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Lived experience and personal narrative: pathways to connection

Abstract:

First person narratives drawing on experiences in mental health settings and services provide important insights into the lived experience of suffering, healing and recovery. An emerging and influential role within mental health services is that of the 'lived experience' worker. People employed in what are known as 'lived experience' roles have powerful stories to share. The use of personal narrative aids connection with current service users, demonstrating that hope for a better life is possible and challenging stereotypical or stigmatizing attitudes by highlighting shared humanity and common human experiences. This article tells one such story, where parallel narratives and multiple perspectives are used to highlight the benefit of encouraging vulnerability to foster connection.

Biographical note:

Dr Louise Byrne utilises her own experience of significant mental health challenges, service use and periods of healing and wellness in her university teaching and research. Louise has used her lived experience in a variety of positions in government, non-government and tertiary settings, including a role as an expert advisor to the Queensland Mental Health Commission.

Keywords:

Creative Writing – Personal narrative – Lived experience – Mental health – Stigma

Background

Narratives, particularly our own, powerfully influence our self-identity (Kinsella 2006). This can be strengthening and enriching, or weakening and soul-destroying, depending on the type of narrative. An example of a more limiting narrative of self, the 'patient identity', develops as a result of mental health diagnosis and psychiatric service use (Mead, Hilton and Curtis 2001). Due to an emphasis on symptom identification and management within service approaches, diagnosis and service use has the potential to encourage individuals to view themselves and to be viewed, through an illness or 'deficit' lens (Whitaker 2010). This deficit perspective, focused on what is lacking, is attributed to the medical model, which emphasises areas of perceived weakness. An alternative lens, one that is growing in popularity, is to appreciate strengths and abilities (Rapp 1993; McAllister 2007; Wand 2010). With a focus on these strengths, people may come to see themselves as having abilities to balance vulnerabilities and consequently develop a more positive self-identity.

Contemporary psychology acknowledges that 'because of the power of language, and the social power that doctors hold, it is easy for doctors inadvertently to impose a narrative account which may be harmful to a patient's sense of self" (Cook 2016: 2). Sociologists also discuss the power of 'redemption narratives' as a motivator for both individuals and social movements to inspire and maintain momentum for change (Polleta 1998). In response, the use of first person narrative in mental health settings and services is rapidly rising with the growing popularity of so-called 'lived experience' mental health roles (Davidson 2015). Lived experience roles employ people with a personal experience of mental health diagnosis, service use and the common challenges of marginalisation, stigmatisation and loss of status that often accompany service use (Deegan 2005), and may focus on systemic advocacy, education or one-on-one support. These roles developed as a response to the hopelessness experienced by many people accessing mental health services, and provide new opportunities for empathy and inspiration (Davidson, Chinman et al. 1999). An integral component of many of the roles is the sharing of stories and use of personal narrative (Faulkner and Basset 2012). Within mental settings, lived experience roles and the narratives they share provide perspective and help to make meaning in ways that are supportive of the patient's experience, providing hope and challenging the limiting narrative of the 'patient identity' (Mead and MacNeil 2006).

Like many people with a lived experience of mental health issues, I have at times viewed myself through a deficit lens. Service use and the unhelpful language and ideas of mental health professionals impacted negatively on my self-identity. I adopted and inhabited the 'patient identity' role and then struggled to find my way to a more meaningful concept of self. I have a tapestry of overlapping, interwoven and, at times, contradictory narratives: from psychiatric patient to successful academic, film-maker, daughter, teacher and friend. My own story is a narrative that includes a lived experience of distress, service use and un-wellness, but also of healing, inspiration and triumph, and is presented below.

Multiple perspectives, parallel narratives

She is dressed casually, a long colourful skirt and mala beads like a pendulum, swinging and telling a story of their own. She is open-stanced, palms up facing the audience. Introduced as academic, doctor, psychiatric patient, singer, she looks more like a hippy, flower child. She admits her nerves and starts to remove items – her name badge, her cardigan. She says they protect her and she wants no protection. She chooses to be here, vulnerable and with them. She chooses to step out of any protective armour to allow for connection with her fellow humans.

She contextualises the psychiatric patient, as a time of darkness and fear. Post-hospital, friendship groups are abandoned in an effort to get 'clean' and sober. She describes the night time, alone. She takes us to a lonely house by the river, she is 29 years old. She is unemployed and unsure. She is huddled in bed with no idea of what the future might hold, still consumed by past pain and the void that is now. She is a broken bird but her song remains. She reaches out and finds the sliver of her faith, her belief in something big, filled with love. She opens the human beak and allows the sounds to rock her to sleep. Over months that song grows, line by line, becoming an anthem for the new life she will build.

In the room, on the day, as doctor, academic, psychiatric hippy, the singer welcomes her colleagues into that past bedroom, future dreams and takes them on a journey of parallel narratives, into the multiple perspectives of her life.

> Sometimes plain language just doesn't cut it. When your soul has entered the darkest pitch of night words alone can't express the way you feel. Please close your eyes now; (raw, gospel vocals) *Oh there's been times, oh precious times, when I did not know, which way to turn, I treasure these times, I treasure these times, because they brought me, so close to you*.

A new narrative, the psychiatric patient with gratitude for her experiences, the broken bird who found grace in her destruction.

> *Can you raise up your hands, can you raise your face, can you see behind suffering, spirit and grace, and I say Oh-oh, and I say Oh-oh, on the path to redemption, I saw only you.*

She appeals to others to see more than the damage, the disability. Another narrative as change-maker, advocate.

> *As the goddess my witness, as grace is my friend, my love and my faith, brought me through in the end, and I say Oh-oh and I say Oh-oh, on the path to redemption, I saw only you.*
>
> *Oh there's been times, oh precious times, when I had learned just what I should do, so I spoke with the spirit, I hid in my faith, and I learned forgiveness will forgive all mistakes, and I say Oh-oh and I say Oh-oh, on the path to redemption, I saw only you.*

Within the room, eyes open, many salted and wet remembering their own dark night or empathising with hers. The song has woven its special magic and some others have shifted their dominant narrative from professional, academic researcher to open, fellow

human. Their body language more relaxed, eyes and smiles warmer, embracing and encouraging. She continues.

> My story is an illness narrative, a narrative of healing, a caution about what can happen when narratives are suppressed. When I was 13 years old I was raped. It changed me dramatically and rapidly. I began to act in ways I now know are typical of a child who has that experience. I was angry, withdrawn, confused and most of all, traumatised. I was taken to a psychiatrist who later lost his medical license, the only one available in my regional town. I was involuntarily medicated, hospitalised in a geriatric ward, as there were no psychiatric spaces for children in my regional town. I was vilified by peers and their parents, shunned, labelled, avoided, talked about. I was further traumatised by the 'treatment' I received from mental health services and by my community. But I was never asked what happened. I was never asked so I didn't tell. My story sat inside me like a long-acting poison, like a toxin infecting my life.

Her story is sad and complicated and spans many years. When she is 15 she has an accident and acquires a Traumatic Brain Injury that is never treated and only properly acknowledged decades later. Another important narrative untold, unheard that ticks away inside her causing pain. She has experienced years of multiple traumas, abandonment, abuse. She has in turn abandoned and abused herself. She has walked to the edge of the bottomless cliff and peered far too long into the abyss. She was homeless, drug user, alcoholic. One of the cast off and pushed aside. Somehow she managed to claw her way out of it and by her mid-twenties has a Masters degree in media production, a boyfriend, a home, a job and a new life in the big city.

She smiles, remembering the brief triumph and respite before the 'crash'.

> Things were going so well, so I quit smoking, I quit drinking and pretty soon the doors in my mind that I thought were locked, opened up all at once. Every trauma alive and replaying, I couldn't get the pain to stop. I got poor medical advice again, medication that made me more anxious and less able to cope. I took a drug overdose, ended up in a psychiatric facility for three months and lost everything. All over again.

When she came out of hospital she was physically very ill. She could not care for herself and was driven back to the regional town where it all began. Her friends, home, job, partner, were gone. Healing and starting again at 27 was very different than it had been the first time. She had lost the ignorance of youth, blissful optimism. Her recovery was long and gruelling. She has footage of it she will share.

> In 2004, I was working on a film for someone else, things were still very tough and I had an appointment with my psychiatrist. I was speaking passionately about something. I was pretty upset. Considering the things that had happened to me in my life. I probably had a pretty good reason to be upset, but my psychiatrist thought I was too agitated. She wanted to involuntarily admit me. Having strong emotions can deprive you of your liberty. She was on the phone to my Mum trying to convince her to agree. I was yelling, she either gave me the phone or I grabbed it – I was very afraid and believed I'd never come back from another hospitalisation. I begged my Mum to trust me. The producer of the film I was working on, had a spare camera and editing suite. With only five days till the screening, he said, 'show me what you experience'. My Mum chose to trust me and

> for the first time someone handed me the reins in my healing journey. That was the beginning of my recovery.

The resulting film, *China Cup* (Byrne 2004) begins with a montage of photographs, the sound track of an old film projector whirring into action. The woman as baby, child, young girl. The sound of the film projector speeds up, less relaxing. The speed of the montage increases. The woman as a teenager, mohawk, rainbow coloured hair. Rock'n'roll shots, defiant glances, the teenage rebel. The montage slows again. The woman in Masters robes, testamur in hand. Shifting roles, emerging narratives.

Throughout the film, a recurring image of a female hand is shown piecing together a broken cup. At times more pieces are assembled, others less. In between, visuals show the woman in times of healing – at the park, running and playing with her dog, laughing and eating with her grandparents. These lighter times are contrasted with times of distress – piling medication into her hand, slumped in the corner with vacant eyes, shutting a heavy curtain as she shuts out the world. The soundtrack features the voices of her loved ones. They introduce themselves one by one. I am her grandfather, her mother, sister, brother, I'm her friend. They each share their impressions of the woman as a young girl, before her 'crash'. She always seemed to be a very normal child, very happy. Very concerned with others less fortunate than herself.

The film continues, the loved ones talk about the woman after her 'crash'. Her brother haltingly shares: 'I could see she was very, sad. And it made me, very sad'. The final statement from her sister shows most tellingly, it was everyone's pain, it was all of their trauma. 'When she had the crash, we were living near each other and life was great, we would hang out, it was a lot of fun. Then when she was in hospital she asked me to let her go'. The sister's voice breaks, she sobs. 'But I was selfish and I asked her to stay and she did. And she's still fighting to be here and I love her for it'.

The film tells many stories, a tapestry of narratives. She is/I am shown as psychiatric patient, loved member of a family. The voice-overs of friends and family provide a glimpse of their narratives, their confusion, helplessness, pain. The woman is also unmasked as film-maker – a skilled woman. She is shown as a survivor.

The role she inhabits on the day, as doctor, academic presenter reveals the thriver. The photographs circa late 1970s are not unlike the photos most people have of their childhood. The voices of the loved ones are not unlike the voices of many people's families, of the ones they love. The image of the cup, more broken, less broken, was an effective metaphor for how people feel at times themselves. The film uses images of hand drawn portraits, people in places of despair. Dark charcoal lines convey frustration; delicate pencil sketches show restraint. Visually, audibly, implicitly, explicitly the film provides multiple perspectives that reinforce the narrative of 'shared role as fellow human being', decreasing perceived differences and challenging the stigma of the psychiatric patient role. This is reflected in the response of colleagues. More tears, many faces now unmasked further, less professional, more 'fellow human'.

She talks about her work over the past decade employed in the mental health sector specifically to speak from her lived experience in a range of roles, in one-on-one

support, training and higher education. She explains the transformative power of personal narrative.

> In my support work at some point every single 'negative' thing that had happened to me became a point of connection, providing hope for someone else. I can't tell you the feeling when you share something and you see the light come on in someone else's eyes. They can see you've survived and suddenly hope for healing is a tangible possibility. As I saw my experiences provide something positive for others, it changed the way I viewed them. Over time I became grateful for the challenges that allowed me to assist in someone else's journey.

She believes story-telling, narrative, happens in many ways and many mediums – like the song, the video, the photos, the drawings in the video.

> The look on my face, the clothes I'm wearing today all tell a story. When we engage with someone in their healing journey, we need to consider the narrative they may perceive when they look at us.

She describes using her multiple narratives in her teaching to provide students with a new way to consider 'psychiatric patients'. As multi-faceted people. As daughters, sisters, doctors, academics. She talks about the hope this gives students who face mental health challenges themselves and the greater insight gained by those who have not. She uses her own story and those of others, videos, cartoons, newspaper articles, photographs, video games. She believes different mediums empower narratives and we should use a variety to ensure everyone is 'reached'. She believes everyone will face their own challenges in time and the best thing any of us can do is start talking about ours so others know that they are not alone.

> The greatest gift we can give is the gift of self. To thoughtfully share parts of our own story can make someone feel less alone, more understood, encouraged, hopeful. When we choose to open up, be vulnerable, we enable connection. Everyone has trauma and faces mental health challenges, or has loved ones that face them. Choosing to be vulnerable, to share some of your narrative within health settings could create an essential connection for someone who desperately needs it. I hope you choose to.

She finishes with another song, a song of hope and connection – leaning on each other. It is a well-known song and the colleagues clap and sing along, smiling.

> *Some time in our lives, we all have failed, we all have sorrow. But if we are wise, we know that there is always tomorrow. Lean on me, when you're not strong, I'll be your friend, I'll help you carry on. For you know it won't be long, till I'm gonna need, somebody to lean on*.

When she finishes, colleagues both new to her and known, line up to thank her, share hugs and their own stories. 'I was raped at 15, I never told anyone.' 'I never knew those things had happened to you, thank you for sharing.' 'My sister, she was so much like you.' 'You've empowered me to speak about my stuff.' As so often happens when she shares her narrative, others are implicitly given permission to share theirs. In that moment, in the post-vulnerability glow, professional masks are momentarily left aside and real connections begin.

Lived experience narratives for current and future practice

The narrative above provides an account of the keynote address I provided at the *Narratives of Health and Wellbeing Inaugural Conference* in 2016. Contained within it are multiple perspectives, parallel and sometimes contrasting narratives, with which I aimed to create a sense of commonality and shared person-hood and to debunk some of the stereotypes about 'psychiatric patients'. I chose to be vulnerable and unveil what is usually hidden, because as Brown (2013) suggests, this opens up an opportunity for connection, empathy and the development of relationships. Within this presentation I utilised multiple modalities and mediums to convey my personal narrative. These included the live, scripted presentation of my personal story as well as song and video. The power of music to stir emotion and provide stimulus to the brain is well established (Schellenberg 2004), but here I took the strength of music further, by demonstrating that my identity is also grounded in music, strengthened by the words of the song.

Filmic narratives, because of their montage of image, sound and story can also engage students deeply, encouraging them to look beyond the diagnosis and encourage empathy (McAllister 2015). I harnessed its power by showing, and not explaining, *China Cup*. Viewers were empowered to make their own connections to the strength and the vulnerability embedded within the story. Music, film art, and other forms of creative work develop identity and embody Davis' (2002) idea of narrative as social protest and change. For me they are a way to resist the reduced and deficient identity of "patient" or "mad". For me they also provide a pathway to happiness and flow (Csikszentmihalyi 1996).

I presently utilise personal story and the diverse narratives of 'psychiatric patient' and 'lecturer' in teaching lived experience-led mental health concepts to both undergraduate and postgraduate nursing students. Research into the effectiveness of my role provides evidence that the use of personal story can contribute powerfully to transformational learning (Byrne, Happell et al. 2013). Nursing students within this study identified significant positive changes in their attitudes towards people with mental health challenges and stated that the lived experience narratives gave them better understanding, insight and provided a reminder of shared 'humanness' (Byrne et al. 2012). The choice to be vulnerable and open also provided positive outcomes as the following quote demonstrates, 'I took my lead from her. The more she gave, the more I wanted to give as well ... It was just incredible and it's changed me as a person' (Byrne et al. 2012: 199).

Society continues to hold stigmatising or discriminatory views towards people diagnosed with mental health challenges (Corrigan, Michaels and Morris 2015). The literature likewise supports the idea that students entering nursing degrees may also hold views about people with mental health challenges that are discriminatory or fearful (Byrne, Happell et al. 2014), while research indicates these attitudes and beliefs need to be contested and transformed to allow students to emerge as empathetic professionals, able to provide effective care for all (Mcallister, Levett-Jones et al. 2015). Significantly contributing to this goal, the use of narrative has been found to provide a powerful means of inspiring the development of new perspectives, assisting

nursing students to let go of their old concepts and values and take on more ethical and equitable worldviews (McAllister, Lasater et al. 2015).

The power of narrative in relationship building is also evidenced in the broader context of health roles. Narratives and the sharing of narratives are seen to encourage respect, openness, empathy and awareness of the inherent privilege in being a health professional (Charon 2006). Particularly within mental health, the power imbalance between the health-care provider and the person accessing the service is profound (Deegan 2007). In the case of 'involuntary treatment' this becomes even more exaggerated, with mental health professionals literally having the power to deprive the 'patient' of their liberty without having committed a crime (Kumar 2000, O'Brien and Thom 2014). The need to strive for more empathetic and equitable relationships within mental health is therefore especially important.

Narrative practices within mental health remove the focus from symptoms and deficits that pathologise experience, and instead concentrate on shared conversations and stories. Within narrative traditions, mental health professionals are reminded to remain open and curious, and to respect that people experiencing mental health challenges are the 'experts of their narratives' (Freeman 2015). This also complements the lived experience perspective that the person with the mental health challenge is an expert by experience (Stratford et al. 2015) and supports the notion of greater mutuality within therapeutic relationships. In the above example, I shared my distress without citing diagnosis or symptoms. Focusing on the common human experiences of trauma and emotional pain allowed for empathy to develop. Making clear my role as loved friend and family member reminds the audience/reader that I am not 'just' a psychiatric patient but a valued part of a social network. Discussing my work also prompts my capacity to be recognised, rather than disability to be assumed.

Lived experience mental health roles are already being utilized in a wide range of settings including in-patient acute care, community mental health and tertiary education (Health Workforce Australia 2014). In those settings, the power of personal narratives is assisting in challenging discriminatory thinking, reducing stigma and aiding in the healing journeys of others. Longitudinal research over a range of studies has found people with a lived experience of mental health provide the most effective means of challenging stigma (Corrigan, Michaels et al. 2015). Use of shared personal story by lived experience roles in one-on-one mental health service relationships has been found to increase hope, enhance connection and provide a sense of belonging (Mead and MacNeil 2006). One innovative project employed people in lived experience mental health roles to assist others with similar challenges to re-enter the workforce. The participants reportedly viewed the people with a lived experience as role models, which ultimately aided them to over-come negative self-image, improve confidence and the ability to find and retain employment (Kern, Zarate et al. 2013).

Future expansion for roles utilizing personal narrative of mental health challenges is indicated within the research in this area. Use of people with a lived experience is already being trialed in the training of some police and paramedics to assist in building empathy and providing more respectful assistance to those experiencing mental health

crises. There is also evidence to suggest the value of exploring roles within additional emergency services, housing, employment and primary and secondary schooling.

Conclusion

Lived experience roles, with their strong use of personal narrative, provide compelling evidence of the power of storytelling in forging human connection. In this instance, a creative means of conveying my personal narrative stimulated and stirred emotions in ways that plain language alone would not. Multiple or parallel narratives contributed to a sense of commonality and shared humanness by creating a more complete picture than a limited narrative of a 'psychiatric patient' alone would have allowed. Narratives of distress and hope as utilised in this example and within lived experience roles more broadly, represent an exciting and timely step forward and provide opportunities for mutual vulnerability, ultimately enabling authentic connection.

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