

HOUSING, SOCIAL SUPPORT AND PEOPLE WITH SCHIZOPHRENIA: A grounded theory study comparing boarding houses and private homes

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Abstract

The aim of this study was to develop a substantive grounded theory describing the relationship between housing, social support, and the mental health of people with schizophrenia. To achieve this aim, data were collected from people with schizophrenia living in boarding houses and living in their own home. Semi-structured in-depth interviews were conducted with thirteen people with schizophrenia to explore their experiences and views regarding the impact of their housing on their mental health. Findings indicate a strong desire amongst all participants to live in their own home. When they do they feel they belong, they feel safe and most importantly they have greater opportunities to make and maintain supportive social relationships..

INTRODUCTION

Historically people with serious mental illness have had restricted choices regarding their living arrangements with institutions often assuming care and making choices for them (Screbnik, Liningston, Gordon & King, 1995). Fortunately, mental health care is now more focused on community care and on supporting consumers to live independently (Rudman, 1996). According to the National Mental Health Strategy (1994), housing is considered the most crucial community support service necessary to achieve the success of the policy of providing community-based care for people with a mental illness. There is substantial support for this view in Australia (Burdekin, Guilfoyle & Hall, 1993; Queensland Health, 1996) and internationally (World Health Organization, 1990). Without the availability of quality affordable housing, other treatment and rehabilitation approaches are jeopardized (Moxam & Pegg, 2000; Stroul, 1989). This view is also well supported by research (Anthony & Blanch, 1989; Baker & Douglas, 1990; Rosenfield, 1990; Stroul, 1989).

People with schizophrenia

People with schizophrenia are the largest diagnostic group serviced by public mental health services in Australia. Of those people receiving mental health care in the community from specialized mental health services, 38% have a principal diagnosis of schizophrenia (Buckingham, Burgess, Solomon, Pirkis & Eagar, 1998). As a result of their illness, people with a diagnosis of schizophrenia have difficulty maintaining many of the essential life roles and resources that most others take for granted. These essential life roles and resources include satisfactory, stable, independent housing and relationships, particularly, close interpersonal relationships with friends and relatives. This loss of life roles and resources seriously impacts on the mental health of people with schizophrenia (American Psychiatric Association, 1994).

There is a body of literature providing argument that people with schizophrenia who live in good quality accommodation perform better on measures of mental health than people in poor quality accommodation. Although the literature varies on the definition of 'quality accommodation' the overall message clearly asserts that the quality of accommodation contributes significantly to people with schizophrenia's mental health (Berger, et al., 1997; Cleary, Woolford & Meehan, 1998; Hansson, et al., 2002).

In general, research suggests that the living environment of people with schizophrenia influences their social relationships (Angell & Test, 2002). For example, researchers have found a relationship between hospitalization and the breakdown of social networks (Holmes-Eber & Riger, 1990; Lipton, Cohen, Fischer & Katz, 1981). Researchers in institutional settings demonstrate that supportive, low-expectation living environments are associated with greater development of social ties within the facility but not outside the facility (Denoff & Pilkonis, 1987; Segal & Holschuh, 1991). Homelessness is associated with having fewer social contacts (Lehman & Postrado, 1995). Less is known, however, about the effects of normative, independent living situations on social relationships (Angell & Test, 2002).

Social function has been found predictive of functional ability levels, as well as hospital admission rates. Positive social function has been found to decrease hospitalizations and shorten lengths of stay for persons with schizophrenia (Lehman & Postrado, 1995). Poor social function has been found to increase admission rates and health care costs; decrease consumers' satisfaction with services; and negatively affect treatment outcomes (Covington & Cola, 2000). These findings have also been reported elsewhere (Angell & Test 2002; Brown 1996; Lehman & Postrado, 1995; Uttaro & Mechanic, 1994).

Relationship difficulties are central to many community integration problems encountered by persons with schizophrenia. Interpersonal discomfort and disability often limit residential opportunities; in turn, this can exacerbate communication difficulties, and, loneliness, and diminish quality of life (Heinssen & Cuthbert, 2001). It is well known that illness characteristics such as psychosis, negative symptoms, and cognitive deficits can contribute to these social dilemmas. However, these features are not the sole determinants of the social competence of a person with schizophrenia. These features interact with social and interpersonal variables to hinder the relationship process (Heinssen & Cuthbert, 2001).

There are a number of studies demonstrating the importance of quality housing and attesting to the positive contribution of social support to the mental health of people with schizophrenia. A study exploring the views of people with schizophrenia regarding the importance of housing and social support is timely.

Types of housing

There are a number of types of housing available to people with schizophrenia. These include living in hospitals, boarding houses, hostels and group homes with varying degrees of supervision, living with parents and independent living in the person's own home with a choice of house mates/partners. There is consensus in the literature that, outside hospital, the most desirable accommodation is independent housing, whilst the least desirable is boarding houses (Anthony & Blanch, 1989; Baker & Douglas, 1990; Carling, 1989, 1990 & 1993; Cleary et al., 1998; Health Care Complaints Commission, 1996; Howie the Harp, 1990; Linhorst, 1991; Moxam & Pegg, 2000; Posey, 1990; Strong, 1995).

OVERVIEW OF THE STUDY

This paper describes the second stage of a project that investigated the impact of housing on people with schizophrenia. Stage 1 used Archival quantitative data to compare length of stay and readmission rates (Browne, Courtney & Meehan 2004) and acute symptoms and global level of functioning (Browne & Courtney, 2004) in people with schizophrenia living in their own home and for profit boarding houses.

Aim of the study

In this study the impact of housing type on the mental health (as reported by the participants) of people with schizophrenia was explored. The experience of those living independently in private homes with those living in a boarding house were used to develop a substantive grounded theory of housing, social support, and the mental health of people with schizophrenia.

METHOD

Grounded theory method was chosen for this study. This choice was based on the researchers aim to further develop a theoretical understanding of the impact of housing on people with schizophrenia. Previous work by the researcher (Browne et al 2004, & Browne & Courtney 2004) indicated that, for people with schizophrenia, maintenance of mental health is an interactive and interpersonal process that lends itself to a constructivist grounded theory approach.

The grounded theory method specifies that it would be inappropriate to carry out a review of the literature prior to commencing data collection (Glaser, 1978, 1992; Glaser & Strauss, 1967). However, having undertaken previous studies that investigated the impact of housing on people with schizophrenia and having had extensive clinical experience as a community mental health nurse working with people with schizophrenia, the researcher was already familiar with the literature and consumers experience in this area, and it would not have been possible to unlearn the knowledge that existed.

The researcher entered the field informed by the previous studies and clinical experience. This seems consistent with Glaser and Straus's (1967) partial framework of local concepts that designate a few gross features of the structure of the substantive area to be studied. The method was driven by Glaser and Strauss' (1967) seminal work, and Glaser's ongoing works regarding the development and refinement of grounded theory methodology (Glaser, 1978 & 1992).

Definitions

For the purpose of this study the following definitions were used:

Boarding house refers to privately operated 'for-profit' public accommodation. These venues consist of sometimes shared, but normally single, bedroom accommodation with shared facilities such as bathroom, kitchen and living areas.

Private home means any privately owned or rented accommodation, usually a house or flat, where the participant lives alone or with family or friends of his/her choosing.

Selection of sample

Following ethics approval from the Queensland University of Technology a purposive sampling strategy was used to select 13 participants for the study. Six participants lived in a boarding house (3 female and 3 male) and seven lived in their own home (5 female and 2 male). Eligibility criteria for the study included:

self-identification of a diagnosis of schizophrenia;

more than one admission to a psychiatric inpatient unit reported;

living in a boarding house or private home;

not acutely psychotic at the time of interview;

have been informed of the purpose of the study and signed a consent form.

In order to recruit participants the researcher attended community-based consumer group meetings and living skills programs. At these meetings the researcher delivered presentations about the study. Those who were interested were given a detailed information sheet and a consent form. Any questions were answered and the volunteer participants were asked to sign the consent.

Data collection and analysis

Participants were given the option of having the interview in their own home/boarding house or to be taken to a local coffee shop for a free cup of coffee. Seven participants took up the offer of a cup of coffee; the remaining six were interviewed in their homes or boarding houses. The in-depth semi-structured interviews that began with formal questions and initially encouraged the participant to share their experiences and views. The interviews lasted between one and two hours. Interviews were taped and transcribed verbatim. Field notes were taken after interviews.

In keeping with Glaser and Strauss' (1967) directions for sample selection, the author began with two participants. Both individuals lived in boarding houses. As theory emerged from interviews the researcher broadened the sample to include individuals living in their own homes and living in other boarding houses. As data collection and analysis progressed the interviews became more focused until emerging categories were saturated, that is, further interviews added nothing to the categories. Although the interviews progressively became more focused the participants were still encouraged to express their views with questions such as "Are there any issues about your housing that are important that I haven't asked about?"

It is important to note, that the stages of data collection and data analysis did not occur in a linear sequence, but were cyclic in nature. However, for the purposes of reporting the research, the process of analysis is described in stages.

The first stage of coding involved transcribing each interview. Following this, Glaser and Strauss' (1967) process of open coding was applied. This entails examining the data/text line by line and identifying the processes in the data. This process of coding is termed "substantive coding" since the groupings or labels codify the substance of the data, often using the language of the participants.

Next, in the second stage of coding, the researcher attempts to discover the key processes, from the point of view of the participants. This level is more abstract and represents a synthesis of the first level codes. During second level coding each label is then compared with each other label and assigned to categories according to fit. This allowed a tentative conceptual framework to be generated from the categorization of the data. The researcher then devises a tentative heading for each of the categories by examining common themes and concepts evident in each of the categories, or, alternatively, by identifying if there is an underpinning process or theme.

The third stage of the analysis sees the development of hypothesized relationships between the categories and the development of the provisional framework. The researcher examined the provisional categories and perceived links; discovered umbrella terms under which several categories fit, as a result of comparing each category with other categories to see how they cluster or connect. The umbrella term or core-category can thus be seen to encompass several initial provisional categories. As discussed above this is not a linear process but a process of constant comparison. The core-categories emerge and the process is continued until saturation is reached.

The final stage in the data analysis includes theoretical coding and selective sampling of (and comparison with) the literature. Constant comparison ensures rigor for the study, and the resulting grounded theory (Glaser, 1998). It also ensures the theory will fit and work "that is, be relevant to the area it purports to study" (Glaser & Straus 1967, p261).

FINDINGS

The basic social process in grounded theory is described as the series of events, situations, and relationships that shape the response of the research participants. The integrated theory of housing and social relationships emerging from this study is comprised of two core categories *Qualities of the Housing*, which had six subcategories and *Relationships*, which had three sub categories. These two core-categories interact, that is, if the qualities of the housing suit the needs of the participant they are more likely to stay in their housing. Meeting their needs means more than just the physical aspects of the housing but includes how the housing can be used. When participants lived in housing that suited their needs (that includes the opportunity to have friends around) they were more likely to stay for longer. If they live in the same place they have better chance of developing supportive social relationships that they used to help them maintain their mental health.

The qualities of housing

This core category included the qualities participants looked for, liked, or would have liked, in their housing. The sub categories that emerged under this core category included "*A place of my own*", "*A space of my own*", "*Cost of Housing*", "*Activities related to the housing*", "*Stability*" and "*Atmosphere*".

A place of my own

Nine participants valued or dreamed of having a place of their own. For those living in their own home it gave them a sense of belonging and feeling that they were in charge of their lives. For those living in boarding houses it was a dream they hoped to achieve one day. A female participant who lived in her own home with her family captured the sentiments of a number of her fellow participants "You invest yourself into your own place ... you feel you belong and it is yours. Where you run your own life". Participants valued the ability to choose with whom they lived and the opportunity to live alone if they wished. They valued the stability and security offered by having their own home.

Participants living in boarding houses expressed a desire to live in their own homes. One female participant, who had long dreamt of living in a housing commission flat, said she dreamt of "... not, having to live with other people, as nice as they are".

A space of my own

Having a special safe place in their accommodation was identified by eleven of the participants as an important contributor to their mental health. This space could be a special chair, or a special room. This special place could be used as a sanctuary, a place to feel secure, and a place to go when they felt vulnerable. Participants living in their own homes observed that “when you have a place of your own you are free to create a safe space”. This freedom was not often available to people living in boarding houses.

One 36-year-old woman who had problems with hallucinations and anxiety described her bed and doona as special “Inside your safe place (your house) you need an even safer place, an extra safe place. Like a bed or a doona [quilt], ...you’re completely cushioned from everything, and you’re just cuddled up, nothing can get to you when you’re in your bed under your doona, I think. You’re completely covered, you’re completely protected? ...like you’ve got that big feather doona around you, it’s a bit like being in your mother’s arms”. Participants living in boarding houses complained about not having access to a special “safe place” because they were sharing rooms or because there were people around all the time.

Cost of housing

The cost of housing was identified by all participants as being a contributor to their mental health. Often the decision to live in reasonable accommodation meant not having enough money to buy the basic necessities. One female participant was living alone in a flat with her dog. The cost of housing meant she did not have enough money to feed her dog. She stated “it houses me, but it’s very expensive, \$130 a week is just too expensive for me, but it’s the only place I could get to go with my dog... the cost, I can’t even begin to think how much that affects my feelings and that ..., I just find that it’s, it’s extremely stressful to have to pay that sort of rent.”

Having the family resources to afford to live in their own home was seen as a great advantage and significant contributor to staying well. For others, there was the frustration of not having enough money (or not being able to handle money) to live where they wanted. Participants suggested: “Where I am is less than ideal but it is all I can afford” and “I wouldn’t mind a flat, but I know I can’t afford a flat for myself.” One male participant, who resided in a boarding house, complained that after rent and board he had little money for extra food: “... I get a bit hungry at night times and cause we have dinner at 5 o’clock and by the time 8 o’clock comes well ... I’m hungry again.”

Activities related to the housing

Twelve participants identified activities that were related to being in their housing as contributing to their mental health. It was notable that people living in their own home all mentioned home-related activities in which they participated; from mowing the lawn to playing guitar and having friends around. None of the people in boarding houses described at home activities other than housework. Boarding house residents normally went out to be involved in social activities for example to a life skills/social program.

Sometimes relationships in boarding houses were strained because of a perceived difference in the amount of housework being done by others. This added to the difficulty of sharing in the boarding houses. One boarding house resident complained “Yeah they mightn’t pull their weight and that affects all of us, ...when their weight’s not pulled around properly... it affects us individually.”

Stability

Stability of housing was valued by all of the participants, in that they thought it was valuable to live in the same place relatively permanently. “If I can get to know my surroundings I feel more comfortable with them.” One female participant who lived in her own home described the importance of the stability of her housing: “See if you haven’t got a stable home environment, every time you move you lose those friends, there might be a couple that are becoming good for you.”

A 53-year-old male participant who lived in his own flat described the value of stability: “I think it helps me stay stable, ... I’ve have moved around a fair bit, and it gets quite dreadful when you haven’t actually got a good house to live in.”

Atmosphere

Twelve participants identified factors that contributed to the atmosphere of the housing—the most significant was the relationships. Sometimes the relationships within a household contributed positively to the atmosphere: “It’s very important, one of the most important things is... a home where everyone supports you if you need to be supported, ... so that’s the main thing.”

Sometimes relationships contributed negatively to the atmosphere, however this was only reported by people living in the boarding houses. Residents of boarding houses complained about the drug use of other residents and other upsetting behaviors: “Greggie’s the one you want to watch because at night he chucks a mental because he’s not watching his show you know, doesn’t share the TV that’s the trouble with him, geez he goes off, really screams at ya, doesn’t matter how good you are to him, he goes off.”

There were also non-specific factors identified that seemed to contribute significantly to the well being of some participants who lived in their own homes; these factors were described concisely by a 53-year-old male participant who said “Being here (in my own flat) just makes me feel better”.

Relationships

All participants identified the people around them as having an impact on their mental health and that their housing had a significant influence on these relationships. It was considered that staying in their home for a length of time allowed one to set down “roots”, an important part of those “roots” was the support network of friends and family that were there to support the participant when “things go wrong”. Participants also wanted the kind of relationship with friends and family, where they could be called on when those friends and family had difficulties. This helped them to feel they were valued and that they belonged. The sub-categories that emerged under this core category were “*People accepting and understanding*”, “*Coming home to someone*” and “*Living with others*”.

People accepting and understanding

The attitude of others towards them as a person with a mental illness, and the community’s attitude to mental illness, were high priorities for ten of the participants in this study. Participants placed a high value on others having a positive attitude towards their mental illness. They felt sensitive to negative community attitudes towards mental illness and took care not to behave in a way that drew attention to their illness. If the relationships within the housing setting were supportive the participants reported that it contributed to their mental health: “you ain’t got someone there that you feel like close to, then you’ve got nothing really. It’s all about the feelings of the person”.

Coming home to someone

Eight participants described having someone to come home to as something they valued. Having someone to talk to help them to test their views/ideas and stopped the mental illness from “taking over”. One male participant who lived in his own flat reported having schizophrenia for 25 years and identified that one of the disadvantages of living alone was isolation. “You get um, when you’re really alone you get nervous and things, you’re get paranoia”

Living with others

All participants provided a response in this category. They all described living with others (whether they lived alone or not) as having a significant effect on their mental health. Participants considered it critical to their mental health that people understood and accepted their mental illness.

Sharing with someone was also considered very supportive: “Yeah, yep, it’s very important, one of the most important things, is, like a home where, everyone supports you if you need to be supported, you know, so that’s the main thing.”

Living with someone else was not always ideal as partners and family could be difficult and sometimes there were disagreements and friction. Generally, it was felt that having someone around who understood helped the participants to stay well. At times, however, being alone made things worse: “and if there’s somebody to talk about those ideas (paranoid ideas) with, I find it much easier, but alone I tend to get lonely and get wound up in the ideas and it tends to take over.”

DISCUSSION

There was a strong desire amongst all the participants to have a place of their own, whether they lived in private homes or in a boarding house. They all expressed a desire to have a place where they felt they belonged and where they could run their own lives—this is consistent with the findings of other researchers (Anthony & Blanch, 1989; Baker & Douglas, 1990; Moxam & Pegg, 2000; Ridgeway & Zippel, 1990; Strong, 1995; Warren and Bell, 2000; Yeich, Mowbray, Bybee & Cohen, 1994).

Participants living in private homes reported that there was a special place at home where they felt comfortable, a place they could go when they were not feeling well or were feeling fragile. Residents in boarding houses complained that they did not have access to a special place because they had to share rooms or because there were always other residents around, this finding is supported by the literature (Cleary, et al., 1998; Health Care Complaints Commission, 1996; Linhorst, 1991; Moxam & Pegg, 2000; Posey, 1990).

The cost of housing was an issue for nearly all participants. Some acknowledged the importance of having family to help them financially with their costs of living. Others had the difficult decision of whether to live in decent accommodation and skimp on other things, or to maintain the necessities (including cigarettes) and live in sub-standard accommodation.

Both groups reported activities related to their housing, but these activities differed. Those living in their own home reported taking part in social and other pleasurable activities in their homes, whilst the only activities in which the boarding house residents participated were housework-related. Stability of the housing was recognized as important by the residents. If they stayed in the same accommodation for a long time they came to feel at home and, more importantly, built up a social network and relationships that many valued as supports.

Participants lived in (from the researcher's perspective) a wide range of housing from nice well-situated homes and flats on the beach, to the other end of the spectrum in a dirty overcrowded boarding house. Although the participants discussed this, and it was an issue impacting on their mental health, they were much more interested in the relationships they had as a result of living in their homes.

All the participants valued highly and benefited from having good quality supportive relationships. These findings have been reported elsewhere (Angell & Test, 2002; Bengtsson-Tops & Hansson, 1999; Lehman & Postrado, 1995; Uttaro & Mechanic, 1994). According to the participants, their housing significantly influenced the number and quality of supportive relationships. Those living in their own homes tended to stay longer in their homes and they used their homes to entertain and maintain those valued relationships. Boarding house residents also valued relationships but had difficulties with other residents and tended to have resided only a short time in the boarding house.

The theory induced in this study indicates that if people with schizophrenia live in quality (by their standards) accommodation they are more likely to stay and therefore build and maintain supportive social relationships. This linear explanation does not fully explain the social process of this grounded theory. A critical aspect of *quality* housing is its' usefulness as a resource for socializing. Stability of housing offers the opportunity to develop social relationships. The two core categories induced in this study, although presented independently are, very strongly linked.

The researcher expected the findings in the core category of *Qualities of Housing*, the strong link between housing and supportive social relationships although was unexpected. These findings may not have been made if another methodology was used. This studies' use of a grounded theory methodology, which allowed the theory to emerge from the data, meant the views and experiences of people with schizophrenia were available to the researcher. Clearly people with schizophrenia can make a significant contribution to our understanding of their illness.

CONCLUSIONS

Although the national and international mental health policy attests to the importance of social skills and resources for the wellness of people with schizophrenia there is still an emphasis on finding a medical/drug solution to schizophrenia. The focus of mental health services is still on medical solutions to schizophrenia.

As discussed in this article there is a body of evidence supporting the view that the type of housing in which people with schizophrenia live has a significant impact on their mental health. This is reported in literature from the USA, South East Asia and from Europe. Another body of evidence demonstrates that if people with schizophrenia have supportive social relationships they have a better quality of life, fewer symptoms, and fewer admissions to hospital. In a related study by the authors of this paper, people with schizophrenia were found to be more likely to be admitted to hospital if they were discharged to a boarding house than if they were discharged to a private home (Browne, Courtney & Meehan, 2004). Their symptoms did not seem to be all that different, nor did their desire for meaningful relationships. The different between the two groups was their opportunity for meaningful supportive

relationships. People with schizophrenia, living in private homes, had greater opportunities to make and maintain these relationships (Browne & Courtney, 2004).

The data from this study demonstrates that, at least for the participants in this study, if people with schizophrenia live in a private home they are more likely to feel they belong and feel safe. They also have the opportunity to develop and maintain meaningful, supportive relationships—relationships in which they can receive support when needed and can feel they make a contribution by giving support to friends and family. If people with schizophrenia live in private homes they have a better chance of developing and maintaining stable and supportive relationships. These relationships help them to lead a more meaningful life, stay well, and remain out of hospital.

If mental health service providers were to invest resources into adequate and appropriate housing and support their clients would be more likely to develop a sense of belonging in their community. This sense of belonging could help in the development of supportive social relationships. The outcome for people with schizophrenia could be improved with a better quality of life, fewer symptoms and fewer admissions.

Further this study has shown that people with schizophrenia can make a valuable contribution to research. It is time we, as clinical nurses and researchers, recognised that people with schizophrenia have expertise we cannot have (unless we have experienced the illness) and began to value that experience.

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