

## **Dimensions of belonging: A phenomenological study of the meaning and experience of belonging for people living with mental health and substance misuse problems**

**Introduction:** People with co-occurring mental health and substance misuse problems are amongst the most excluded in society. A need to feel connected to others has been articulated in the occupational science literature although the concept of belonging itself has not been extensively explored within this paradigm. This paper reports findings from research which explored the meaning and experience of belonging for four people living with dual diagnosis in the UK. The study is funded by the UK Occupational Therapy Research Foundation (UKOTRF).

**Method:** Researchers employed an interpretative phenomenological approach to the study. Four semi-structured interviews were carried out. The interviews were guided by questions around meaning of belonging, barriers to belonging, and how belonging and not belonging impacted on participants' lives. Data analysis facilitated the identification of themes across individual accounts and enabled comparisons across accounts. Ethical approvals were given by the two UK academic institutions where the first author was working when the study was carried out.

**Findings:** Findings contribute nuanced understandings of the complexities of belonging including belonging in family, belonging in place, and embodied understandings of belonging.

**Conclusion:** The findings add further insights into the mutable nature of belonging. A link between sense of belonging and attachment theory has been proposed, along with a way to understand the changeable and dependent nature of belonging through 'dimensions of belonging'.

### **Introduction**

The motive to belong is central to human existence and culture (Malone et al 2012) with belonging understood by some as a basic human need (Maslow 1970). It has been defined as feeling valued and respected in the context of relationships which are built on shared experiences beliefs and characteristics (Mahar et al 2013). A need to feel connected to others has been articulated in the occupational science literature, with belonging described as the interpersonal connection of people to each other as they engage in occupations (Wilcock, 2007), and the necessary contribution of social interaction mutual support and friendship and a sense of being included (Rebeiro 2001). **The**

most up to date definition of belonging is provided by Hitch et al (2014, p242) who describe it as a sense of connectedness to other people, places, cultures, communities, and times, and the context within which occupations occur.

## Literature Review

Substance misuse is the most common co morbidity for people with living with severe and enduring mental health problems (Drake et al 2001). In the UK it is estimated that between 20 and 37% of people with a primary diagnosis of a psychotic condition also have an alcohol or substance use disorder (Carra and Johnson 2009). Amongst those with a primary substance use disorder there are co occurring rates of mental illness in the order of 6-15% (Carra and Johnson 2009). People with co-occurring mental health and substance misuse problems are at risk of social exclusion (Todd et al, 2004) and are considered amongst groups of people with 'severe and multiple disadvantage' (Duncan and Corner, 2012, p1).

Despite the introduction of government guidelines for service delivery and treatment for people with a **dual diagnosis (DoH 2002)**, such clients often fall between the gaps in service delivery, fitting neither the criteria for mental health services nor for drug and alcohol services. Consequently they continue to be vulnerable to exclusion both from society and from treatment services (Lawrence-Jones 2010). Successive UK governments have adopted policies for tackling social exclusion (DoH 2012). These have only been partially successful and there remain disadvantaged groups of people still living on the edges of society (**Page and Hilberry,2011**). Furthering understanding of the experience of being marginalized for people living with dual diagnosis may provide clues to alternative ways of addressing current issues.

A contemporary western interpretation of sense of belonging has lead to the construction of social inclusion. Social inclusion refers both subjectively to a sense of belonging and objectively to a physical involvement within the local environment (Hacking and Bates 2008). Social inclusion entails having rights, connectedness and citizenship within the community (Ware et al, 2007). Understood from a mental health perspective, social inclusion has been linked with recovery and rehabilitation in an interconnected, interdependent and complex relationship (Gould et al 2005).

. The Occupational Perspective of Health (OPH) described by Wilcock (2006) offered occupational therapists a theoretical foundation for occupation focussed practice with the development of the concepts of *doing, being and becoming*. *Belonging was added later (Wilcock, 2007)*.

Wilcock's theoretical framework defined *doing* as engaging in meaningful activity; *being* as having self-regard and self-esteem; *becoming* as building skills and self-efficacy; and *belonging* as having

acceptance and interpersonal connection (Wilcock 1998, 2006, 2007). This construction turns on the understanding within occupational therapy and occupational science of the necessity of engagement in occupations for health and wellbeing (Wilcock 1998, Yerxa 1998).

A continuum of occupational engagement has been identified by Sutton and colleagues (2012) which ranges from complete disengagement to full engagement; everyday engagement and partial engagement are situated along the continuum. In their study of people who identified themselves as being in recovery from severe and enduring mental health problems, these authors found that there were gradations of occupational engagement which participants found necessary at different times within their recovery processes.

Other authors have questioned the emphasis that the occupational therapy and occupational science literature places on occupational engagement or 'doing'. Feelings of well-being may be of greater significance than the current emphasis on 'doing' (Hayward and Taylor 2010). As the evidence presented by these authors suggests, sense of belonging and feelings of well-being are connected and an emphasis on the importance of doing may obscure attention to the experience of being. Furthermore Hitch et al (2014) contend that belonging is the least explored and understood of Wilcock's occupational perspectives of health and that it has not entered occupational therapy's consciousness to the same extent as doing, being and becoming (p7). Therefore the current study was designed to explore the meaning and experience of belonging as a means to discover more about this key concept within occupational therapy and occupational science.

## **Method**

A phenomenological approach was chosen because methods associated with phenomenology are helpful in elucidating the meanings of intangible concepts. Phenomenological approaches to research have at their core a drive towards the exploration of the life-world of individuals and the meanings that their experiences hold for them. The aim is to obtain layered, rich description of lived experience and an interpretation of subjective meanings. From the many phenomenological methods available (Finlay 2011) an interpretative method (specifically Interpretative Phenomenological Analysis IPA, Smith et al, 2009 ) was selected because the emphasis on interpretation acknowledges the intertwined relationship between an individual and their world with the researcher as part of that world. Furthermore, IPA is rapidly gaining acceptance within occupational therapy research (Clarke 2009, Cronin-Davies et al, 2009) as a phenomenological method which can add to the body of understanding that informs occupational science, as it allows a

focus on personal meaning and sense-making for people who share a particular experience or context.

IPA starts with, but goes beyond, a traditional qualitative thematic analysis. It is an approach in which there is an emphasis on individual accounts with the analytic work creating a thorough phenomenological account based on interview transcripts. Themes from individual accounts can be compared across cases. Overarching themes can be developed which can then be used to interrogate the extant literature on the topic. This can yield further insights and understanding and reveal previously hidden meanings about the phenomenon being explored. The steps described by Smith et al (2009) were followed in carrying out this study.

### **Participants**

Participants were recruited via an advertisement on the Rethink Mental Illness website and via Twitter. Both notices invited people over 18 and who had experienced or were currently experiencing any type of mental health problem (diagnosed or not) **and** drug and alcohol problems to get in touch via email with the researcher (first author).

In total six people made contact, with four of these subsequently agreeing to take part in the study. The two who did not take part gave no reason for not doing so. Participants were given the choice of telephone or face-to-face interviews. Two participants opted for telephone interviews; two for face-to-face. All four interviews were carried out by the first author. The telephone interviews were made from a private room in the researcher's home; the face to face interviews were carried out at the University where the first author was employed, also in a private room. The interviews lasted between 45 minutes and an hour and fifteen minutes. All interviews were audio recorded and transcribed by a professional transcription service.

### **Interview questions**

The questions in the table below were used in all of the interviews.

Table 1 here

These are typical of the types of questions used in phenomenological research. They are sufficiently open to allow participants to reflect on and describe their own experiences. Smith et al (2009) describe the interview as a conversation with a purpose. The emphasis on specific concrete examples from participants is important in accessing individual lived experience and meaning

making and in avoiding generalizations. Questions about how experiences affect daily life are intended to assist the participant in reflection upon their experiences. This combined with the researchers' interpretive analysis is the essence of interpretative research (Finlay, 2011)

The four participants have been given pseudonyms to disguise their identities. As they were recruited via an international web advertisement and social media it is highly unlikely they could be identified by other information so some context is given to help the reader.

- Adam, telephone interview, Jewish, gay man, diagnosed with generalised anxiety disorder. Did not disclose drug use.
- Jenny, telephone interview, employed mother to a small child, mental health problems, ex drug user.
- Vivienne, face to face interview, (lapsed) Catholic, married with two young adult children, alcoholism and depression.
- Tracey, face to face interview, voluntary worker, mother to two grown up children, currently single, bipolar and personality disorder.

#### Data analysis

Data analysis was lead by the first author. Overall the analytic process remained fluid and ever-evolving with imaginative leaps of intuition as well as systematic working through iterative versions over time in discussions with the second and third authors. IPA prioritizes rich description but it also acknowledges the inevitable role of interpretation (van Manen 1990). The authors attended to contextual meanings including knowledge of the participants' situations and how researcher subjectivity was inextricably intertwined with interpretations made (Churchill 2007).

an idiographic approach was adopted, making no assumptions about a shared reality ranging across different individuals. Only after developing textured experience-near descriptions was there an attempt to thematize these through carefully chosen language.

Interpretation was invoked via the use of a 'double hermeneutic' whereby participants make sense of their experiences while researchers make sense of the participants' sense-making (Smith et al, 2009 ). Notes made during the analytic process were transformed into multiple descriptive categories , which were eventually clustered into the four core themes presented in this paper.

## Findings

Interpretive data analysis revealed four emergent themes - *Belonging in family*, *Belonging in place*, *Embodied feelings of belonging*, and *Barriers to belonging*.

The themes will be presented in turn illustrated with excerpts from the participant interviews.

Theme 1 *Belonging in family* – “*I wasn’t part of my father’s world*”.

This theme is presented first because it was the most frequently occurring, being spoken about at greatest length by all four of the participants – but more as an absence rather than a presence. The participants’ narratives contained accounts of difficulties with feeling a sense of belonging that began in early life. They described Feeling different, oppressed, unwanted and abused, and like an outsider. These feelings were presented as being linked with difficulties in feeling a sense of belonging.

All four participants spoke of feeling that they did not belong in their families when they were growing up, however the precise ways in which they felt different or excluded from their families varied. Adam felt different because of his lack of interest in football - an occupation that would usually bond fathers and sons within the working class, northern culture in which he grew up. Tracey suffered physical and sexual abuse at the hands of first her father and then her mother’s subsequent partners, feeling alienated from her family as a result of not being protected by her mother.

*‘My father and grandfather like many men in [northern region], are passionate about football. I couldn’t be less interested in the game. But it meant that I wasn’t part of my father’s world and this made me feel ... not a part of my family’.*(Adam)

*‘I’ve had a very difficult sad childhood. It was hard, really hard. I was sexually abused from the age of three by my father and then by my stepfathers’.* (Tracey)

Jenny spoke about choosing not to belong in her family despite conflicting feelings of love and aversion –

*‘My family in particular is a big area where I don’t feel I belong at all because I don’t like who they are. My brothers beat their wives cheat on them and there’s loads of things I don’t like even though they are my brothers but I don’t like them and that is hard not to like the people you come from because I do also love them. It’s also scary because I don’t want to be like them’.* (Jenny)

For Vivienne a sense of being different had begun in her family and was something she'd carried with her into her adult life -

*'I've always felt different from other people like an outsider starting with my own family'.(Vivienne)*

Only Adam appeared to have managed to make an asset of his differences, revelling in his homosexual identity, his Jewish heritage and his academic prowess -

*'Now ... I'm quite proud of my differences – my sexuality, my Jewish heritage, my intellectual abilities and academic achievements'.(Adam)*

Negative early experiences in family of origin characterised the accounts of the participants. They appeared to link these aversive early experiences with subsequent difficulty in feeling a sense of belonging within their families. For Jenny there seemed to be an element of choosing not to belong because she did not like the types of people that her family members were. However, this gave rise to an uncomfortable ambivalence around disliking and loving at the same time.

## Theme 2 ***Belonging in place*** – “At AA I felt ... at home ’

Belonging in place means being part of a world (e.g. a gay community, a synagogue). It offers a sense of community identification and attachment that transcends oneself. There is a feeling of acceptance, validation and welcome. Belonging in place enables a sense of ease and at-homeness.

Two of the four participants spoke about places where they did or did not feel a sense of belonging. Adam, who had found school to an especially alienating experience (*'the place was like a playpen for untrained and uncontrollable coyotes'*), described a strong sense of belonging in a synagogue which he visited whilst on holiday in southern Europe -

*'I recently visited a very old and beautiful synagogue when I was on holiday and immediately felt comfortable in there even though I am not really 'frum' [Yiddish word for devout pious observant]. As soon as I stepped through the door I was completely and utterly mesmerized and didn't feel any sense that I shouldn't be there. The security people allowed me in as soon as I said I was Jewish – there was a trust between us and that gave us a bond even though I didn't know them and would never see them again there was a common bond which joined us and I felt really safe and like I belonged in there'.(Adam)*

Adam found himself in place where he felt he belonged because of his Jewish ancestry. Although not religiously observant, the shared bond of Jewishness between him and the security guards and the building itself gave Adam a sense that he belonged and was welcomed there.

Vivienne found a similar experience in her AA (Alcoholics Anonymous) meetings -

*'It wasn't until I went to AA ...to address my drinking that I finally found somewhere where I felt I fitted in, belonged. Where I felt I was like other people not different, where we had things in common. At AA I felt accepted at home, validated'. (Vivienne)*

This description from Vivienne in which she described belonging as feeling 'at home' is painfully ironic given that it was at home where the four participants first felt that they didn't belong and were not part of their families. For Adam belonging in place was linked to feelings of safety not available to him during his schooldays.

Theme 3 ***Embodied feelings of belonging- "Self-harming is something that belongs to me"***.

Two of the participants, Adam and Tracey, described experiences connected with belonging that can be understood as physical or embodied manifestations of what belonging meant for them.

*'When I'm in [an academic] library I feel very relaxed and tranquil able to contemplate my life. I feel as though I'm engaged in a very superior kind of occupation – reading and learning. It's not something everyone wants to do but I like it because everyone else there is there by choice and because they are passionate about learning... when I'm in an academic institution I feel like I belong there. I don't feel I shouldn't be there or feel excluded. I feel I can be there because I belong there and I belong there because I'm a thinker'. (Adam)*

In stark contrast Tracey offered a different embodied understanding of belonging. Having been physically and sexually abused for many years from an early age self-harming could be understood as a means of reclaiming her body for herself and gives a glimpse of a shadow or darker side of belonging than is usually reported in the literature.

*'Self-harming is something that belongs to me. It is my release and after I've self-harmed I nurture myself by cleaning the wound and being my own nurse. Can you understand that?' (Tracey)*

Embodied feelings of belonging and belonging in place are themes that overlap to an extent because the feelings identified by participants that made them feel they belonged were strongly associated

with particular places – AA meeting hall, synagogue, library. Tracey’s account of self-harming behaviour as something that belonged to her is notable for its bleak contrast to the relaxed feelings experienced by Adam and Vivienne in their places of belonging.

Theme 4 ***Barriers to belonging: stigma and shame*** – *“People think we’re all robbers and skanky...”*

Experiencing a feeling of non-belonging the participants expressed a sense of existential outside-ness (Relph 1976); a sense of being different, a stranger experiencing oneself as alien and out of place. Barriers preventing a sense of belonging come in the form of rejection in the eyes of others and are experienced as insurmountable.

For some of the participants a sense of shame seemed linked to feelings of non-belonging. Jenny and Tracey felt that the stigma attached to their mental health problems prohibited a sense of belonging. For Vivienne, her somewhat socially deprived childhood engendered feelings of shame for not owning a television and thus not having friends round after school. This contributed to her sense of being different and therefore of not fitting in not belonging.

As an ex drug user, alcoholic and person with mental health problems, Jenny feels negatively judged by others *‘...there’s a big stigma to people on drugs People think we’re all robbers and skanky...’* (Jenny)

Similarly Tracey described not feeling welcome at an amateur dramatics group she attended –

*‘I felt awful. Like an outcast because of my mental illness. I felt like an outsider. I wanted to leave. I was out of synch with everybody else. I felt ashamed and left out. They didn’t want me so I left’. (Tracey)*

For Vivienne a sense of shame engendered by the lack of a television in the family home created a shameful pretence in order to try and fit in -

*‘I didn’t really feel I fitted in at school either. We were poor and not allowed to invite friends home. We didn’t have a TV but I would pretend that we had a TV. I’d pretend I’d seen programmes I hadn’t and couldn’t invite friends home. I was terrified of being found out’. (Vivienne)*

Adam had identified himself as different (*‘gay Jewish’*) and was badly bullied at school. However he seemed to be the only participant who had somehow made a virtue out of being different and almost seemed to revel in that. In a sense he resists belonging -

*'I believe it's important to know who you are and be proud of who you are. I'm very proud to be a gay man now. I was embarrassed and ashamed and it was really awful when I was younger. I imagined that sometimes people would look at me and think 'who is this bizarre person? Where on earth has he come from? How can he be so different from us?' Now however I'm quite proud of my differences – my sexuality my Jewish heritage my intellectual abilities and academic achievements'. (Adam)*

Barriers to belonging that were identified within the participants' accounts appeared to have their origins in the attitudes of other people. Jenny, Tracey and Vivienne seemed to have internalized the stigmatizing or judgmental attitudes of others to a sense of shame or self-stigma which made feeling a sense of belonging difficult for them. Only Adam, perhaps having come to terms with his differences, presented an account of contentment with his dissimilarity to others including his family.

## **Discussion**

The dominant understanding of belonging is as a positive element of life expressed via temporal and cultural contexts (Ikuiga and Pollard 2015), a precursor to a meaningful life (Tajfal and Turner 1979), and contingent upon occupational engagement (Rebeiro 2001, Wilcock 2006). Narratives of belonging in the literature present it primarily as a positive construct. . There has been little exploration of the shadow side of belonging such as the self-harming behaviours described by one of the participants in the present study. Recent work by Twinley, (2011) has begun to address this, and Hitch et al (2014) have suggested that there may be occupational risk factors associated with *belonging*, as there are with *doing*. However at present Within occupational therapy and occupational science, *belonging* remains somewhat mysterious, with understanding of it underdeveloped (Hitch et al 2014).

The themes that emerged from the analysis of the participants' accounts in the present study offer additional and nuanced insights into the meaning and experience of belonging. Probing the participants' understandings and experiences provides support for current evidence and further understanding of this complex phenomenon. As people with co-existing mental health and substance misuse problems, the participants identified as part of an excluded social group. For each of them belonging had been experienced as problematic from an early age, as their accounts of early family life revealed. It is possible that having difficulties with developing the secure attachment in their early relationships (Bowlby 1969), the participants experienced difficulty in forming the securely attached relationships necessary for belonging in later life. An exploration of the relevance

of attachment theory for occupational therapists (Meredith 2009) suggests that clients' styles of attachment may be important for therapists to understand when forming therapeutic relationships and planning interventions. An exploration of early experiences of belonging may also prove useful in this regard. The language used to talk about belonging may prove more useful in discussion with clients than attachment theory.

The participants' narratives revealed other sources of difficulty with belonging in addition to their early family experiences. Feeling different because of their mental health or substance misuse (*'people think we're all skanky and robbers'*), the participants identified stigma as a barrier to belonging. Although there is a large body of literature on stigma related to mental health problems, much of this has been developed through studies of public attitudes. The views and experiences of people who are affected by stigma are largely absent from the literature on stigma (Schulze and Angermeyer 2003). People who experience internalized or self-stigma often struggle to feel accepted with social groups and therefore with belonging (Knight et al 2003).

The participants' accounts revealed some existential aspects of belonging such as belonging in place and embodied understandings of belonging. Accounts of 'doing', where this is understood as engagement in the performance of personally meaningful occupations, were offered by the participants but not emphasised as ways to access a sense of belonging. Although participants spoke of places where occupations would be performed (library – reading and learning, AA meeting – sharing with other people, amateur dramatics group – performing) it was the places themselves or the connection with other people which seemed to hold, or withhold, the most potent sense of belonging. Thus it may be that simply by being in a place where one feels a sense of belonging (at home-ness) or by being with other people, powerful feelings of belonging can develop, and occupational engagement may not be as critical as has been previously thought. As suggested by Sutton et al (2012) there may be degrees of occupational engagement needed for recovery from mental illness; similar gradations of doing may be connected with belonging. **There may be a need to understand withdrawal and isolation as legitimate and beneficial choices when people are feeling overwhelmed by their personal circumstances, and the manifestations of their mental health conditions. Self isolation may not necessarily be a sign of distress but as a means of managing that distress.**

It may be helpful to think in terms of a continuum of belonging or to consider 'dimensions of belonging'. Thus, ***belonging to*** – my body belongs to me; ***belonging in*** - Adam belongs in his differences his academic ability his otherness (gay, Jewish, football-hating man); and ***belonging with***

– an integrated sense of feeling valued and accepted and authentic sense of being ‘at one’ with the world and in one’s own skin.

## Conclusion

Some writers have been critical of the occupational therapy profession’s focus on doing at the expense of being (Hayward and Taylor 2010,) and the findings from this study would support a need to focus on ways of belonging that are not exclusively dependent upon doing. Ways of supporting clients to access places and people where they feel a sense of belonging may be equally valuable. Ways of enabling clients to connect with embodied feelings of belonging through promoting relaxation, tranquility, meditation and mindfulness may also be of value.

The findings contribute to the occupational therapy and occupational science literature by developing the language necessary to talk about concepts such as belonging that may be helpful in practice; by encouraging therapists to not assume that belonging has a fixed meaning and means the same to each individual. As the stories of the participants reveal, belonging is mutable, fluid and idiosyncratic. It is not always a happy experience, and painful feelings of not belonging can be a powerful influence and driver. As occupational therapists we have much to learn from our clients by exploring what belonging means to them. It may also be constructive to consider what belonging and not belonging means for us as occupational therapists.

**Limitations of the study** Since this study had just four participants, a judicious approach is required in interpreting the findings. Small sample sizes present a challenge to the generally accepted norms of transferability. However, trustworthiness of the study was attended to in a number of ways. One of the strengths of a small study is that it enables the illumination of the ambivalence, ambiguity and complexity of responses (Smith et al, 2009). The phenomenological approach and the interview style used were sufficiently open to enable the participants to share what was relevant to them around the topic of belonging and not belonging ,and facilitating depth of enquiry (Kvale and Brinkman, 2009); The second and third authors were involved in checking the themes extracted which facilitated corroboration of some elements of the analysis. Inclusion of the questions used in the interviews and extensive verbatim quotes from each participant adds to the transparency of the study.

## Key Messages

1. Doing is important for health and well-being but may not be necessary for belonging. There are other means to achieve sense of belonging.
2. Painful feelings of not belonging can be powerful influences in peoples' lives. How a person identifies their belonging is uniquely individual.

### **What the study has added**

A nuanced understanding of different ways in which belonging may be experienced. The authors propose an understanding of 'dimensions of belonging' as a means to appreciating the mutable, fluid and idiosyncratic nature of belonging.

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