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ORIGINAL ARTICLE

Lived experience practitioners and the medical model: world's colliding?

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Abstract

Background: Australian mental health policy requires that mental health services facilitate meaningful and genuine consumer participation in all aspects of mental health services. Roles for practitioners who work from their own experience of significant mental health challenges and mental health service use have been implemented in many services to promote participation and the development of more consumer focused services.

Aims: To enhance understanding of perspectives of individuals working in lived experience roles to more closely understand their experiences and opinions about these roles.

Method: A grounded theory study interviews were conducted with 13 lived experience practitioners.

Results: The medical model was a core category arising from this work. Participants described the medical model as a prevailing culture within mental health services from their personal and professional experiences. This culture imposed a major limitation on the implementation, effectiveness and development of lived experience roles and themselves as individuals. It was also seen as a major limitation to the progress of Recovery orientated reform.

Conclusions: The development of Recovery oriented services requires a strong lived experience practitioner workforce, with appropriate resourcing and support available. The current medical model approach requires critique to facilitate reform and avoid tokenism.

Keywords

Consumers, lived experience practitioners, medical model, mental health services, recovery

History

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Introduction

National policy in Australia has supported consumer participation in mental health service delivery since 1992 (Australian Health Ministers, 1992). Successive Government plans, policies and standards (Australian Government, 2012), increasingly emphasise the requirement to actively involve consumers (Australian Government, 2012). The employment of consumers is identified as a priority area for achieving these goals and facilitating the development of Recovery-focused services (Department of Health and Ageing, 2009). However, research illustrates the mental health sector struggling to meaningfully collaborate with the lived experience perspective of consumers (Happell et al., 2015a). It is acknowledged that the consumer and carer workforce "... has not been systematically developed or implemented in Australia compared with other parts of the world." (Department of Health and Ageing, 2009, p. 51).

The consumer movement has parallels to other liberation movements as a struggle for equal rights (Perkins & Slade, 2012). Empowerment of consumers is a widely

accepted strategy to progress this agenda (National Mental Health Consumer and Carer Forum, 2010; World Health Organization, 2010). Empowerment is also considered a key strategy in promotion of health and reduction of disease (World Health Organization, 2010), situating empowerment of consumers as an issue of international significance. This focus has led to a growing evidence base highlighting the essential role of lived experience practitioners (LEP) within the mental health sector (Canady, 2013; Gillard et al., 2013; Happell et al., 2014; Hussain, 2010; Salzer et al., 2013; Walker et al., 2014).

Widespread acknowledgment of the usefulness of lived experience roles exists throughout the literature, in effecting better outcomes, increased quality of life for consumers and reduction of service costs (Brice et al., 2014; Davies et al., 2014; Moran et al., 2012; Perry et al., 2013; Repper & Carter, 2011; Salzer et al., 2013; Walker et al., 2014). However major barriers to the development of the lived experience workforce are also identified (Ahmed et al., 2014; Gillard et al., 2013; Happell et al., 2015b).

The need for lived experience workforce development in Australia has been highlighted in a range of studies (Bennetts, 2009; Community Services Health and Industry Skills Council, 2010; Craze Lateral Solutions, 2010; Happell,

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2009; National Mental Health Consumer and Carer Forum, 2010; Sierakowski, 2010) Many factors are currently impacting on the evolution and development of the lived experience workforce, both here and overseas, including lack of acceptance from non-lived experience colleagues within the workplace (Ahmed et al., 2014; Happell et al., 2015b). This is compounded by a critical need for workforce development including; articulated position descriptions, career pathways, access to training, appropriate support and supervision and, national standards for remuneration (Community Services Health and Industry Skills Council, 2010; Moran et al., 2013). The need for leadership from within the lived experience workforce is also frequently raised (Bennetts, 2009; Craze Lateral Solutions, 2010; Gordon, 2005; Happell & Roper, 2009).

While many studies acknowledged the incidence of stigma or discrimination; isolation and lack of acceptance in the workplace (Bennetts et al., 2011; Bennetts et al., 2013; Brosnan, 2013; Community Services Health and Industry Skills Council, 2010) no focused inquiry into the issues and how they impact on the effectiveness of the role within the wider workforce has previously been undertaken. Facilitating development of the lived experience workforce and allowing LEP to evolve to full potential requires a more comprehensive understanding of experiences in these roles. The aim of this study was to generate a theory that would explain the experiences of LEP in the development and implementation of their roles. The medical model was a core category emerging from the data explaining the experiences of the LEP. The meaning of this core category and its perceived impact will be the focus of this paper.

Method

Research approach

Due to the scarcity of literature available on the lived experience workforce and the lack of lived experience perspectives within literature, Corbin & Strauss (2008) iteration of grounded theory was considered the most appropriate methodology to guide this research. Grounded theory methodology facilitates the researcher to generate a theory that has emerged from the data, thus explaining the reality of the participants views (Strauss & Corbin, 1990) rather than testing a pre-existing hypothesis (Roberts & Taylor, 2002).

The principal investigator in this research has lived experience of mental health challenges, service use and Recovery. She has held a number of lived experience roles in the mental health sector for over 10 years, including government, non-government and tertiary settings and had diverse responses to her role within different organisations. This research was stimulated from her own experiences, and a desire to explore what other LEP were experiencing in a range of roles and settings and ultimately to contribute to supporting the LEP workforce.

Participants and recruitment

A total of 13 respondents participated in this study. Recruitment was undertaken through a range of national,

state and district wide lived experience networks. An email introducing the project was distributed throughout these networks inviting participation. Participants were purposively sampled across a range of districts including metropolitan, rural and regional locations. Participants were similarly selected across a broad range of work roles and settings to ensure the broadest possible range of perspectives and experiences.

Procedure

Semi-structured individual interviews were undertaken with participants. During interviews LEP were broadly asked to describe their experiences of working as LEP.

Ethics

Before participant recruitment, ethical approval was obtained for the study through the relevant Human Research Ethics Committee. Included in the initial email to participants was information regarding confidentiality and the right to withdraw without penalty at anytime. All participation was entirely voluntary. Prior to analysis, all transcripts were de-identified and coded to protect the confidentiality of participants. Codes were stored in a separate, locked system, accessible only by the researchers.

Data analysis

Participants for the initial interviews were selected to represent the broadest range of perspectives, in line with the open coding approach of Grounded theory (Strauss & Corbin, 1990). As Grounded theory employs a cycle of data collection and analysis known as constant comparative analysis (Corbin & Strauss, 2008), once a small number of interviews had been conducted they were analysed and the data emerging from those interviews was used to purposively select the next participants. In line with Corbin & Strauss (2008), analysis involved open, axial and selective coding. As data collection and analysis progressed, repeated concepts were tagged with codes. With further data collection and analysis, the codes were then grouped into concepts and ultimately categories. The categories became the basis for the overall theory. Data collection and analysis continued until the point where no new concepts emerged from the data. At this stage saturation had occurred (Corbin & Strauss, 2008). Once this point was reached, discriminate sampling occurred until the substantive theory was refined with feedback from participants and ultimately validated.

Findings

Medical Model

The prevailing medical model approach to service delivery was seen as a major barrier to the effectiveness of LEP roles and to shifting from the medical model paradigm to a Recovery focus. As a result, a lack of understanding of Recovery and limited adoption of Recovery principles by mental health services was evidenced. Furthermore, the primacy of medical knowledge and legal authority created significant power differentials and interpersonal barriers between LEP and health professionals.

Medical model concepts were identified as; an over-emphasis on labelling/diagnosis, a culture of mistrusting consumers, consumers developing patient identity as a result of authoritarian or paternalistic systems, and ideas and beliefs that contradict Recovery or positive attitudes. Some participants had experienced the detrimental impacts of this approach in their own dealings with the mental health system;

The psychiatrist I was seeing when I was mad, she'd say things to me like, "You'll never recover, you're going to be on medication for the rest of your life. Don't worry, we'll give you an ECT when things get too bad. You'll never work again." Alex

While some consumers like Alex were able to defy the prognosis given to them, not everyone was considered to have the same independence of thought;

Those people [consumers who do not challenge authority] feel quite disempowered by the system... I've had people [disempowered consumers] say to me, "Can you get better?" Never, ever even considered the concept that you can actually get better." Alex

Participants provided many examples where medical model informed clinicians told consumers they won't recover;

That their [consumer's] best hope is to take pills that give them huge side-effects for the rest of their lives and maybe the symptoms might abate somewhat. Margaret

Other participants shared similar experiences;

The number of friends who've told me their psychiatrist has told them, "You'll never amount to much. You will never have a good life. You will just exist", while they were severely unwell. It's frightening. Roger

The presence of lived experience practitioners was seen to facilitate a Recovery informed environment, whereas traditional mental health professions were not seen to have the same strong focus on core Recovery concepts;

I find that mainstream mental health services and psychiatrists in particular don't give that hope and that's our main role, instil hope. Alex

Although exceptions were noted, on the whole, the more medically focused the training of mental health professionals, the more "medical model" their thinking was perceived to be;

I think there's a lot of good people and a lot of good clinicians with good intentions. I actually think that the upper echelon around the psychiatric level is the most difficult to challenge. Nigella

Where service attitudes were seen to have changed in positive ways, lived experience practitioners were cited as leading the transformation;

People who have been around a little while who are reasonably outspoken but who bring some valuable knowledge, experience and challenge what has been known before and anecdotally show people what they've thought is wrong. I look at the consumer and carer consultant in our mental health unit. They're great people with great skills and they're well respected. Nigella

The need for change to existing mental health services was frequently raised by participants. While some improvements were acknowledged, they were not consistent or prevailing;

I get really heartened at times that things have changed and attitudes are improving and then something will slap me in the face and I'll be going "oh God, we're still hearing those same sorts of issues". Frances

The need to shift clinician thinking from a medical model perspective to a more Recovery-orientated approach was viewed as critical in establishing best practice outcomes for people who use mental health services;

so that they [clinicians] have more knowledge and a deeper understanding of what that individual's going through and how their [clinician's] behaviour can actually increase the stigma and reduce their [consumer's] capacity for Recovery. Leean

Examples of how medical model thinking impacted negatively on the Recovery outcomes of people who use mental health services were provided;

My old team leader was a mental health nurse and worked in the public sector. At times we'd be going through the referrals and she'd go, "Oh, no, I know that person. They're not going to comply or they're not going to get any better". I go, "Look hang on a minute. If you were employed here and you didn't have that knowledge, you'd give them a chance." Trying to point out that Recovery is about finding the right window of opportunity and maybe that wasn't last week or last month or last year but it might just be today. Leean

The essential dichotomy between medical model thinking and training and Recovery concepts and approaches was seen to play a large role in the ongoing need for change and as a barrier for reform;

It's a huge shift from the medical way of "I'm the expert and if you're my patient or my consumer then I'm the expert in this relationship" to say "no, we have different expertise that we can both bring to the table. Zeva

The lived experience contribution in achieving cultural change was central, with some participants focusing on shifting the attitudes of their non-lived experience colleagues;

I share little bits over time and sometimes I challenge their [clinician's] concepts. I find just doing that subtly, quietly,

at opportune moments after I've built up bit of a rapport with people. Nigella

Other participants concentrated their efforts on people who are currently experiencing mental health challenges and using services;

Promoting Recovery philosophy and seeing the lights go on and seeing people recover and get on with their lives and improve and develop. Roger

Commonly, participants viewed lived experience practitioners as crucial to ongoing Recovery implementation and reform;

I think we will transform the system as we develop our own ways of doing things and our own ways of opening up space for our distress and experiences to be understood in multiple ways, in ways that are actually through our experiences. Brydie

Discussion

Consumers of mental health services and mental health professionals have been found to hold differing beliefs and concepts about what is valuable and effective in service provision (Aston & Coffey, 2011; Kogstad et al., 2011). Within this study, participants generally viewed the continuing dominance of the medical model as the most significant barrier to the success of mental health reform, which in turn impacts strongly on LEP roles. The foundation of the medical model approach is the DSM or Diagnostic and Statistical Manual of Mental Disorders which psychiatrists use to categorise the mental health experience of consumers (American Psychiatric Association, 2013). The service consumers receive, often with a strong pharmaceutical focus, is guided by the diagnosis drawn from the DSM which has been described by both consumers and mental health professionals as pathologising distress and maintaining medical model dominance within the mental health system (Carlat, 2010; Mead & Hilton, 2003; Scott, 2010; Welch et al., et al., 2013).

Over time, research has shown the damaging ramifications of adopting an "illness identity" and feeling limited in life choices as a result of diagnosis (Deegan, 1988; Magliano, 2007; Mead & Copeland, 2000; Yanos et al., 2010) with increased risk of suicide, decreased hope and self-esteem, and limitations on potential social roles identified (Yanos et al., 2010).

The release of the DSM – V in 2013 highlighted the disconnection between the life experiences of people and the medical model approach, with vocal concerns about the validity of the document expressed by mental health professionals and consumers alike (Echeburúa et al., 2014; Health Workforce Australia, 2014a; Kumar, 2000; Munchel, 2013; Welch et al., 2013).

At a time when the call for person-centred and holistic services is mandated by government strategy and plans (Australian Government, 2012; Department of Health and Ageing, 2009; Government of Western Australia, 2012), this latest DSM has taken the pathology of human experiences

further than ever, creating significant controversy (Kumar, 2000; Mendoza et al., 2013). Historically, the diagnostic approach has focused on the psychiatrists' examination of symptoms and consequent diagnosis with less attention paid to the social, historical and environmental factors impacting on the individual's mental health (Carlat, 2010; Rufer, 2007) and limited the ability for consumer's to input into their own healing journey (Ostrow & Adams, 2012). This creates and sustains the power imbalance between the consumer and the psychiatrist as all knowledge of perceived value within the relationship is seen to reside with the psychiatrist (Deegan, 2007; Rufer, 2007; Strickler, 2009). Further contributing to an inability to create mutual or collaborative partnership between consumer and psychiatrist is the extraordinary power the psychiatrist has over the liberty of the consumer, based on societal perceptions that people with mental health challenges are somehow 'defective' and unable to be trusted to make their own decisions (Kumar, 2000).

It is within this culture of marked unequal relationships between health professionals and consumers that LEP currently exist. Recent research also identifies mental health professionals' resistance to change and reluctance to relinquish power directly impacting on LEP (Happell et al., 2015a). LEP belong to a disempowered and discriminated sector of society by virtue of their status as mental health consumers (Goffman, 1968). The LEP currently has little real power within services or organisations compared to that of established mental health professionals and often experience discrimination in their work roles because they are mental health consumers (Ahmed et al., 2014; Moran et al., 2013).

As research has identified, when those who hold power – in this case mental health professionals informed by the medical model of care – do not share power with LEP, LEP roles are significantly restricted in their ability to effect change or be impactful (Bennetts et al., 2011). Perhaps unsurprisingly, the vast majority of participants cited medical model approaches and attitudes as a significant barrier to the efficacy and evolution of the LEP role. As participants described, many mental health professionals do not understand or accept their roles, often openly refusing to collaborate with them. An array of literature supports these experiences (Ahmed et al., 2014; Bennetts et al., 2011; Cleary et al., 2011; Health Workforce Australia, 2014b; Moran et al., 2013). By refusing to collaborate with LEP, LEP become isolated and unable to impact meaningfully on the wider work around them, marginalising LEP and rendering them tokenistic and ineffective (Happell & Roper, 2009; Health Workforce Australia, 2014a).

Participants expressed their opinions that the medical model is not only a significant barrier to the success of LEP roles but also to the shift towards the Recovery approach in mental health as the Recovery approach and medical model are philosophically in opposition and unable to be employed simultaneously with any success. Considering the design of the medical model encourages power imbalances in favour of professionals, whilst the Recovery approach insists on collaborative partnership and autonomy for consumers (Gordon & Ellis, 2013) demonstrating conflicting agendas, this seems a reasonable conclusion to draw. An emphasis on medication and an 'expert knows best' attitude, prevalent in

the medical model is disempowering for consumers (Drake et al., 2010; Scott, 2010). Conversely, Recovery and LEP theory respects that the individual is the expert on their own mental health and aims to build the confidence of the consumer to direct their own healing journey (Mead & Copeland, 2000; Mead & MacNeil, 2006). The medical model is risk averse in a way that makes consumers afraid to take positive risks necessary in order to grow and move past their current difficulty (Scott et al., 2011) doing ‘for’ instead of ‘with’ (Scott, 2010) and fostering dependence on the system (Department of Health and Ageing, 2013).

Recovery takes a strengths perspective and focuses on what the consumer already possesses that will assist them to heal, while the medical model focuses on deficits and symptoms (Davidson et al., 2008; Department of Health and Ageing, 2013), disempowering the individual and impacting negatively on their belief in themselves and their ability to heal (Drake et al., 2010; Yanos et al., 2010). Recovery holds hope that *all* people can create a life that is meaningful beyond the constraints of illness (Ostrow & Adams, 2012), while medical model ideology contends that an individual’s life will be dominated and limited by their illness (Ramon et al., 2007). As LEP work cannot be separated from Recovery principles – they are mutually informed and developed – the same conflicts with medical model concepts impact on LEP roles.

Questions are then raised about the potential impact on both mental health reform and the individual experiences of consumers and LEP while the medical model approach, currently antithetical to true partnership with consumers, continues to dominate and inform much of mental health service delivery. A previous version of the DSM included homosexuality as a mental disorder (Corrigan, et al., 2013) and the act of ‘labelling’ is acknowledged by some mental health professionals as depersonalising and an attempt by professionals to distance themselves from the consumer by creating difference (Scott, 2010). True commitment to the Recovery approach would suggest a more radical review of the informing concepts presently ingrained within mental health service systems, including the reliance on documents like the DSM (Rufer, 2007).

Limitations

Limitations of this study primarily reflect those inherent in qualitative research. Given the focus is on depth of understanding, the number of participants able to be included is relatively small, and unable to truly reflect the broad diversity in the structure and aims of roles, and the differences in service delivery approaches and geographical locations. These factors limit the extent to which these findings can be presented as representing the views and experiences of LEP more broadly. Furthermore, no participants were from an Aboriginal or Torres Strait Island background, and research is required as a matter of priority to capture these perspectives and experiences.

Conclusions

For mental health reform to be truly effective, a more evidence-based, Recovery oriented approach to assisting people to understand their experiences must be developed

and LEP are highly qualified to assist in this process. Lived experience roles are therefore essential to the government reform agenda. The success or otherwise of these roles requires support and resources, and probably most importantly an environment that facilitates the implementation and development of these roles to make an effective and meaningful contribution to consumer-oriented mental health services. The study findings suggest the medical model culture prevailing throughout mental health services presents a major barrier to LEP being able to realise the potential of the roles and contribute effectively to Recovery-based reform. In effect the expectation is to ‘fit in with’ the system, rather than allow and indeed encourage the system to change as a result of the inclusion of LEP as key players in mental health reform. Achieving policy expectations for Recovery-oriented services and enhanced consumer participation requires a willingness to reflect on the prevailing culture of mental health services and the barriers to change that may be embedded. Critiquing rather than purely accepting the prevailing culture provides an important starting point to consider the changes required for true reform, avoid tokenism and move to create the preferred future.

Declaration of interest

The authors report no conflicts of interest.

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