

Research Article

Culture and Spirituality in the Process of Mental Health and Recovery: Users and Providers Perspectives

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Abstract

Background: Spiritual beliefs are known to impact on mental well-being and recovery, yet professionals and clinicians often fail to explore user and carer perspectives on these.

Aims: Explore views of ethnically diverse service users, carers, service providers including Early Intervention in Psychosis service (EIS) professionals and spiritual care team representatives on the significance of spirituality, culture and religion on mental health recovery.

Method: Eleven focus groups were conducted with service users, carers, health professionals and representatives of spiritual care.

Results: Thematic analysis uncovered three main themes on service users' mental health recovery: Shame and Creating a Positive Sense of Self; Meeting Cultural, Spiritual, Religious and Individual Needs; Spiritual and Religious Beliefs impact on Well-being.

Clinical Implications: Healthcare professionals should consider the impact of spirituality on services users' mental health recovery and well-being. Further training, guidance and support are needed to increase professional competency.

Keywords: Culture; Healthcare; Mental health

Introduction

Mental health patients with spiritual beliefs consider these to be important, as do professional bodies [1-3]. However, standard practice still focuses mainly on biomedical and social with no consensus on whether services should address spiritual needs of patients and how this should be done [4].

This paper is part of the ENRICH research program focusing on socio-cultural determinants of ethnic differences in pathways to care in first episode psychosis (FEP) [5]. The study site Birmingham is one of UK's most culturally and ethnically diverse cities with significant Black and Minority Ethnic (BME) communities -British Pakistani (13.5%), British Indian (6.0%) and Black Caribbean 4.4% (Birmingham City Council, n.d.). Here we report the views of service users, carers, service providers and spiritual care team representatives on the significance of spirituality, culture and religion on mental health recovery. We aimed to explore the role of cultural and spiritual influences in how illness and recovery were experienced and understood.

Methodological Approach

Design

Using a topic guide, 11 focus groups were conducted as follows: 6 with service users (n=22), 3 with carers (n=11), 1 with health professionals (n=9) and 1 with representatives of spiritual care (n=8). Participants in each group were purposely included to uncover any differences and discrepancies or similarities that exist between professionals delivering EI services and those receiving

these services. Spiritual attributions and cultural meaning of distress, and faith-based help-seeking were specifically explored during focus group discussions with all participants.

Participants

The study was carried out in and with the support of Birmingham and Solihull Mental Health Foundation Trust. All participants in this study were recruited from EIS Birmingham.

Service users

The aim was to recruit participants who represent the ethnic mix within each locality in the city. Hence, the inclusion criteria for service users were to be from an ethnically diverse background and a current or past EIS user. For detailed information about the process of recruitment visit Islam et al 2015. Out of the 22 participants 12 were male and 10 were female (self-ascribed ethnicity: 9 British Pakistani; 5 British Caribbean; 3 mixed White and Black Caribbean; 3 Black British-African; 1 'other'; 1 British Bangladeshi). They described their religious/spiritual affiliation as: Muslim (n=11); Christian (n=6); no faith (n=2) and 'other'(3).

Carers

In total, 14 carers were recruited 3 of whom formed the pilot study focus group (8 females; 3 males). The majority described themselves as Black British-Caribbean (n = 5) and British Pakistani (n = 3). Others included: 1 Black British-African; 1 mixed White and Black African; 1 White British.

Professionals

Nine clinicians (5 females; 4 males) were recruited - service

managers ($n = 2$), care coordinator ($n = 1$), senior social worker ($n = 1$), community psychiatric nurses ($n = 2$), student nurse ($n = 1$), vocational worker ($n = 1$), and senior occupational therapist ($n = 1$).

Spiritual care representatives

A total of 8 spiritual care representatives within BSMHFT were recruited (3 females and 5 males) including the service manager and chaplains, and volunteers from a multitude of diverse faith backgrounds, including Christian chaplains, Muslim Imams, and a humanist.

Ethical approval and informed consent

Ethical approval was granted by the Warwickshire Research Ethics Committee; the study was also approved by the BSMHFT research and development unit prior to approaching any potential participants. All participants gave their informed consent before the start of the focus group interview.

Data collection and analysis

All focus groups were facilitated by ZI to ensure consistency of approach, accompanied by a note-taker, who observed and recorded the non-verbal interactions and documented the general content of the discussion to aid analysis. De-briefing meetings were held immediately after each focus group see Islam et al 2015 for further discussion [6].

All focus groups interviews were conducted in English with the exception of one with service users in which an interpreter was used to translate for one service user in Arabic. In the same focus group the facilitator translated for another service user in Urdu. Similarly in two carer's focus groups the facilitator translated on behalf of three carers in Urdu. All other stakeholder focus groups were conducted in English. Each focus group lasted up to 90 min. Each interview was audio taped and transcribed verbatim.

Analysis was conducted using a thematic approach to systematically code, classify, and organize the focus group content into key themes and sub-themes [7]. Drawing on Krueger and Casey's [8] framework analysis, each line of the transcript was numbered and then printed and read by the facilitator and another member of the research team to identify recurring concepts and categories [8]. Transcripts were then re-read by the facilitator to identify how these concepts and categories formed the basis of a conceptual thematic framework [7]. This framework was used to code and classify data and then modified and refined throughout the analysis to reflect the content and issues expressed by respondents across all focus groups. These coded categories were then sorted into broader core themes based on similarity and content by the facilitator and checked by FR.

For the purposes of this paper three key themes are discussed in the context of the significance of spirituality, culture and religion on service users mental health recovery: *Shame and Creating a Positive Sense of Self; Meeting Cultural, Spiritual, Religious and Individual Needs; Spiritual and Religious Beliefs impact on Well-being.*

Illustrative quotes are provided to aid transparency of categorization and theme representation. To protect anonymity, every participant in each focus group was given a letter code and assigned a number: that is, service users (SU), carers (C),

professionals (P) and spiritual care representatives (SC).

Results

Shame and creating a positive sense of self

Coming to terms with mental illness was a difficult process for all service users. Spiritual care representatives stressed it challenged the way they felt about themselves and how they related to others:

'They [service users] internalise that shame, they can't accept being given a diagnosis because that seems to be the worst thing possible, the most awful thing that could possibly happen to them is that they could be told they're mentally ill.' (SC7).

Services users go through several emotional stages before coming to terms with having a mental illness 'recreating any new sense of self' or 'positive self-identity'. In an attempt to maintain a positive sense of self, in most cases there was a period of conscious and/or unconscious denial of reality and resistance to accepting illness: *'I felt really suspicious of everyone and everything...I can't explain it, I'm still trying to comprehend what went wrong'* (SU22, British-Pakistani, Male).

Some service users did not accept that they were unwell and began normalizing symptoms and developed coping strategies/ explanations to maintain a sense of normality:

'Yeah I just thought you know what I am who I am and I think I control my own destiny and then God probably gave me this' (SU20, Asian British-Pakistani, Male).

For others this was often followed by anger and grief: 'But I don't want them [voices] to be there because I was never like this. I can't live hear some people talking' (SU5, Black British-African, Female).

Some carers also cited religious and cultural beliefs as explanations for initial symptoms: *'... this went on for a period of time where it was getting worse for him... I started to think, as a black person there was something wrong, I thought there's a ghost in the place'* (C12, Black British-Caribbean, Female).

For the majority of service users, family and community members encouraged faith-based help-seeking. This included visiting multiple faith and spiritual healers. For some this practice proved to be beneficial and positive in bringing temporary solace for both the service user and their family. Some service users from Pakistani Muslim backgrounds continued to visit faith healers even after coming to EIS. Some became victims of financial exploitation: *'...he asked me for £500 ... I actually went to the cash point withdrew £500, ...he gave me that egg anyway and he goes when you gonna go somewhere far, throw it over your shoulder and pray for what you want and don't look back and walk away and don't go back there again...'* (SU13, British-Pakistani, Female).

Service users highlighted that returning to a state of psycho-social well-being was a difficult process. Becoming well often resulted in the 'rejection of the old self' and 'acceptance of the new self' in terms of, exercising personal agency by abstaining from behaviour and practices such as drinking, smoking cannabis and spending time with friends who were involved in such activities:

'...as soon as we smoke weed or we have alcohol we're not pure,

our bodies are not pure so we are prone to attack from evil forces' (SU20, British-Pakistani, Male).

EI service staff, were considered to play a useful role in aiding the creation of new social networks, through activities and events arranged for service users this included art therapy, and social media classes. These gave them the opportunity to network and also enhance their CV.

Meeting cultural, spiritual, religious and individual needs

Spiritual care representatives raised concerns about EIS professionals' lack of knowledge and understanding of cultural and spiritual needs of their clients:

'We had ... a Baptismal Service, ...one of the service users suddenly spoke in tongues, ...The result of that was a bit of a shock wave, and his Psychiatrist was thinking of upping his medication... I was then, able to speak to that particular Consultant Psychiatrist...I acquainted him to the fact that according to, the Christian Scriptures, this was something that was happening in the early Christian days, with all the early Christian leaders in the beginning, and from time to time it happens. So... this Psychiatrist said, "Oh, so I don't need to up his medication?" I said, "No, ... this happens"' (SC3).

'Well, I think this is where it's important that the Health Care Professionals and the Psychiatrists or Consultants and the Nurses, work with the Imams and try and understand Islamic perspective on Mental Health...these are the things that one needs to look at, ... which would differentiate from, someone, suddenly going into this transit of speaking in tongues [or becoming mentally unwell]' (SC1).

Services users also acknowledged that EIS professionals did not have sufficient understanding about ethnically diverse cultural beliefs. Those that continued to visit faith healers after coming to EIS did not disclose this to EIS professionals for this reason:

'We can't blame them because their upbringing is different is like westernized, they can't understand if we talk about Jinn's.' (SU20, British-Pakistani, Male)

The majority of professionals recognised that great variation exists between and within cultures, reflected in views held by service users in terms of explanations of mental illness, and how preferred treatment options differ. Hence these issues needed to be considered on an individual basis in care plans. Professionals also recognised that although some information around individuals' beliefs and values was collated through the 'Health and Social Care assessment', "*this was underutilised*" (P5 and P6), the main reason being workload and time-constraints: '*...in, my experience I think we're a bit behind in terms of understanding the depth of other cultures, sort of different ways of looking at things and so I think it's tolerated more than embraced*' (P6).

There seemed to be a general consensus that there was not enough cultural training given to EIS staff. Current diversity training focuses on superficial differences of appearance, clothes diet etc. rather than spiritual beliefs. Instead EIS staff learnt about nuances between different cultural groups through speaking to colleagues from the same background as the service users as well as by making mistakes and learning through experience: '*... I've never had a day of dedicated cultural awareness [other than the one day Trust cultural and diversity training]...so I've learned through*

blunders I've made. Through asking families, from colleagues' (P6).

Spiritual and religious beliefs impact on well-being

There was consensus amongst some service users and carers that a return to spiritual and or religious beliefs and practices was potentially a sign of mental well-being: 'right because before he started this, entire he used to read the Bible but he put down the Bible and then he started to get funny... ' (C4, Black British Caribbean, Male). Decreased interest in religious practices or loss of faith as well as undertaking behavior such as substance misuse was viewed as potentially a symptom of psycho-social ill-health:

'... You know he liked to pray to God and suddenly he didn't want to do it anymore, he didn't want to go to church and then he would just go for days and I wouldn't know where he was....'(C14, Black British-Caribbean, Female).

'I just stopped reading the bible, I smoked too much weed, but I've cut down on the weed now.' (SU12, Mixed White and Black-Caribbean, Male).

'I had a big faith until I was 17, 18,...but then so much stuff happened in the family and then the devil just broke me down and then it broke me down in such a way that he whispered on my ear all this time you were good. All this time you did everything the right way. What was it all for? What did you get rewarded?... I was like f... this now watch; I'm going to do as much bad as I can' (SU20, Asian British-Pakistani, Male).

Equally, becoming consumed in existential and religious issues was also viewed as a potential sign of psycho-social ill-health:

'Then he made up some notes of comparison, comparing Christianity with Islam, with Paganism, idol worshipping and he said that the area he ripped off the Bible, it's the bad one ... Eventually I managed to, after begging him, managed to push the door, with the help of someone who lived with me so that was when I saw him, he ripped up his Bible and notes' (C3, Black British-African, Female).

'But I just start to get all depressed thinking you know, you just realise the truth say if I die you know what's going to happen in the grave and you know what's going to happen in the after-life and then you question yourself in the sense well I didn't ask to be born so what am I being tested for, what am I you know? There are angels, there are Jinns, there's God, there's Devil. So what are we then? Are we angels, are we Jinns? What are we human beings, where are our souls going to go?' (SU20, Asian British-Pakistani, Male).

Hence, having spiritual/religious well-being did not automatically equate to having psycho-social well-being. As one SC representative stated if the 'fruits of their spirituality...[are] being useful and constructive then fine, if it's being destructive and obliviously, not getting anybody anywhere or being difficult for people, then, harmful, then it's not fine. Discernment it's called' (SC7).

Discussion

The significance of spirituality, culture and religion on service user's mental health recovery is complex and varies for each individual. Our findings demonstrate that returning to a state of psycho-social

well-being from a psychotic illness was a multifaceted process. Becoming well often resulted in the ‘rejection of the old self’ and ‘acceptance of the new self’ in terms of, exercising personal agency by abstaining from destructive behaviour. This echoes the notion of “recovery capital”, highlighting the role of supportive and inspiring new relationship with self and the significant others including health care professionals, family members, friends, cultural and socio-environmental resources in empowerment and recovery [9].

The concept of “social recovery” also has recently been argued by Winsper and colleagues (2020) and their proposed logic framework clearly indicate the importance of psychoeducational, peer, social inclusion, and pro-recovery and mental health literacy training and their outcomes at the service user, mental health service, and general public level [10].

Activities and events arranged for service users by EIS staff was described as key in the creation of new social networks and can be linked to previous research which emphasizes the importance of key coping strategies “proactive coping” [11]. Previous qualitative research describes this ‘proactive coping’ as being part of the way people with mental illness who show significant improvement in functioning overtime replace previous activities and routines with those that provide a “sense of self” [12,13].

Our findings also suggest that rather than simply reaching a point of ‘true engulfment’; that is being consumed by their mental health issues, service users are active agents and can exercise choice in selecting and constructing their identities [14] and eventually capable of constructing and recreating alternate identities to that of a passive and powerless ‘patient identity’ [15]. The process of moving towards psycho-social wellbeing and ‘creation of a new sense of self’ is not based on an equal or rigid series of sequential or uniformly timed steps, some stages may be revisited (i.e. relapse) or not be experienced. There are numerous challenges and opportunities for wellbeing and a ‘creation of a new sense of self’ or ‘positive sense of self’ as illustrated in Figure 1.

Like Slade et al. [16] our findings highlight that the user held view of “personal recovery” is based on their beliefs. This includes their spiritual and religious well-being and experiences [16]. Hence it is vital that we explore the spirituality of service users and its influence in their personal recovery. Lack of respect and understanding in relation to religious and spiritual beliefs has been highlighted in previous studies [17, 18]. Data from Koenig [19], Department of Health [20], Rabiee and Smith [4] also clearly suggest the therapeutic role of religion for people with mental illness, and spiritual leaders as an important source of contact and support for some BME communities. In line with this notion Tokpah [21] argues that spirituality dimensions should be addressed and considered as part of holistic patient care and psychiatric nursing care. Yet standard clinical practice still focuses mainly on biomedical needs and there is no consensus on whether mental health services should address spiritual needs of patients and how this should be done [4, 22]. It is clearly evident from our data that professionals need to consider the impact of spirituality on services users’ mental health recovery and wellbeing. However in order to do this they require further training, as well mentoring, guidance and support from Spiritual care Advisors and experienced colleagues.

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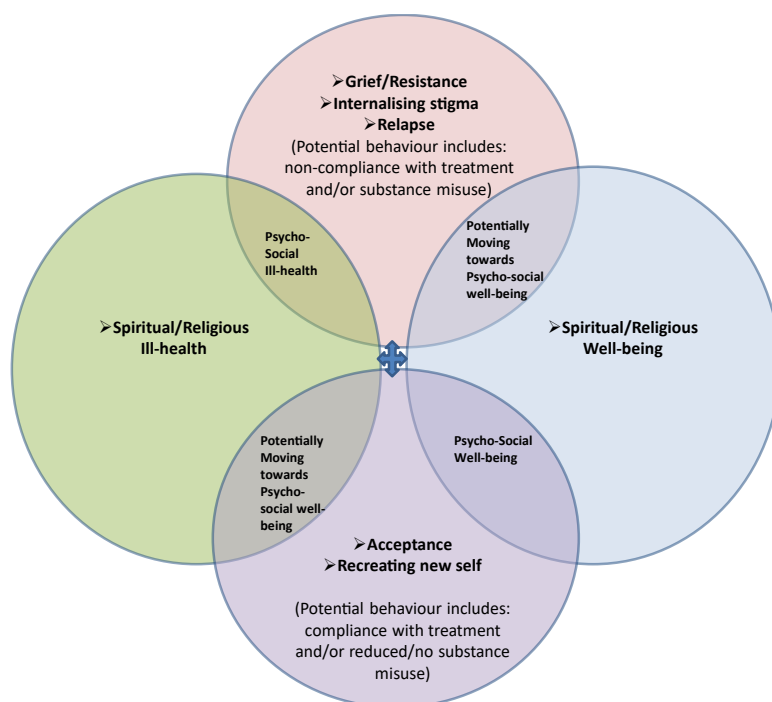


Figure 1: Challenges and Opportunities for wellbeing and a ‘creation of a new sense of self’ or ‘positive sense of self’.

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