence-based practice for the treatment of schizophrenia and bipolar disorders (McFarlane, 2005), family members' observations related to treatment outcomes, service utilization and the intervention processes are not routinely incorporated into practice. This may, in part, be due to differing perceptions between mental health agency staff and families (Lasalvia et al., 2012).

Correspondence: Chia-Ling Chung, M.S.W., Mandel School of Applied Social Sciences, 10900 Euclid Avenue, Cleveland, OH 44106, USA. E-mail: cxc575@case.edu

Even though family members may not be directly involved in rehabilitation programs for their relatives with mental illness, because of their extensive involvement with their relatives, they are a significant source of providing a unique perspective of whether treatments or programs have any positive or negative affect on their loved ones. The current investigation involves an examination of family members' perspectives of their loved ones who participate in a recovery-oriented program, the Clubhouse. Qualitative inquiry has been used to study family narratives about mental health treatment of adult relatives with severe mental illness (SMI) (Marquez & García, 2013). Yet, to date, there has been no systematic investigation of family perspectives of relatives with SMI who are participating in Clubhouses. Given that families continue to serve as the largest source of social support for members (Biegel et al., 2013; Pernice-Duca, 2010), it is critical that family members' perspectives of the impact of Clubhouses on their relatives be examined.

The Clubhouse model

Clubhouses are community-based mental health organizations providing holistic psychiatric/psychosocial recovery services. The model is predicated on a sense of community through

voluntary participation and offers opportunities for competitive employment, education and ongoing peer support (Doyle et al., 2013). Clubhouses emphasize the importance of partnerships between consumers (members) and the professional staff (Doyle et al., 2013). There are currently over 300 Clubhouses worldwide and over 200 in North America (Clubhouse International, 2015). With such a significant presence in the world, the Clubhouse Model is underrepresented in research examining the impact on individuals by those who care for them (Pernice-Duca et al., 2015).

Aims/objectives

The aim of this study is to document the role of the Clubhouse from the perspective of a significant social network member (e.g. a parent, a sibling or an extended relative). This inquiry focuses on reports collected from significant family members about behavioral or attitudinal changes perceived in their relatives living with SMI and involved with the Clubhouse.

Methods

Approach

In-depth semi-structured confidential interviews were conducted with individual family members identified as key family support persons by active Clubhouse members. The interviews were designed to document the experiences of family members of Clubhouse members and to learn if they perceived changes, if any, in their loved ones. Gathering family reports about experiences with mental health services is an established methodology to investigate the impact of treatment (Marquez & Garcia, 2013). This study builds upon previous research and further investigates whether key family support persons corroborate experiences reported by Clubhouse members.

Procedures

Study interviewers were graduate students in social work and psychology training programs who were previously trained in qualitative methods as part of their academic work. Interviewers completed several hours of interview training for this project. During the training, each interviewer received a training manual clearly describing the purpose of the study, the role of the interviewer, the interview protocol and human subject protection. The training also involved pairing interviewers to role play interviews. Interviewers were closely supervised by the study investigators.

Key family members were identified by Clubhouse members who were randomly selected for a larger study located in a metropolitan area of the USA and described elsewhere (Biegel et al., 2013). Family members were interviewed via a structured approach designed to elicit responses about changes, if any, perceived in their relative's behavior since joining as a Clubhouse member. All interviews were ~1.5–2 h in length and were audio-recorded with informed consent and then transcribed. One research staff carefully checked the accuracy of the responses by simultaneously reviewing the audio recording and transcription. No significant deviations were identified between the recorded interviews and transcriptions. The authors' University Institutional Review Board for human subjects approved all study procedures.

Research participants

The sample of family members was recruited from a sample of Clubhouse members ($N = 126$) from the parent study (Biegel et al., 2013). In the parent study, a random sample of 126 Clubhouse members who were active members of the Clubhouse, aged ≥18 years and with a self-reported mental illness, were recruited by the Clubhouse staff and received in-person interviews. Clubhouse members in the larger study were asked to identify a family member who provided a significant level of social support within their social support networks. Thirty-eight family members were invited to participate, and 24 agreed and were scheduled for an interview. One participant was interviewed twice due to having two relatives participating in the Clubhouse, thus yielding a total of 25 interviews.

The 24 family members ranged in age from 25 to 87 years (Mean = 60.5; SD = 16.6). Two-thirds of the participants were female, mostly parents (59%) or siblings (38%) (Table 1). The quality of the family relationships perceived by Clubhouse members of the interviewees in this study is reported in the following dimensions. The average frequency of family contact was about once a week to several times a week. Clubhouse members expressed very positive relationships with their family members in terms of closeness to them (2.6/3), importance to them (2.7/3) and satisfaction with their relationships (3.3/4) (Table 2).

The 25 Clubhouse members of the interviewed family members ranged in age from 19 to 59 years (Mean = 41.6; SD = 11.0). The average length of being a Clubhouse member was a little more than 3 years, and the average number of Clubhouse visits was 176 times. More than two-thirds of the members were male. Three-fifths of them lived in a private apartment/house, and five of them lived with their families (Table 3).

Table 1. Characteristics of family members ($N = 24$).

Age (years), Mean (SD)	60.5 (16.6)
Gender, *n* (%)	
Male	8 (33)
Female	16 (67)
Relationship to the member, *n* (%)	
Mother	9 (38)
Father	5 (21)
Sister	5 (21)
Brother	4 (17)
Aunt	1 (4)
Education, *n* (%)	
Graduate school	5 (21)
College	5 (21)
Some college	10 (42)
High school or less	4 (17)
Marital status, *n* (%)	
Married	13 (54)
Never married	4 (17)
Widowed/divorced/separated	7 (29)
Ethnicity/race, *n* (%)	
African-American	16 (67)
Caucasian	8 (33)

Table 2. Quality of family relationship reported by Clubhouse members ($N = 25$).

	Mean (SD)	Observed range
Frequency of family contact (1 = Less than once per month; 6 = Almost every day)	4.2 (1.3)	1.7–6.0
Closeness to the family member (1 = Not very close; 3 = Very close)	2.6 (0.4)	1.4–3.0
The importance of the family member to your life (1 = Not very important; 3 = Very important)	2.7 (0.5)	1.0–3.0
The satisfaction of the family relationship (1 = Very dissatisfied; 4 = Very satisfied)	3.3 (0.7)	1.0–4.0

Table 3. Characteristics of Clubhouse members ($N = 25$).

Age (years), Mean (SD)	41.6 (11.0)
Length of membership (days), Mean (SD)	1145.4 (1129.4)
Number of Clubhouse visit (times), Mean (SD)	176.0 (167.8)
Gender, *n* (%)	
Male	17 (68)
Female	8 (32)
Diagnosis, *n* (%)	
Schizophrenia- spectrum disorder	15 (60)
Depression	5 (20)
Bipolar disorder	2 (8)
Other	3 (12)
Living status, *n* (%)	
Private apartment/house	15 (60)
Lives with family/significant other	5 (20)
Residential care	5 (20)

Measures

A structured interview was designed for inquiry about family members' experiences in a variety of domains relevant to supporting a relative with a psychiatric disability. The interview protocol was reviewed by an expert in qualitative methodology and underwent pilot testing. Participants were asked a number of sub-questions related to an overarching question about their relative's behavior since joining the Clubhouse (e.g. ''Have you noticed any changes in your relative since he/she started attending the Clubhouse?''). Questions were neutrally worded and follow-up probes were used to assist participants in providing depth or detail to their responses (e.g. ''Has there been a change in his/her coping with mental illness since joining the Clubhouse– Can you give me an example?'').

Analysis

Transcripts were analyzed using a method of describing, classifying and interpreting the text with a circular process wherein each transcript was reviewed multiple times in a circular or back and forth fashion, instead of in a linear manner (Creswell, 2007). To ensure credibility, two of the authors were directly involved in the data collection process. Two research staff who had attended the interview training reviewed transcripts to identify and classify plausible underlying meanings, to compare and categorize key narratives, to interpret and contextualize responses and to represent findings while utilizing a Consensual Qualitative Research approach (Hill et al., 2005). This methodology involved using open-ended questions to gather data, a team consensus approach to decision-making and at least one auditor to check the work of the research team. This multilevel inductive procedure involved the three research team members and the principal investigator (PI). Atlas ti 6.2 software (Berlin, Germany) was used to manage and analyze data.

For the first level coding, two research members worked independently to identify significant phrases relevant to the research question by making notes, generating initial codes and using the participant's exact phrase to represent the first level codes (Creswell, 2007), and then they met to establish consensus. The PI resolved discordant codes through reviews of each discordant code and discussions with team members and then made a final determination. Second level coding consisted of combining first level codes into broader, more concrete sets of categories. For the third and fourth level coding, inter-related themes and concepts were aggregated into several dimensions. The same procedures to establish reliability were used for the second, third and fourth level coding. To demonstrate the conformability, the use of direct quotations from respondents was employed.

Results

Family members were probed to report on any changes, positive or negative, pertaining to their relatives' Clubhouse participation. All interviewees noted at least one marked positive change. After coding, these responses were collapsed into four domains representing these changes: positive affective changes, improved goal-directed and challenging behaviors, positive attitude changes and greater social interactions.

Domain I: positive affective changes

This domain reflects interviewees who reported marked changes in their relatives' moods as it related to Clubhouse attendance. Interviewees described an increase in positive moods, such as their relative being ''happier than before'' or ''looking forward to attending the Clubhouse to meet and see people''.

> ''When he goes to the Clubhouse he's happy because everybody [is] happy to see him too''. [#003]

> ''I've noticed the times I've talked to him and I've seen him, he's much more behaved than he was before and much happier''. [#004]

> ''He just seems a lot more outgoing and a lot happier, a lot calmer, more confident. [The Clubhouse] gives him a purpose''. [#021]

In addition, interviewees indicated that their relatives became more active and engaged socially, which led to greater positive emotions.

> ''He's at work. He's social. He goes to the Clubhouse. He goes to church. His waking hours he's with people, and then I used to feel bad that he's home alone a lot, but he's

only home in the evening for a couple of hours and then he's in bed and getting ready for the next day''. [#021]

Domain II: improved goal-directed and challenging behaviors

Interviewees reported marked changes in members' daily living skills, less challenging behavioral issues, and a greater demonstration of initiative and motivation to engage in tasks and activities.

Improved daily living skills

Two-thirds of interviewees reported these important behavioral changes, such as keeping a regular daily schedule and sustaining better personal hygiene.

''Showering, getting up on time, getting dressed, clean clothes, keeping her apartment clean. Really I used to have to say 'Don't forget to wash your clothes. Don't forget to vacuum', and she's done it on her own''. [#021]

''She's very untidy. She could have on brand new stuff, but she'll just let them hang on her or she won't try to fix herself up, but now since . . . goes to the Clubhouse, now she started doing a little better than she was''. [#007]

Further, a greater motivation to complete daily living skills in order to go to the Clubhouse was highlighted across several narratives. This was one of the most consistent changes reported.

''Before the Clubhouse, he wouldn't get up until close to noon and 12:30, 1:00, whereas now he's getting up 7, 7:30 getting ready to go to the Clubhouse''. [#025]

Fewer challenging behaviors

Interviewees reported less ''problematic behaviors'', such as drug use or suicidal behaviors, as a result of Clubhouse attendance.

''He's more calmed down and he sees things differently than he did before. He couldn't see things too good before 'cause he was on drugs, but now that he's not doing that, he's not doing drugs, he's interested in going back and forth to the Clubhouse with his friends. He's doing much better now". [#007]

''I guess his behavior was that you know I told you he was suicidal, so that's changed. He's not as suicidal''. [#018]

Interviewees also described their relatives as demonstrating fewer behaviors that are often an aspect of their specific clinical disorders or a lack of self-regulatory skills that impact adult role functioning.

''She's much calmer, and she holds a much more now adult conversation with you. She kinds of reasons more, don't you think now?. . .'Cause before she would fly off the handle and oh storm and slam the door, but she has more of an adult behavior now''. [#011]

Domain III: positive attitude changes

Changes in the members' self-regard were reported, including reports of positive self-concepts, greater interests in hobbies and leisure activities, and/or motivation toward vocational/educational pursuits.

Changes in self-regard

Interviewees reported their relatives' attitudes toward life and themselves seemed more confident, responsible and reflected a greater sense of hope.

"His confidence levels are rising because when he does things for them at the Clubhouse, like help move furniture, at first he couldn't pick anything up because he was just so weak, but now he's getting stronger. He's standing up straight. He's keeping himself clean and he combs his hair every day, so he has got a great boost in his confidence''. [#016]

Changes in interests

Interviewees observed changes in their relatives social, recreational and personal interests over time.

''. . . he's done a lot of different things that he didn't do particularly before. He loves to go bowling and he loves it when they have movies or a hike or something like that''. [#023]

Higher motivation for work or educational pursuits

Interviewees reported that members showed a higher motivation in pursuing higher/formal education and interest in employment.

''He likes to read more, and he would like to get his GED. I think it has to be in the right setting. He does want to further his education, 'cause sometimes he tells me . . . He walks around this university and you know looks at the people and he's like 'Oh they look so smart'''. [#016]

''That's one thing specific that I know for certain that the Clubhouse had a part in. I know he's glad to be working, but I know with regard to working, he wants to be able to work . . . He wants to be able to support himself''. [#013]

Domain IV: greater social interactions

Family members described how the Clubhouse helps members have contact and sustain relationships with others. There is a perception of an enhanced social network in terms of both quality and quantity. Improved family interactions were also reported.

Greater social interaction and social skills

Interviewees noticed that the Clubhouse led to greater connection with peers, a sense of support and improved communication skills/social interactions.

''He was just so isolated, wouldn't talk or anything like that, and since he's been going to the Clubhouse, they have these little parties and they finally got him to dance after four years. So now he's a party machine''. [#016]

''He's more settled down and he's not so argumentative. He used to be real argumentative and doing different stuff like that. You couldn't tell him nothing, and doing things like that, but now he done kind of settled down a little and he's much better. Things are much smoother now''. [#007]

Larger and better quality social networks

Interviewees also reported that members' social networks have extended and improved – not only making friends within the Clubhouse, but also reaching out in the broader community.

''The social network has improved dramatically also, but he's always made friends wherever he goes, but now he has all the friends that he's made at the apartment complex and the members of the Clubhouse and wherever he goes. So well it's increased''. [#001]

''I think he's made new friends, just from taking the bus down there . . . I know he's definitely got friends in general and makes new friends still''. [#024]

Improved family relationships

Besides the peer network, interviewees also reported that members became more involved with their families.

''Before she started going Clubhouse, she would like to stay in the room, dark room, wouldn't watch television, but once she started doing that, she will watch television, she gets back into her game shows and things. She gets up and socialize with the family. Before she didn't do that''. [#014]

''She's much more helpful. She even calls and checks on her grandmother, where before she was against the world. She was against us, didn't want to help her grandmother, and now she'll call and 'Do you want me to bring you something from the store? Give me your list. I'm going to the store,' and she wants to make sure her grandmother has different little items that she wants. So she's more in tuned to people and more in tuned to helping now''. [#011]

Conclusion

Researchers have found that Clubhouses facilitate personal hope and recovery (Herman et al., 2005); bolster a sense of community that strengthens social connections (Pernice-Duca, 2008); and promote opportunities for individuals to work (Schonebaum et al., 2006). This qualitative inquiry revealed that family members corroborate many of the outcomes associated with the Clubhouse model. Though these interviewees were less educated and aware of the function of the Clubhouse, all interviewees identified as least one domain of change and made overwhelmingly positive responses, given the neutrality of the questions. This study provides a systematic and empirical investigation of family perspectives using a qualitative interview approach that allowed family members to discuss observed changes in their relatives without the constraints of specific clinical jargon, conceptualizations or expectations of change.

The Clubhouse program is posited within a humanistic framework with principles of social cognitive theory to guide specific elements that lead to recovery (Doyle et al., 2013). A non-judgmental, supportive and open interpersonal environment is at the core of driving both emotional and behavioral changes. Interviewees reported their relatives had less problematic behaviors, became more positive and developed better daily living skills/attitudes. These new findings directly correspond to previous studies about the benefits of recovery-oriented services like Clubhouses (Jung & Kim, 2012).

The emphasis on self-determination and a shared decision-making philosophy between staff and members, as the program's key tenets, work to facilitate members' personal empowerment and competencies. This brings outcomes such as improved self-regard and increased self-efficacy. Through exposure to social and recreational activities in the Clubhouse, members engage in various activities. This study found meaning in new experiences, such as going bowling with friends, as members experienced greater joy, confidence and social connection. Motivation to engage in leisure activities has been associated with increased recovery among people with SMI (Lloyd et al., 2007).

Further, interviewees identified increased helpfulness and responsibility. Greater reciprocity of support with family members is also predictive of greater recovery experiences (Pernice-Duca, 2010). Psychosocial programs have the potential to meet members' needs for affiliation by providing social connections and social support (Corrigan, 2003). Interviewees identified that their relatives had greater non-kin social support networks that led to the development of outside friendships. Along with expanded personal and social roles, social integration is an essential element of recovery (Turner-Crowson & Wallcraft, 2002), which may be helpful in maintaining healthy relationship with families (Östman & Hansson, 2004).

The Clubhouse model is based on the premise of psychiatric rehabilitation with an emphasis on psychosocial functioning and community inclusion. Although person-centered care is a method of customizing services and goals for consumers, Clubhouse is a holistic experience that is centered on building relationships through shared work and decision-making. These skills are theorized to translate to the wider ecology and provide a foundation for recovery from mental illness. Both Clubhouse and person-centered care emphasizes an acknowledgement of the patient as a ''person'', by understanding the individual personal meaning for mental illness, and the sharing of power and responsibility between mental health professionals and clients, which recognizes the sensitivity to patients' preferences for each shared decision-making (Mead & Bower, 2000; Gask & Coventry, 2012). Thus, Clubhouse aligns well with the philosophy undergirding person-centered care/personhood, however, it extends well beyond by providing a larger community for a consumer to belong and participate in their own recovery process. It is not

a service done onto a consumer, but the consumer empowered to partner with professionals to operate, lead and participate in the working community of the Clubhouse (Doyle et al., 2013).

Implications for practice

Although family members are not required to participate in the Clubhouse, they may hold formal board positions or sit on advisory committees; these are particularly important roles for them because participation allows for a differentiated level of family involvement, rather than being involved directly with their relatives' Clubhouse activities. These differentiated forms of family engagement within the Clubhouse community offer a setting for loved ones to develop their *own* social networks and social skills, apart from their kin. Further, this model reinforces that Clubhouses are akin to a business structure, providing a place for consumers to establish identities that lead to skills that help them move toward becoming valued and contributing members of society.

It is vital for practitioners to get the word out and to raise community awareness about psychosocial Clubhouses. Caregivers regularly identify the lack of services and supports to ''help their relatives regain skills to live independently'' (p. 6) and the lack of respite services as significant sources of frustration (Shankar & Senthil, 2007). Essentially, the lack of psychosocial rehabilitation programs thwarted any improvements or gains their relatives made during in-patient psychiatric care. Furthermore, family members report stress and frustration related to being solely responsible for finding activities and follow-up care to keep their relatives motivated to maintain their gains.

Limitations and future research

Transcripts indicated that interviewees had very little involvement with and information about the Clubhouse, which minimized their biases. With little firsthand knowledge, they had limited expectations of change. Further, they were not aware of the term ''recovery'', so the narratives were absent of jargon. The state in which the study was conducted operated only two Clubhouses, which may account for the lack of awareness of the model. We can be confident in the trustworthiness of the narratives given the lack of mental health jargon used by the respondents.

This study recruited 24 interviewees from one Clubhouse, which restricted the diversity of experiences represented in this study; however, reliance on one venue also allowed for greater control in identifying how this model may have contributed to the changes observed by them. As a systematic investigation of family members' perspectives on Clubhouse outcomes, this study provides an initial baseline for future studies that can increase sampling sizes within and across other sites.

Finally, interviewees were nominated through members' interviews as ''the most supportive member of your social network''. This can be viewed as both a constraint of the study and as an expectation of this type of methodology. For example, nominating the most supportive member of the network may lead to reporting only positive experiences. However, it may also be an artifact that family members are often identified as the most significant sources of support (Corrigan & Phelan, 2004; Pernice-Duca, 2010). Therefore, conducting this study again without asking the Clubhouse members to nominate their most supportive social network member may yield similar findings.

In closing, the study addresses an important gap in the current understanding of the impact of Clubhouses on members' social ecology. First, this study demonstrates that relatives of Clubhouse members indeed observe the similar evidence of recovery processes that are captured in other empirical studies that focus on member self-reports (Pernice-Duca & Onaga, 2009). Second, this study provides corroborating evidence of how Clubhouse participation results in observable psychosocial changes. Third, these findings demonstrate that Clubhouse involvement has the potential to improve family relationships and dynamics, which can be the focus of future studies in this area.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

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