What does well-being mean to mental health peer workers?

Jenny Edge and Susan Wheatley

Abstract

Purpose – *This paper aims to gain a detailed understanding of their experience of well-being from the perspective of mental health peer workers.*

Design/methodology/approach – *An interpretative phenomenological analysis design using semi-structured interviews was conducted with four peer workers. Interviews were transcribed verbatim and then analysed using thematic analysis.*

Findings – *Participants described their experience of well-being in terms of a journey over time that followed an unpredictable course. They understood their well-being in terms of their engagement in occupations. An occupational science framework was used to understand the participants' experience of their well-being in terms of doing, being and becoming.*

Originality/value – *This paper is among the first to approach the exploration of the experience of well-being for peer workers using an Interpretative Phenomenological Analysis design.*

Keywords *Peer workers, Community mental health, Well-being, Recovery, IPA, Qualitative research, Occupational science*

Paper type *Research paper*

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Introduction

In the past two decades, there has been a growing interest in understanding what constitutes well-being and positive mental health. There has been increasing interest in the topic of well-being with a paradigm shift from illness to health and a relatively new focus on well-being and wellness (Foresight, 2008; Bracken, 2012).

Well-being literature has focused on living well and traditional mental health services have focused on getting rid of illness (Moncrief, 2008; Bracken, 2012; Keyes, 2002; Aked, 2008). The recovery approach brings these together in a realm of living well with illness (Slade, 2017). A widely accepted definition of recovery developed by Anthony, one of the founders of the recovery movement in the 1990s, describes recovery as "a deeply personal, unique process of changing one's attitude, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness" (Anthony, 1993, p.12). There is recognition of the different relationship required between service users and professionals and the importance of the service user experience being central (Perkins and Slade, 2012). A shift in understanding of the concept of recovery has occurred, particularly in mental health, from that of a 'final destination' that a person reaches when an illness has been cured to an individualised view with an emphasis on the subjective personal experience of the 'recovery journey' and not a focus on a return to normal (Anthony, 1993; Davidson, 2005; Slade, 2017).

Peer workers were selected for this study as they can be seen as experts from a dual aspect of lived experience of mental health issues and lived experience of recovery. Peer workers have been defined as someone "in paid employment [. . .] whose lived experience of mental illness provided one of the main qualifications for employment" (Cleary, 2018, p. 1267).

The authors would like to thank all the participants who gave their time and shared their personal experience to bring this study to life and to all the staff who supported this research study.

The value and importance of peer support in mental health services is gaining momentum and is emphasised at a national policy level (DoH, 2011; Watson and Meddings, 2019). It is recognised that peer workers provide a valuable addition to the mental health workforce through integration of their own lived experience of mental health issues alongside peer training to role model self-care, instil hope and improve quality of life (Davidson, 2018).

To date there has been a lack of exploration of the meaning of well-being to peer workers. Using the following search terms "peer workers, mental health, wellbeing and recovery", a search of the literature in the previous 10 years produced limited results. There are however a number of research studies exploring the experiences of peer workers of their work role in a mental health setting as opposed to their experience of maintaining their mental health and well-being, as explored in this study (Berry, 2011; Repper and Carter, 2011; Walker and Bryant, 2013; MacLellan, 2015; Vandewalle, 2016; Cleary, 2018).

Investigation into the well-being experience of peer support workers would add to existing literature exploring well-being and could be of value in developing our understanding of how mental health service developments could diversify from traditional practices.

Method

Study design

The following question guided this study.

Q1. How is well-being experienced by people with lived experience of mental health issues who are in recovery?

A qualitative approach was adopted due to the focus of the study on exploring lived experience.

An interpretative phenomenological analysis (IPA) design was chosen as it provides idiographic analysis of participants' lived experience and has been used effectively in health-related studies (Smith *et al.*, 2009). It provides a framework within which to explore the well-being experience of peer workers. IPA is a qualitative research approach which allows the researcher to add their interpretation to the participant's interpretation of their own experiences and search for meaning in the rich personal accounts generated (Smith *et al.*, 2009) and as such is a relevant approach for his study.

The IPA design involves semi-structured interviews, in this case, with peer workers employed in an NHS mental health Trust. Ethical approval for the study was obtained from the University School of Health Sciences – School Research Ethics and Governance Panel. Approval was also gained from the employing NHS Trust Audit Committee as participants were employed as members of staff.

Participants

Participants were recruited by email circulated to all peer workers employed by the Trust which invited expressions of interest, four peer workers replied. There were no incentives offered for participation in the study however participants were paid at their usual hourly rate. The small sample size of four is considered normative for an IPA study where 3–6 participants are suggested (Smith *et al.*, 2009). Participants' age range, gender and ethnicity are listed in Table 1. Participants' mean age was 59 years. As recommended by Smith and Osbourne (2008), participants represent a relatively homogenous, purposive sample.

Procedure

In response to expressions of interest respondents were provided with a participant information sheet by email. Those wishing to take part were asked to complete a consent

form which was returned via email.The recruited participants attended semi-structured interviews with a focus on exploring their experience of well-being within the context of their mental health. The research interviews were designed and conducted in accordance with guidance from Smith *et al.* (2009). The format and content of the interview questions was developed in co-production with a peer worker not involved in the study. Prior to any interviews being conducted a pilot interview was conducted with an additional peer worker employed by the NHS Trust but not otherwise involved in this study. Participants were contacted to arrange a venue for interview, selected from the premises of the employing Trust most local to them. All participants were sent a copy of the research on completion.

Interviewees were asked to speak broadly about their experience of well-being and what this means to them (Appendix). Individuals were also encouraged to explore in detail the aspects of well-being that were important to them and were asked to expand on significant individual topics as these arose. Participants were advised of support available if required on the Participant Information sheet. Interviews were recorded and transcribed verbatim internally within the employing NHS Trust.

Data analysis

Transcripts were analysed as per an IPA approach (Smith and Osbourne, 2008). The data analysis followed Smith *et al.* (2009) four stage process. Each interview was read and reread a number of times and significant phrases were highlighted in the text data. The text was coded line by line and then emergent themes were identified (Table 2). A list of themes and sub themes were produced with coding to link the themes to the specific participant, patterns were then interrogated across the data to produce a master list of themes for the group. Emergent themes across the data were analysed to identify overriding themes with related sub themes. A brief extract from each of the transcripts was then used to illustrate each sub theme identified and ensure that the participant's voices were grounded in the data (Reid, 2005). Links between themes and the data set were again checked at this stage. The coherence and grounding of themes in the data were also checked by an academic research supervisor. The congruence of the themes identified by the researcher

Table 1 Participants

Pseudonym	*Gender*	*Age range*	*Ethnicity*
Maria	Female	45–74	White British
Ingrid	Female	45–74	White British
Adam	Male	45–74	White British
Owen	Male	45–74	White British

Note: A broad age range were utilised to maintain anonymity

Table 2 Themes and sub-themes

Themes	*Sub-themes*
1. Well-being and recovery journey	1.1 Over time 1.2 Future 1.3 Self-awareness 1.4 Hope
2. Well-being and meaningful occupations	2.1 Interests 2.2 Exercise 2.3 Connections 2.4 Work

was also confirmed for accuracy with the participants at this stage by sharing with them via email including quotes from their transcripts used to ground the themes in the data.

Reflexivity

The researcher has worked for 29 years in various settings within NHS and private sector mental health services as an occupational therapist and has a particular interest in mental health and well-being; these interests could impact on the interpretation of the data. The researcher therefore aimed to maintain awareness of the factors potentially impacting on her interpretations by regularly referring to research notes and transcripts and using reflection and a research diary. The research process and decisions were checked at regular intervals with two separate research supervisors this enabled the researcher the opportunity for discussion and justification of research decisions on an ongoing basis as the study developed.

Results

The participants all referred to their well-being in respect of it being an experience of a journey in which they encounter both challenges and triumphs. All participants also highlighted the importance of their ability to engage in activity that had purpose for them as an indicator of their well-being.

Analysis of the data revealed two super-ordinate themes: well-being and recovery journey and well-being and meaningful occupations. These two themes contained a further eight sub-themes (Table 2).

Well-being and recovery journey

The theme of recovery as a journey developed from the participant's exploration of their experience of their well-being as having occurred over a long period of time. There is a sense of them having experienced a change in position and movement in the view of themselves and their capacity to recover over time. There is an acknowledgement of changes in awareness of themselves, self-belief and an experience of hope impacting on their recovery and their sense of their own well-being.

Over time. All participants described a sense of their well-being over time and recognised an experience of movement in their expectations and sense of their own potential to recover. Improvements in this seemed to take many years and comprise a convoluted journey towards recovery. There was also an acknowledgement of the impact on them of others' expectations and belief in their potential to improve.

> "It was 30 odd years ago when I was told that I would never hold down a job that involved thinking [. . .] when a psychiatrist says that you sort of believe it and I wasn't able to see that he might be wrong for many, many years." (Ingrid)

There is a suggestion of an opening out over time from a position that has become restricted. There is a sense of tentatively reconnecting with the external environment again in order to embark on a process of moving towards recovery and a bigger world that has taken years to achieve.

> "From being suicidally depressed and not able to go out of the house and now being able to lead a more [. . .] back to a bigger world if you like [. . .] It's been six years to get to this stage." (Adam)

The participants describe an experience of improvements in their well-being taking tenacity and determination.

Future. There was variation in what was meant by the future across participants. Some described looking backwards to when there was not a sense of a future. Others expressed

a contrast between a sense of no future experienced in the past and a positive future and potential for recovery looking forward from the present.

> "Another thing which happened in the past was the realisation that I used to be able to do that, but I can't do it anymore or, because of being ill that door is closed to me." (Owen)

Owen reported feeling that door is "closed to me" which appears to indicate a sense of finality of something that cannot be accessed again and is lost, the closing of that door preventing the anticipated journey onward.

Others appeared to experience the future as a frightening prospect related to fear that they may not be able to maintain and continue a path towards recovery and improving well-being.

> "It's nice for the first time in my life even though I am nearly 50 to be feeling good and I am so scared it is going to stop." (Maria)

The fear of what the future may bring is so powerful that it may detract from the positive experience of the progress in recovery and well-being that has been made in the present. It also indicates that at times the grasp on recovery and a feeling of well-being could feel tenuous.

Self-awareness. All participants described their experience of developing increasing self-awareness and the impact of this on their well-being and progress in recovery.

> "Recognising your limitations, what you can do and what you can't do so if you're not aware, not self-aware in that sense, you try and do too much and end up not doing anything because you have burnt out." (Owen)

Self-awareness is described by the participants as an essential factor in maintaining well-being and supporting recovery.

> "Things started to improve in that I started to understand some of the things that might have been going on in my mind and what some of the causes might have been which also helped." (Adam)

Having an increased understanding of one's own responses and potential triggers was identified as having a positive impact on well-being.

> "Me listening to myself and learning to trust myself again, me challenging things that I found difficult, me having a voice again and not supporting things that I don't agree with anymore. Doing all these things and becoming a bigger and better person." (Maria)

The process or regaining and relearning trust in oneself and a personal ability to overcome obstacles was emphasised.

> "I think of things that might help me to move from a bad place to a better place which is often dropping something rather than picking something up if that is pulling me down." (Owen)

The importance of being true to oneself is also touched on and exercising autonomy in choices that are made are additional factors that participants described as having an impact on their well-being.

Hope. Participants reflected on the challenge of sustaining hope in their ability to recover and the importance of hope in maintaining a sense of well-being. A loss of hope, a sense of hope being out of grasp was highlighted as having a significant and extremely negative impact on well-being and self-efficacy.

> "I had lost all hope and it sadly led, eventually, to a suicide attempt [. . .] I find hope really important for my mental well-being." (Ingrid)

The experience of recovering well-being following a period of acute mental health breakdown was seen in terms of restoring hope in the possibility of reclaiming life and central to recovery.

> "For me, well-being has been central for my recovery. For me, it meant that I actually could get back my life. It meant that much. It was so significant." (Maria)

Well-being and meaningful occupations

There was a focus for all the participants on exploring and understanding their experience of well-being through the things that they do. It appeared that the presence or absence of engagement in meaningful occupations provided concrete feedback that was used by participants to judge their own well-being.

Interests. Participants highlighted the positive impact of interests on their well-being and also some participants recognised how a negative state of well-being reduced their ability to engage in activities they found fulfilling.

> "I write music and the tunes would come into my head. I wrote on a piece of paper one time, some people hear voices and they are called schizophrenic, I hear music and they call me a composer [. . .] and generally if I haven't been good for a while and the tunes start coming back I think yes, I'm feeling better." (Owen)

A comparison was made by Owen between the experience of hearing music and the psychotic experience of auditory hallucinations; in this case hearing music is a sign of improvement and a re-engagement with an interest. One participant reflected that he lost access to the skills he needed to engage in his interests.

> "I simply cannot access the skills to do it [. . .] the skills literally eluded me, which is an odd thing." (Adam)

Adam gives a sense of knowing that he has the skills required but being unable to grasp and utilise them. It appears that he finds it challenging to understand when he describes this experience as an "odd thing".

Exercise. Most of the participants referred to the impact of exercise both in terms of the positive impact on their well-being but also how well-being can negatively impact on their ability to be physically active.

> "For me exercise is a tool I use to break the way I'm thinking and give me space and the opportunity to take notice and think positively." (Maria)

Exercise was described as a tool that could be used to enhance an experience of well-being.

> "When I'm doing exercise the core system starts behaving, my mind starts behaving and I start to get some pleasure, joy and happiness." (Maria)

> "I used to have very physically active hobbies [. . .] that was a huge loss to me when I lost all that because it was my way of coping with life was through sport." (Ingrid)

One participant emphasised the mind body connection for improving well-being and the importance of physical health for mental health.

> "We kind of tend to live from our heads whereas our bodies I think [. . .] It's got to be connected and yoga is brilliant for that, for working on that connection but my body without my health, my physical health, my life would be over again."(Maria)

Connections. All participants referred to their experience of the influence of connectedness on their experience of well-being.

> "The biggest difference between people who are unwell and those who have mental health is community, connecting and social interaction." (Maria)

This ranged from considering their connections with others, including animals as well as people to the importance of feeling connected with a sense of self.

> "So that really reiterated that mental well-being needs to be in place in order to socialise, I believe, although a lot of people say that maybe people who socialise have less mental health problems [. . .] I don't know about that." (Ingrid)

One participant identified the positive impact of his connection with his pet dog.

> "I know she was only a dog, she was a pet but the things that she managed to do, I don't think it's too strong to say that she contributed to saving my life and that's really, really important." (Adam)

Work. All participants referred to the impact that specifically having a paid work role had on their well-being.

> "What really helps me is getting out, doing things, meeting people and feeling I am doing something useful." (Owen)

The participants all related work in the present to current experiences of well-being and one participant referred to the devastating impact on her when she thought that paid work would not be achievable for her.

> "I used to do things like sheltered workshops where you made baskets and it was the most depressing, distressing and outrageous, it was just terrible. Being paid £1 a day, you know, it was like [. . .] it was so depressing and I would go there and I would come home and I would cry and it was quite devastating to me, that's all I was capable of and if I had been left there who knows" (Ingrid)

Ingrid contrasts experience with her current work situation and experience of achieving what she had thought was not possible and the positive impact this has had on her.

> "In the last few years as a peer support worker and recovery college trainer I haven't had a day off sick, which is amazing." (Ingrid)

Discussion

The key findings from this study will be related to an occupational science framework in order to explore the well-being of participants considering their individual and collective experience of occupational engagement.

The field of occupational science is based on a fundamental belief that occupational engagement is directly linked to well-being (Wilcock, 1993, 1998, 2007; Hitch, 2014) and provides a framework that can be used to structure and develop an understanding of the data gathered in this study. Wilcock developed a theory to understand the interplay between the things that people do, how these impacts on who they are as human beings and that through the process of engaging in occupations people are in a constant state of becoming different (Wilcock, 1998). Wilcock distils these aspects of occupational engagement into *doing, being* and *becoming*.

Participants in the current study all made references to the impact of their engagement in occupations that had meaning to them in relation to their experience of well-being. It has been documented that definitions of *doing* would include areas such as work, self-care and leisure (Hitch, 2014) areas highlighted by participants in this study.

It has been suggested that mental health recovery follows a developmental process in which the individual systematically reconstructs their self-identity and meaning in their life (Merryman and Riegel, 2007). The participants in the current study describe losing touch

with previous skills in occupations. They highlight impairment in their capabilities with familiar and valued activities as a factor that reduces their sense of well-being.

Hitch, (2014) explores Wilcock's concept of *being* in terms of making sense of who we are as occupational beings. They identify that "personal capacities are important for the *being* of people in recovery from mental health issues" (Hitch, 2014, p. 236). Wilcock described *being* as "how people feel about what they do" (Wilcock, 2007, p. 113). The participants all reflected on seeing themselves in relation to what they were able to do and not do, and the importance to them of feeling capable and having hope in their potential for recovery and a positive future.

The significance of maintaining hope and optimism about the future in mental health recovery is supported by the work of Leamy (2011) who found that this was identified as a significant aspect in the recovery process in 79% of 97 studies that were reviewed in their paper. When considered within Wilcock's (1998) framework this can be most clearly linked with the individual's ability to feel comfortable in a state of *being*. It could be considered that this requires the ability to be in the moment with oneself and acceptance of this experience. Participants emphasised the importance of self-awareness, of the potential interruption to a state of *being* and a temporary loss of touch with self without this.

When looking to the future a sense of being engaged in a process of *becoming* appears fragile and to lack a firm foundation and grounding in the minds of the participants. The state of *becoming* described as a progression and development over a person's lifetime (Wilcock, 1998) can be aligned to the theme of well-being as a recovery journey, drawn from the interview data. The theme and experience of recovery as a journey has been well documented which supports the validity of the representation of this as a theme in the data (Shepherd, 2008; Read and Rickwood, 2009; Kelly, 2010; Leamy, 2011). Leamy's (2011) review of 97 research papers focused on personal recovery in mental health has shown that the recovery journey is not linear and that it is characterised by periods of achievement but also setbacks which also fits with Wilcock's concept of *becoming* (Wilcock, 1998).

The participants describe an almost unrecognisable change in themselves over time and in some respects disbelief in the process of *becoming* and that the transformation had even been possible. The perspective of the participants highlights an experience of life "opening up" and offering more or different opportunities. There is a sense of them experiencing a change in their experience of themselves, developing in new directions that they experience as positive. Comparisons can be drawn to the concept of *becoming* as described by Wilcock (1998, p. 251) in terms of "becoming holds the notions of potential and growth, of transformation and self-actualisation."

The participants appeared to feel a lack of confidence and control over maintaining and continuing the journey of recovery and transformation, of *becoming* that they experience as an improvement in their well-being. This lack of faith in themselves and their ability to continue the process of personal growth into the future appears to be reinforced by the judgements of others. Also highlighted by Deegan in her recollection of being told by a psychiatrist "if you take medications for the rest of your life and avoid stress, then maybe you can cope" (Deegan 1996, cited in Davidson, 2005, p. 59).

When viewed through the lens of occupational science and specifically Wilcock's (1998) notion of the process of *doing*, *being* and *becoming* through occupational engagement the impact on well-being can be understood. The experience of well-being described by the participants in the current study can be seen to be achieved through a balance of occupations that allow the individuals to have a positive experience of *doing* and *being* to achieve an experience of personal transformation that is *becoming*. In the field of mental health Wilcock's (1998) description of *becoming* is closely aligned to descriptions of the concept of recovery (Anthony, 1993). For the participants in this study their experience of *becoming* appears closely linked to the "good fit" that they experience with their roles as peer workers.

Strengths and limitations

The study used semi-structured interview and an IPA approach to gather and analyse data which was ideally suited to the research topic as it produces a rich account of participant experiences of well-being. It has been documented that the exploration of individual's experience and occupations is too complex and varied to be conducted using simple reductionist techniques such as questionnaires (Wilcock, 1998; Reid, 2005).

A high degree of rigour was applied in the research design. For example, the involvement and co-production of the interview schedule with peer workers not included in the study and the inclusion of a pilot interview prior to commencing the research interviews. The use of checking with participants in relation to themes and supporting quotes provided important checks on validity. Discussion of the data with supervisors enabled the researcher to apply reflexivity and again check on validity.

For the purposes of IPA the homogeneity of the participant sample is a strength. In this case the participants were similar as they were all peer workers employed in the NHS, and of the same White British ethnic group. The inclusion of equal numbers of male and female participants was also a strength thus incorporating potential gender differences. The older age range of the participants all with a breadth of experience of being mentally unwell and also of recovery gives the study's findings added weight.

Several limitations of the research can be noted however, the study brings with it the limitations of qualitative research, the findings of the study cannot be generalised to the wider population due to the highly selected small sample size. There is also the possibility of researcher bias, given the researcher's background as an occupational therapist. It is possible that emergent themes may have an unintended occupational bias. However, attention was given to the hermeneutic in this area. The research sample is not ethnically diverse however this lack of diversity is reflective of the demographic of the area in which the study was conducted where 88.9% of the population are recorded as White British (Katsande and Clay, 2019).

Future recommendations

The current study explored experience of well-being with a limited sample in terms of age and the sphere of NHS peer work. It would be an interesting focus of future research to conduct a similar study with a younger adult group or peer workers employed in mental health services outside of the NHS.

The findings of the current study could be used to guide further study applying a Grounded Theory approach in order to generate a theory of well-being that might then inform clinical practice. Additionally, the analysed themes could be used as a basis from which to develop a questionnaire to assess and monitor well-being and job satisfaction in peer workers. Previous studies have identified the considerable challenge that these roles present for those employed in them and the importance of providing appropriate support (Repper and Carter, 2011; Lawton-Smith, 2013; Cleary, 2018).

It could also be of interest to explore further the impact that the approach of services can have in offering or removing a sense of hope whilst holding in balance supporting service users to have a realistic sense of expectation of what their future may be.

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Appendix

Interview schedule

Provide Participant Information Sheet to read

Provide Consent Form to sign

Introductory information

The topic of well-being is very broad and means different things to different people. I am interesting in hearing your views on well-being so there are no right or wrong answers, your experience is your experience. I am likely to ask you to expand on the things that you tell me, this may be because I am making sure that I understand what you mean or it may be because I am interested to find out more.

Do you have any questions?

**********Test the equipment at this point**********

Why did you volunteer to take part in this study?

1. What does well-being mean to you?

Additional questions that can be used to develop a more in-depth response to any question:-

Can you expand on that? Can you tell me more about that?

You have mentioned [. . .] what does that mean to you?

2. What does mental well-being mean to you?

3. What has a negative impact on your well-being?

4. What supports your well-being?

5. What else would you like to say about your experience of well-being?

Thank you.

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