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Abstract

This article considers the relationship between where a person lives and who they live with and their mental health and well-being. In particular, this article considers the regional locale as an important factor in understanding the perspective of a person with lived experience of mental illness. This article questions the influential, yet somewhat narrow, argument that living in the community and in the family home is somehow better for people with mental illness. The arguments presented in this article illustrate that for some people with mental illness, the issues of stigma, autonomy, and lack of alternatives (choice) are just as prevalent for them now, living in the community, as when they lived in institutions. The assumption that place alone can redress the lack of choice and autonomy is unfounded.

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Where you live and who you live with, matters: Housing and mental health

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Abstract:

This article considers the relationship between where a person lives and who they live with and their mental health and well-being. In particular, this article considers the regional locale as an important factor in understanding the perspective of a person with lived experience of mental illness. This article questions the influential, yet somewhat narrow, argument that living in the community and in the family home is somehow better for people with mental illness. The arguments presented in this article illustrate that for some people with mental illness, the issues of stigma, autonomy, and lack of alternatives (choice) are just as prevalent for them now, living in the community, as when they lived in institutions. The assumption that place alone can redress the lack of choice and autonomy is unfounded.

KEYWORDS: Community integration, deinstitutionalization, mental health

Background

The impact of mental health issues on individuals, communities and the economy is becoming increasingly apparent, with 7.3 million Australians between 16 – 85 yrs (45%) estimated to experience a mental health-related disorder over their lifetime. Within this age bracket, one in five people are estimated to experience symptoms of a mental disorder (Department of Health and Ageing {DoHA} 2009).

The annual expenditure on mental health in Australia is significant, symbolizing a national health problem that is rapidly increasing. The increase in expenditure from 2006 to 2007 was 5.7%. In 2010 to 2011, almost \$6.9 billion was spent on mental health services. Of this amount, \$4.2 billion was spent on state and territory specialized mental health services (\$1.8 million in public hospitals and \$1.6 million in community services), \$307 million was spent on specialized private mental health services, \$851 million in benefits for mental health related services funded by Medicare (Australian government universal health insurance

scheme), and \$854 million on medications subsidized through the Australian Pharmaceutical Benefits Scheme (Australian Institute of Health and Welfare [AIHW], 2012). In addition, 15 million mental health-related general practitioner visits occurred in Australia between 2011 and 2012 (AIHW, 2013). Indeed, 2010 Australian of the Year, Professor Patrick McGorry (2005, p. 3) asserted that, “mental health and mental illness are the major public health issue in Australia. Mental health problems and mental illness affect everyone both directly and indirectly.”

The kind of expenditure outlined above is simply not sustainable and more emphasis needs to be placed on prevention and early intervention rather than hospitalizations and treatment. One important preventative strategy is ensuring that people with a mental illness have a safe and affordable place to live in the community.

Permanent, stable and affordable housing, along with a system of appropriate support networks, are the foundation stones of successful community integration programs and the prevention of inappropriate institutionalization (Bentley, Baker, Mason, Subramanian, & Kavanagh, 2011; Moxham & Wilson, 1997; Swadling, Hegarty, & Hoppner, 2014). However, the community mental health field in Australia continues to be plagued with a myopic view of appropriate accommodation that fails to take full heed of the psychosocial needs of the person.

Over a decade ago, Moxham and Pegg (2000) argued that the shift from institutional to community-based living for people with mental illness had been accompanied by a lack of systematic planning but had also been exemplified by inadequately placed support systems and limited financial support. Indeed, more recent research has suggested that evidence for the success of deinstitutionalization in Australia has not all been positive (Hamden, Newton, McCauley-Elsom, & Cross, 2011).

Housing affects people’s health at several levels (Howden-Chapman, Chandola, Stafford, & Marmot, 2011; Liu, Njai, Greenlund, Chapman, & Croft, 2014), with the availability of suitable housing in the community being integral to the provision of mental health care in the least restrictive way (Forchuk, Csiernik, & Jensen, 2011). So important is this issue, it was identified in the initial 1992 Australian National Mental Health Strategy (NMHS). It has since been repeatedly acknowledged that the provision of appropriate housing enhances the effectiveness of treatment and rehabilitation services and is necessary if treatment gains are to

be maintained (Padget, Stanhope, Henwood, & Stefancic, 2010). Without strenuous attention to appropriate housing, the morbidity and mortality arising from mental illness in the community will continue to be compounded. The purpose of this research was to achieve a deeper understanding of the housing environments inhabited by people with mental illness in the community following a period of institutionalization. It also aimed to understand how these environments ameliorated or contributed to feelings of stigmatization and lack of control.

Methods

This research utilized a qualitative exploratory approach. Silverman (2010) commended the use of exploratory method for research projects where relatively little is known about the topic. A qualitative approach is an inductive process that generates information about unknown aspects of a phenomenon (Teddle & Tashakkori, 2009). Exploratory design encourages an open-mind, facilitating greater flexibility to explore the nature of the research problem.

Participants and setting

This research took place in a regional Queensland city. Fifteen people (eight women and seven men) over 18 years of age, all of whom had been diagnosed as living with a mental illness, were purposively selected to participate in this study. Recruitment occurred as a result of flyers handed out at the local CAG (Consumer Advisory Group) meetings and via community mental health. Potential participants contacted the researcher, indicating their willingness to be involved. At the time of the study, participants reported to have been given the following diagnosis: schizophrenia ($n = 5$), bi-polar disorder ($n = 4$), schizoaffective disorder ($n = 5$), and dysthymic disorder ($n = 1$). Every participant's diagnosis had been made longer than five years ago, but for some, the diagnosis had changed many times.

Procedure

The principle method of data collection was a semi-structured face-to-face individual interview using open-ended questions and "probes designed to elicit more detailed information" (Polit & Beck, 2008, p. 394). This choice of data collection technique enabled a guided, concentrated, focused yet open-ended communication event that was co-created by

the investigator and participant. Interviews were taped and transcribed verbatim by the investigator to be used for data analysis. After re-affirming consent, the interviews began with a grand tour question that allowed the researcher to begin to examine the perceptions of participants and how they give meaning to their experiences (Liamputtong, [2009](#)). The grand tour question was: Tell me what it's like for you as a person who has a mental illness to live in a regional city. Further questions emerged as a result of the response but other open-ended questions included: Describe for me how much individual choice you have when it comes to decision making, and tell me if you have ever felt stigmatized as a result of having a mental illness.

Ethical Considerations

The study was approved by the Human Research Ethics Committee (HREC) of the university. Participants were informed of the voluntary nature of the study and their right not to participate or to withdraw participation if they chose. Written consent was obtained before data collection commenced. Ethics approval was cumbersome, with HREC members being particularly concerned about the “fragility of the cohort,” illustrating the ongoing extent to which stigma and stereotypes about people with a mental illness are still held in the community.

Data analysis

Data analysis began when collection of data commenced, in that information was processed as it was gathered by intuiting, analyzing, and synthesizing the ideas participants were imparting. Synergies were identified whilst simultaneously being explored and verified through subsequent data collection.

The first interview acted as a “pilot.” The verbatim transcription was examined and ideas identified were incorporated into the subsequent interviews. The meaning developed in the first interview assisted with the thematic conceptualization of data from the larger sample. Codes were written next to appropriate segments in the text and the topics that were identified in the interviews were placed into columns labeled as major topics, unique topics and “other.” The emergence of new topics and codes was tested against this preliminary coding schema and analysis continued in this iterative manner until all the interviews were

completed. The most descriptive word/s were identified to define each topic. Categories were formed and refined by grouping related topics.

Following the initial coding, more focused coding was selective and conceptual, forming meaningful and coherent conclusions from the data. Data were examined and re-examined, with newly emerging categories being repeatedly checked. Refinement enabled identification of variation, which promoted contextual understanding. By adhering to these steps, categories were comprehensively developed, rather than being simply labeled as topics or themes.

Findings

Three comprehensive categories were identified in the interview transcripts: autonomy, alternatives, and stigma. Each thematic category is described below, drawing on the participants' voices as much as possible to illustrate the theme.

Autonomy constrained by place

The first theme related to consumers' descriptions of their experiences and the factors they identified as contributing to the lack of autonomy they felt. Autonomy is an important component in the quality of life. The word autonomy is derived from the Greek *autos* (self) and *nomos* (rule) and asserts a right of non-interference to make decisions for oneself, or to be self-determining. Autonomy is related to the ability to make informed choices. Many participants with a mental illness lived with family members, usually in their parent's home, and as a result, they were often not in a position to make their own choices. This was partly because of them being perceived as the "child" in the home. Even participants who did not live with their parents were conscious of their lack of autonomy. For example, Helen (58 years), who resided in her own home, described how she believed events were taken out of her control even though she had been "well" for many years. When discussing what she perceived to be the biggest problem faced by people with a mental illness, she said,

... they lack the opportunity to make their own decisions. Other people are always making them for us and act as if it's OK to do so. Because of this you're always living up to someone else's expectations rather than your own. (Helen, aged 58)

Despite living in a place of his own, Bill was also restricted in what he could do. His story reveals how home impacts directly on choice and subsequent mental health:

... I would like to have a dog. I get very lonely here. I had a dog in my other house but I had to give him away when I moved here. I don't even know if he's alive anymore. I had him with mum for seven years. (Bill, aged 46)

Although some respondents said there were no rules about what they could or could not do at their accommodation, when asked if they could come and go as they pleased (despite answering yes), comments revealed the restrictions on their lives,

... I can come and go as I want as long as I'm here to cook mum's tea and breakfast. Then I can go out. I have to clean up too but when that's all done I go when and where I want. (Laura, aged 30)

Mick (aged 39) also said he could “more or less” do as he wanted, although it was conditional upon telling his mother “where I’m going and when I’ll be home.” The study revealed that despite the age of person, participants all had many rules and restrictions placed on them as a result of their housing conditions. One participant said she could “only have one pet,” was “not allowed to smoke in the house” and had to be “home at night.” Rhonda (aged 30) lamented,

... basically I have to be home at night. Mum doesn't like me going out say after ten or eleven because she's afraid something might happen to me. I've got to be at home continuously. I can't go and stay with the boyfriend because I'm not allowed to because she's got old-fashioned rules about that. (Rhonda, aged 30)

These rules caused great contention between Rhonda and her mother. Rhonda elaborated by saying that these restrictions to her autonomy made her “feel terrible.” She said that her mother’s rules,

... aren't exactly my rules because she is 74 years old and she comes from a different generation. The new generation is slightly different, we think differently. They think it's not OK to live together before marriage and all this sort of thing and I sort of think, yes it is OK to live with people before marriage and yes it's OK to stay out at night because I want to be with my boyfriend and I should be able to be with my boyfriend. (Rhonda, aged 30)

Two participants wanted to put some posters up on their bedroom walls but were not permitted to do so by their mothers, and as it was their mothers’ houses in which they lived, they did not “disobey.” One participant, despite his ongoing desire to do so, resigned himself to not being able to put up a poster of a “fast car”:

... it's not my house. Mum says when it's my house I can do what I like. While it's her house she can do what she likes and I can lump it if I don't like it. It's her house so I can lump it I guess. I would like to put some fast cars in my bedroom though but when it's my house I will. (Michael, aged 39)

Restrictions to autonomy also permeated participants' financial situations.

I am very grateful to mum for having me. She doesn't take all of my money [for rent and board]. I get \$40.00 left of my pension to do what I like with. (Michael, aged 39)

Bill (aged 46) said the "Trustees Office allocates me a certain amount of money each fortnight" to cover living expenses, but if he "spent more than I am allocated, I have to apply in writing to get some more." This situation made him very angry and Bill said he would do everything in his power to have this decision overturned. Bill felt that even though it may have been necessary when he was unwell, but "it should not be the case now I am well." Bill's situation demonstrated that despite his recovery and despite living independently, structures prevented his choices.

Alternatives: Not available and not appropriate

The majority of participants in this study did not complain about their housing circumstances. As a result of knowing "the system" [mental health treatment facilities and services] and being a part of it for many years, they were fearful of the alternatives to their current living arrangements. Complaining or voicing an opinion about their accommodation could lead to eviction, which for them would result in worse circumstances. Fiona, a participant, who also had a son who had a mental illness, described her son's situation,

...he was only there [accommodation for people with mental illness] for a couple of days. He never stayed there, only had his things there but that's where they wanted him to go and I got Diedre [community worker] to ring him up and tell him that he wasn't obliged to live there but Christina [case manager] told me he was obliged to do it. She told him that he was obliged to live there but Diedre told me he wasn't but I didn't tell him that as I didn't want to cause trouble. (Fiona, aged 46)

Given the limited accommodation options for people with a mental illness, eviction could mean re-hospitalization. Even though the home lives of most participants were restrictive and unsatisfactory, everyone described how, no matter what, it was better than the alternatives. Hospitalization or living in a hostel was considered by all participants to be the worst thing that could happen to them. Laura, who described a volatile and violent relationship with her

mother, tried living in a hostel at the insistence of her public mental health case manager. Laura stated that she hated living with her mother—"I hate it, I hate it"—but described an even more traumatic experience of living in the hostel,

...they put me there from mental health [public mental health service], said it was better than here [at home with mother]. It's pretty rotten here but at least I don't have blokes knocking on my door at all hours of the night wanting a root [sexual intercourse]. I stayed there for four nights once and nine blokes wanted to root me. Fucking awful place, I came back here. (Laura, aged 30)

Positive alternatives were rarely available to participants. For instance, Greg talked about his desire to win Lotto and get a place of his own for him and his children. He was not allowed to bring his children to his mother's house, despite them being her grandchildren, but he was compelled to stay with her due to financial reasons.

...I mean to say, while I get the [affordable] board that I do here, it makes you stay. I'd like to move out but with the price of rent these days, on the disability pension, it's just not worth it. (Greg, aged 37)

Alternatives were often prevented by those working in the mental health field, who made judgments about where people should live based on their condition. For example, Michael (aged 39) described how the social worker told him "it was better if someone like me should try to live with others like me." When asked to explain what he meant, he said that he thought she meant that he should live "with someone from the hospital. You know, someone who is a schizophrenic or something."

Neighborhood Stigma

People with a mental illness who live in regional areas of Australia are more disadvantaged with respect to all services, including housing (National Rural Health Alliance, 2009), than people who live in urban areas. As a result, people with a mental illness often remain in housing circumstances that are not best suited to their needs. For those who live in regional Australia, the stigma they experience is exacerbated by their heightened visibility in relation to the size of the population and their lack of choice of services (National Rural Health Alliance, 2009).

Brian, an intelligent and quiet man, has lived in his own home for 20 years and has immaculately maintained it by himself. Brian reported experiencing stigma first hand from

his neighbor, whom he described as a “professional.” His experience of stigma appeared to be related to living in a small town where his privacy was challenged.

... one neighbor chose not to come near me after he found out I have a mental illness. I still don't know how he knows but I think his son plays soccer with one of the doctor's sons at the hospital and he told him. Quite unethical that of course but I have no proof. So I don't speak to him, his wife, or his three children at all. The children all seem to be quite scared of me. Well they did when they were younger but now that they are in their mid teens, they ignore me. They used to call out, “mummy or daddy, he's outside he's outside.” I am sure their father filled them with fanciful stories but I have no proof. (Brian, aged 43)

Felicity (aged 31) lived close to the mental health service, in the house where she grew up. At times she believed that some of the neighbors might know she had a mental illness because they saw her “going there” [to the mental health service]. Felicity has never revealed to her neighbors that she has a mental illness because she says when people find out “they treat you differently.”

Bill described being tormented by his neighbors because he had a mental illness.

... they call me “psycho” and “schizo” and stuff like that. I have bi-polar disorder so that's how much they know. They don't even know what mental illness is. They believe all the stigmas. Mentally ill people are very vulnerable and need help. If they had a mental illness I would be very patient with them and help them out. (Bill, aged 46)

Bill described the traumatic nature of his interactions with his neighbors, demonstrating the powerful negative impact of neighborhood stigma. He said his neighbors,

... smear shit on my door handles and even threw a petrol bomb on my roof. The 15 year old calls out insults when I am outside, plays loud music which he knows I hate, accuses me of having sex with his dog and calls me psycho. His mum and dad also say hateful things to me and sprayed my letter box with water once so all my letters got wet. They make my life hell. (Bill, aged 46)

Discussion

Merinda Epstein and Anne Olsen, both people with lived experience of mental illness (2001), described how consumers live within power relationships that are constructed by others and through means of social control. They argued that the balance of power is “entrenched, fixed and resistant to change” and is not in the control of the consumer (Epstein & Olsen, 2001, p. 9). This power, which contributes to the perceived lack of autonomy inherent in the lives of people with a mental illness, comes from often being thought of as incompetent. Importantly, this study has shown that this lack of autonomy is perpetuated through the context of

accommodation. No one in a modern world has absolute autonomy; everyone is bound by social constraints, but, for people with mental illness, these constraints are many. Instead of maximizing their potential, accommodation in the community often dominates and restricts them, resulting in unhappy and unfulfilled lives. People with a mental illness want to be treated according to the principles of justice—norms and rules that apply to all people consistently and continuously (Butler 2001). Having a mental illness can mean that people become identified by their illness and their autonomy is lost. Burdekin summed up this loss of autonomy in his seminal report *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with a Mental Illness*, when he stated,

... many witnesses recounted the loss of their identity once a diagnosis had been made. They felt that society saw only their label, and with this they ceased to have the same needs, emotions and rights to make decisions about their lives. (Human Rights and Equal Opportunity Commission [HREOC], 1993, p. 445)

Accommodation plays a critical role in perpetuating the loss of autonomy by placing people in vulnerable circumstances that are tenuous and dependent on continued obedience. Fear of alternatives to their current living arrangements becomes a constant reminder that security of tenure is vital, even if that means accepting substandard conditions. At any time, people with mental illness risk readmission to hospital or other institutional settings, which can occur against their will, according to the Mental Health Act in their state or territory of residence. This coercive control of differentness is perpetrated (albeit unwittingly) by some mental health professionals. Coser (1962, cited in Short, Sharman, & Speedy [1993, p. 89]) argued that in a hospital setting, mental health professionals act as social control agents to bring about conformity in “bad” patients, who are subsequently afraid they will not receive adequate care in the future if they do not behave as expected. This research has found that consumers who live in the community also “conform” because they too are afraid that the visiting mental health professionals who “check up on them” will admit them to hospital or some other unpleasant accommodation setting against their will. Ironically, positive accommodation options are prevented by the stigmatizing attitudes of mental health professionals who make judgments about where people with mental illness can live.

Stigma, the burden that is attached to “differentness,” is faced by people with a mental illness every day and leads to gross violations of their human rights. Despite the move to community living, stigma appears to be no less a phenomenon today than it was a century ago in institutional settings. Although most people with mental illness now live in “ordinary”

housing, they are not considered “ordinary” at all. Indeed, some living environments contribute to increased stigma. Perhaps the only means of alleviating stigma is a reinterpretation of the moral framework of society to create more inclusive structures that can facilitate the lives of those who have historically been excluded on the basis of being different (Johnstone, 2001).

Safe and secure accommodation is a central aspect of this moral reinterpretation. No other basic human need has such an impact on the fundamental dignity, quality of life, or capacity to exercise citizenship than the need for a home. Whether community-based services are successful or not is crucially related to the nature and availability of suitable accommodation options. Problems facing people living with a mental illness who are seeking adequate housing include the inadequate discharge process, inappropriate referral process, lack of housing choices, lack of supported living services, and discrimination in the neighborhood.

Conclusion

More than 50 years after Dr. Wolf Wolfensberger first advanced the normalization principle and then developed the theory of social role valorization, it is difficult to believe that issues regarding appropriate and affordable housing for people with mental illness remain so prevalent and profound. Although there is general agreement among researchers that permanent, flexible, and individualized housing leads to better outcomes, the systems in place in Australia to provide housing and living support are typically separate from each other. In reality, therefore, people with mental illness have little choice about where they live and who they live with.

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