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#### INTRODUCTION

Lived experience practitioners have experienced mental illness, recovered and learned to use their 'lived' understanding of mental health challenges to assist others (Byrne, 2014; Byrne, Happell, Welch, & Moxham, 2012). Lived experience practitioners are utilised in a range of mental health settings to challenge stigma, advocate and be an inspiration for those currently accessing services (Ahmed, Hunter, Mabe, Tucker, & Buckley, 2014; Segal, Silverman, & Temkin, 2010; Warner, 2010). People are employed to work specifically from their lived experience of mental health recovery in a range of roles and organisations: providing hands on support, education and training, systemic advocacy and contributing to system design (Health Workforce Australia, 2014a). A range of titles exist but all the roles share a core qualification of a lived experience of recovery and the unique understanding of what people accessing mental health services are experiencing (National Mental Health Consumer & Carer Forum, 2010).

The uniqueness of lived experience perspective includes understanding the experiences of marginalisation, oppression, stigma, self-stigma and loss of social status that commonly accompany mental health diagnosis and service use (Health Workforce Australia, 2014b; Marino, 2015; Rüsch et al., 2014). The lived experience role provides empathy, connection, genuine understanding and importantly hope for people currently struggling with their mental health (Basset, Faulkner, Repper, & Stamou, 2010; Davies, Gray, & Butcher, 2014; Franke, Paton, & Gassner, 2010; Repper & Carter, 2011). When employed to provide education or within systemic positions, lived experience practitioners provide a bridge of understanding to facilitate better understanding of the needs of those accessing services and assist services to provide more effective support (Ostrow & Adams, 2012; Pinches, 2011).

A significant body of research suggests that when used effectively, lived experience practitioners can supplement traditional mental health services, improve outcomes for people with mental illness and reduce overall health care expenditure (Faulkner & Basset, 2012; Stratford et al., 2015; Trachtenberg, Parsonage, Shepherd, & Boardman, 2013). However the roles are currently impacted and impeded by high incidence of stigma and discrimination within the workplace (Bennetts, Pinches, Paluch, & Fossey, 2013; Moran, Russinova, Gidugu, & Gagne, 2013) as the following paper confirms.

# **METHOD**

## RESEARCH DESIGN

There is a paucity of literature currently allowing the perspectives of lived experience practitioners to be heard. Therefore the grounded theory approach of Strauss and Corbin was deemed appropriate for this study (Corbin & Strauss, 2008). Grounded theory aims to facilitate accurate representation of participant experiences by allowing the theory to emerge and be built from the data rather than testing a pre-existing theory (Birks & Mills, 2011).

### PARTICIPANTS AND RECRUITMENT

Participants were recruited through existing formal networks at national, state and district levels. An email was sent to the networks explaining the aim and design of the project and inviting interested persons to make contact. The total number of participants for the study was 13, which comprised of eight female and five male participants. Purposive sampling ensured participants represented geographically diverse settings, and work roles within a broad range of employment situations.

# **PROCEDURE**

Interviews with participants were in-depth and semi-structured. In line with grounded theory all participants were asked to broadly describe their experiences of working in a lived experience role.

# **ETHICS**

Prior to participant recruitment, ethics approval was granted by the relevant Human Research Ethics Committee. Participation was entirely voluntary and participants had the right to withdraw at any time without penalty. Confidentiality was ensured by de-identifying and coding all transcripts before analysis began. As demonstrated in the findings below, pseudonyms were given to all participants.

All identified material and codes were stored in locked storage systems, separate from de-identified material and only accessible to the researchers.

#### **ANALYSIS**

Constant comparative analysis was employed, providing a simultaneous process of data collection, analysis and subsequent data collection. In line with the open coding approach of Strauss and Corbin (1990) each cycle of data collection and analysis guided the next iteration. Concepts that were frequently occurring informed the early development of the substantive theory during axial coding. In order to validate and confirm the substantive theory, relational and variational sampling was then employed. When no new concepts were found to be emerging from the data, discriminate sampling validated findings and was utilised to verify the substantive theory.

# **FINDINGS**

The issue of stigma/discrimination was frequently raised by participants. Data analysis revealed stigma and discrimination as the basic social issue participants were responding to. The prevalence of stigma/discrimination was found to impact negatively on lived experience practitioners and subsequently on the central category, 'efficacy and evolution of the role'. This paper focuses on concepts emerging from the data in relation to participant perceptions of stigma and discrimination. Data analysis identified the concepts relating to stigma/discrimination as: stigma normal, treated differently and professional isolation, as represented in Figure 1.

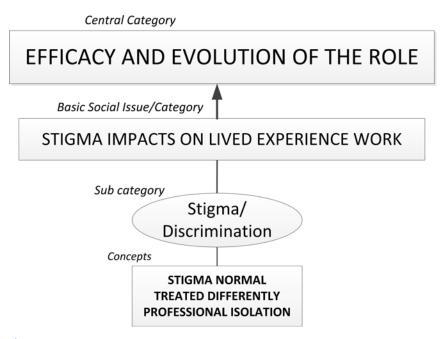


Figure 1

#### STIGMA NORMAL

Stigma and discrimination were reported as common experiences for all participants, with most having come to accept it as a natural or 'normal' part of their working life. Possibly because of this, participants appeared to be desensitised to discriminatory treatment and some even saw stigma as something 'one brings upon oneself':

...what I say about stigma generally is it's a bit of an optional thing if you receive stigma from mental illness. If you've got enough clues about life you won't say "I have a mental illness" or "I have this or that disorder". Claude

Other participants expressed beliefs about lived experience practitioners needing to be thoughtful in the way they present themselves. Particularly, to be careful of not reinforcing what were perceived as low expectations and stereotypical attitudes from some of their professional colleagues. Similarly, several participants felt they were being scrutinised by some of their colleagues and had to overcompensate by always appearing professional or risk being seen as 'unwell' and therefore a liability:

I do think I've had to overcompensate. I'm aware of how I dress, of how I move, of how I engage, that there is always the potential that I will be misread as being inappropriate, and that being due to my lived experience rather than just a personality thing. Brydie

Participants were willing to accept what were deemed to be 'lesser' degrees of stigma as Claude described:

... I don't judge people badly if they hold slightly stigmatised attitudes.

Overall, Leann's resigned view towards stigma and discrimination was quite common:

...there's always going to be people who are going to stigmatise...I guess you get conditioned to being treated that way.

At times participants seemed to have difficulty describing their experiences. There was some disagreement about the appropriateness of the term stigma as a descriptor, as Brydie stated:

I don't think the concept of stigma has been useful to us ever. I don't think it's just been co-opted, we don't talk about stigma in race we talk about racism, or in gender we don't talk about the stigma of being a woman, we talk about sexism and oppression and limited ideas of what women are capable of ...the system uses stigma to mean ignorance and [assume] what people need is more information and they provide the information. If we keep using the word stigma it often means the solutions are provided by someone else in a way that I think is damaging to us...

Despite concerns, Brydie as well as all the other participants did use the term stigma in relation to their role. To accurately represent the language that was used by participants, this paper uses the terms stigma and discrimination but with an awareness that existing language may be insufficient to accurately describe the experience.

Stigma and discrimination manifested in a variety of ways for the participants, including a perception of being treated differently within their work environments.

#### TREATED DIFFERENTLY:

Some participants described professional colleagues asking questions about their life that they found intrusive and inappropriate. These instances were perceived as examples of lived experience practitioners being viewed and treated differently to other employees:

Somebody asked me a question about what my diagnosis was at one stage and I thought "God nobody's asked me that for freakin' years and I've had seven, which one would you like?" I don't answer that question anyway. I just said "sorry, I don't answer those questions".

Commonly, participants felt that some mental health professionals struggled to differentiate lived experience practitioners from current service users and consequently interacted with lived experience practitioners in ways that were viewed as inappropriate or belittling:

Certainly they might think they know all about consumers because they treat them [consumers] all the time, but I'm not unwell. I'm not somebody they need to medicate or organise services for. So their role with me is quite different even though I identify as someone that has mental health problems. Nigella

Participants also described professional colleagues expressing surprise when they produced high quality work. This reinforced the idea that little was expected from lived experience practitioners within some settings. Some participants were of the opinion their lived experience knowledge was not valued or understood by their colleagues, and other professional experience and qualifications were apparently also discounted:

...reactions from some staff makes me feel that the stigma of identifying as having a lived experience runs before me, before any sort of professional credibility. I was a high level performer in community development in the non-government sector before I took this job and I come in here and it's as if the only thing people see is the tag of "consumer" and you have to work really hard to get recognised.

Zeva

This perception of some professional colleagues not valuing lived experience contribution and viewing lived experience practitioners as requiring help and guidance was seen to significantly contribute to discrimination towards lived experience practitioners. Frequently participants offered the opinion that this way of viewing lived experience practitioners was partly as a result of the work environment itself. Specifically, that many mental health professionals only see consumers while they are in crisis and not during times of healing. As a result, participants believed many mental health professionals, particularly within acute care environments do not understand that consumers also go through periods of wellness:

I have suffered a lot of discrimination in the past, particularly from mainstream mental health services [government services]. I think mainstream mental health services have this view, they only see people that are in crisis and that are really, really bad and I don't think they have much of a concept of Recovery and what people can achieve in Recovery. Alex

A lack of understanding of the concepts of Recovery and what people are often able to achieve in Recovery was seen as a major barrier to understanding and accepting the value of lived experience roles, contributing to ongoing stigma and discrimination. Another component of what participants perceived as being treated differently was professional isolation.

# PROFESSIONAL ISOLATION:

Roger described his current situation at length, his disappointment that his colleagues didn't interact with him and the consequential lack of collegial interaction:

Some people can get very protective of their professional boundaries... I keep pretty much to myself unless I'm asked to help someone. But it doesn't happen very often... what I'm saying, the mental health workers don't talk to me.

For Roger a lack of interaction around his area of speciality was particularly concerning:

No one has ever asked; no other mental health professional; one of the nurses, social workers, occupational therapists or psychologists have asked me about recovery. Ever. I think that's damning, 'cause I don't know if you're getting the sense, I know a little bit about recovery.

Marginalisation and isolation of lived experience practitioners working within government organisations was reported as particularly common. Margaret provided an example:

A psychiatrist was talking about how consumers and carers belong under the table. I went, "I'm a consumer consultant," and they literally jumped backwards, stepped away from me in fear. There was a lot of stigma in that particular organisation. I was left to my own devices, no-one noticed if I rocked up or not and given tokenistic and menial jobs to do.

Participants expressed feelings of surprise and dismay facing what they described as a greater incidence of stigma working for a government mental health service than they had within the general community. Participants described feeling so demoralised and unimportant within government services they choose not to remain within those roles:

I think in the government system we felt like very low down pawns in a very big superstructure. So even when I basically had a job ongoing for me I didn't even apply for it. Claude

Other participants reported favourably on moving from government to non-government and lived experience-run services, commenting that their treatment and inclusion within the wider workforce was far more positive. Several participants explained the relief they felt joining an organisation where they felt accepted and valued and contrasted this with their previous experience within a government service:

In NGOs [non-government organisations] it's really amazing to see how much I'm welcomed as part of the team and that my experience is actually seen as something worthwhile that I can contribute rather than in clinical [government] where it seems to be the opposite. Margaret

Some participants discussed the consumer consultancy role common within government services and were critical of what they saw as restrictions placed on the role:

... if you look at the consumer consultant's job description, they're supposed to be at meetings all the time. So people don't have access to the lived experience, or consumers don't and workers just tend to be scared of it. Margaret

Participants shared a perception that attitudes within government services were still entrenched in 'medical model' thinking, which was seen to include stigmatising or unhelpful beliefs about consumers. Leean offered a solution:

If we could get them [lived experience practitioners] in there [government services] and we could get them really well supported, I actually think we'd start to challenge some of that stigma thinking.

# DISCUSSION

Participants used the terms 'stigma' and 'discrimination' interchangeably, however stigma refers to the act of being set apart or made 'other' while discrimination is a consequence of stigma and refers to illegal acts of exclusion (Anti-discrimination Commission Queensland, 1991; Bates & Stickley, 2013). Stigma includes acts of discrimination but also negative beliefs and attitudes that are not legislated against (Clark et al., 2013). Frequent derogatory media depictions of people with mental health challenges provide obvious examples of stigma that is legal and socially accepted (Corrigan, 1998; Nestor & Galletly, 2008). As raised by participants, the current language may be insufficient to accurately describe the experience. Some research supports this idea and suggests a stronger emphasis on the term discrimination rather than stigma to encourage legal action in response (Thornicroft, Rose, Kassam, & Sartorius, 2007). As raised by participants, other research promotes the idea of alternate language, equivalent to the terms racism, sexism or homophobia (Perlin, 2013). These authors argue for the need to highlight prejudice inherent in stigmatising attitudes, as described by terms like mentalism (Chamberlain, 1978) and sanism (Perlin, 2013). It may be difficult however to achieve increased protection under the law while involuntary treatment is still a feature of the mental health act, which has for some time been described as institutionalised discrimination (Campbell, 1994). International treaties like The Convention of the Rights of Persons with Disabilities and the findings of the UN report on torture and other cruel, inhuman or degrading treatment may assist in ensuring more equal rights for consumers in the longer term (Bartlett, 2012; Méndez, 2013). For the purposes of this paper, the term stigma is deemed appropriate as it reflects the language of participants and describes the wider experience of both illegal discrimination and negative but legal attitudes and beliefs.

Participants of this research frequently raised issues relating to stigma and discrimination. Recent longitudinal international research identifies stigma originating from both mental health professionals and the general public as one of the greatest impediments to Recovery-orientated care internationally (Shera & Ramon, 2013), and consequently to the effectiveness of lived experience work (Byrne, Happell, & Reid-Searl, in press).

Research has demonstrated that when an experience of mental health difficulty becomes known, people facing mental health challenges frequently encounter rejection from loved ones and in their social and work roles (Ilic et al., 2013; Wahl, 2012). Their opinions, abilities and perceived competence are devalued (Wahl, 2012) and contradictory beliefs or strong emotions are assumed to be manifestations of their mental health issue and therefore not given credence (Goffman, 1968; Wahl, 2012). Just as people who access mental health services are subjected to stigma and discrimination within service systems (Charles, 2013; Mendoza et al., 2013; Shera & Ramon, 2013) the literature demonstrates lived experience practitioners face stigma as part of their working roles (Bennetts, 2009; Bennetts et al., 2013; Chinman, Young, Hassell, & Davidson, 2006; National Mental Health Consumer and Carer Forum, 2010). Many participants of this study were so accustomed to stigma and discrimination they saw it as a normal part of their working experience.

Like consumers, participants believed their opinions, abilities and perceived competence were at times devalued by their professional colleagues due to their acknowledged experience of mental health challenge. Despite increasing government insistence on lived experience practitioners within service delivery (Department of Health and Ageing, 2009) literature also reports some mental health professionals are sceptical about the value of lived experience roles (Bradstreet & Pratt, 2010; Chinman et al., 2006; Nestor & Galletly, 2008). The literature frequently reports attitudinal barriers on the part of mental health professionals as inhibiting the efficacy and evolution of lived experience roles (Bennetts, 2009; Browne & Hemsley, 2008; Happell, 2008, 2009; Nestor & Galletly, 2008; Roper & Happell, 2007). Within the literature attitudinal barriers were seen to contribute to lived

experience practitioners working in "...a culture where stigma is the norm and discrimination or abuses are tolerated" (National Mental Health Consumer and Carer Forum, 2010, p. 21).

Participants, particularly in government organisations described being professionally isolated and treated differently within their workplace. Some participants described professional colleagues being fearful or simply not interacting with them. Recent research has also discussed the unique challenges of lived experience practitioners being professionally isolated, feeling outnumbered and ostracised, which was exacerbated when only one lived experience practitioner was employed (Moran et al., 2013).

Participants suggested that the 'consumer consultant' role, frequently found within government services, spends too much time in meetings and not enough time visible to consumers and their families. The design of roles, including where roles sit within an organisation as well as aim and functions may need to be examined in relation to professional isolation. Although the existing literature does not address that issue specifically, there is certainly a great call for roles to be better defined (Health Workforce Australia, 2013; National Mental Health Consumer & Carer Forum, 2010; O'Hagan, McKee, & Priest, 2009; Stewart, Watson, Montague, & Stevenson, 2008). The suggestion by participants that more lived experience roles are needed to counter-act isolation and challenge 'stigma thinking' within organisations, is supported by studies emphasising the benefits of networking and of having more than one lived experience practitioner within services (Bennetts et al., 2013; Moran, Russinova, Gidugu, Yim, & Sprague, 2012).

Wide spread dissemination of empirical research and training to encourage mental health professionals to understand the value of lived experience roles may contribute to more supportive and collaborative workplace culture (Basset et al., 2010; Moll, Holmes, Geronimo, & Sherman, 2009). Addressing common myths may also engender a more inclusive work environment (Repper et al., 2013). Concerns about funding should take into account the long-term cost benefits of lived experience work (Trachtenberg et al., 2013). In addition, dissemination, education or change management strategies would benefit from accountability mechanisms to ensure uptake is meaningful (Gordon & Bradstreet, 2015).

The role of lived experience practitioners in reducing stigma is indicated both explicitly and implicitly by participants within this research. Literature supports the important role of lived experience in stigma reduction; (Basset et al., 2010; Corrigan, Kosyluk, & Rüsch, 2013; Davies et al., 2014; Happell

et al., 2014; Segal et al., 2010). However as some participants pointed out, at times the term stigma and the anti-stigma campaigns that purport to address it have been co-opted, as a recent Australian study demonstrates. Yap (2013) asserts that 'accurate' application of psychiatric labels and concurrent media campaigns educating the public about psychiatric diagnoses decrease stigma (Yap, Reavley, Mackinnon, & Jorm, 2013). However, such work has been described by others as pushing the agenda of psychiatry and acting as a public relations campaign for psychiatry itself (Schulze, 2007). Research also suggests that despite wide-scale effort and significant financial investment in public education campaigns, the biogenetic and diagnostic approaches to stigma reduction have not been effective (Read, Haslam, Sayce, & Davies, 2006; Schomerus et al., 2012). Further research asserts that focus on diagnoses can contribute to stigma by increasing the desire for 'distance' (Corrigan, 2007; Read et al., 2006). It could therefore be questioned whether such attempts at antistigma in fact rob people of the most effective way of describing their experiences, instead reinterpreting and co-opting the term. Recent research concludes that it is the role of lived experience practitioners to act as an intermediary between people experiencing mental health difficulties and those who would potentially stigmatise (Ilic et al., 2013), supporting the idea of lived experience leadership in stigma reduction initiatives (Corrigan et al., 2013; Rüsch et al., 2014). It could be surmised that as Friere (1972) proposed, the oppressor cannot liberate the oppressed, particularly using the structures and ideas that have maintained oppression (Freire, 1972), in this case the language and definitions of psychiatry.

# LIMITATIONS AND FUTURE RESEARCH

As a result of the focus on in-depth understanding, participant numbers were relatively small. This limits the generalizability of findings, but the broad range of roles purposively sampled still allows for transferability across diverse lived experience roles and employment settings. The findings in this paper were not the sole outcomes of the study. Reporting in additional publications examine other outcomes in relation to lived experience work practice. The findings in this paper therefore only represent a portion of the overall findings. More wide-scale research into the incidence of stigma in relation to lived experience roles would contribute to the evidence base and provide additional insights and directions for future practice.

# CONCLUSION

Lived experience practitioners can potentially play a vital role in lessening stigma and discrimination but they must be supported to do so and not face the additional burden of stigma within the workplace. The experiences of stigma and discrimination described by participants and literature highlight the need for wide-scale change management to address workplace culture. Redefinition of lived experience roles, particularly within government services and employment of more lived experience practitioners may help combat professional isolation. Dissemination of research on the value of lived experience roles will likely help to address some of the attitudinal barriers. However this research or training will need to be supported by accountability mechanisms to ensure the mental health sector is a safe space for lived experience roles.

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