"I need help": A study of spiritual distress among people diagnosed with bipolar disorder in Malaysia

ABSTRACT

Introduction: Little is known about spiritual distress in people with bipolar disorder, where they are inclined to maladaptive coping. Given the contextual influence of religion towards Malaysians, this study is aimed at exploring the phenomenon of spiritual despair and the recovery, as experienced by a group of people with bipolar disorder. **Materials and method:** A qualitative one-to-one interview was conducted on 25 participants of multi-religious background and diagnosed with bipolar disorder recruited from two psychiatric clinics in Kuala Lumpur, Malaysia. All interviews were audio-taped and transcribed verbatim. The interview data were analysed using a thematic analysis approach. **Results:** This paper presents the theme of 'Restoring hope, meaning, and purpose' with three subthemes; 1) experiencing spiritual despair, 2) engaging in spiritual meaning-making, and 3) orienting the spiritual life. The finding captured the participants' experience of having despair in God over the 'fated experience' (*takdir*) and they abandoned religious practice during the period. However, participant narratives also indicate the possibility that their spiritual despair can be mitigated, endured, or transformed through the support of family members. The participants also highly recommended that spirituality may be combined with medical interventions, such as medication prescribed by their psychiatrist. **Conclusion:** This study highlights the importance of supportive family in advancing towards religious-spiritual pathways, and the advantages of medical interventions in terms of controlling the bipolar symptoms during their spiritual despair. This study is in favour of extending the role of mental health service in providing sessions for the users to voice out their spiritual concerns.

KEYWORDS: bipolar disorder, religion, recovery, spirituality, spiritual distress.

INTRODUCTION

Spiritual distress when a person is confronted with a life crisis is a crucial issue in mental health as it leads to the feeling of despair, hopelessness and senselessness that can impact the relationships of individuals with God (according to the person's religious beliefs (1). This phenomenon, when bound within the religious system, places religious values at stake, marked by the expressions of pain, anger, fear, doubt, and confusion (2). Pargament and Lomax (2013) suggested that unsolved spiritual distress would lead to psychological problems that could be seen in people who are reported to have negative and suicidal thoughts (3). Nevertheless, only a smaller body of work has focused on the links between spiritual distress and its negative impact on mental health outcomes (4).

Literature addressing spirituality and religion in bipolar disorder is still in its infancy while the concern is that people living with bipolar disorder appear to have maladaptive coping (5-7), as they may experience emotional distress and suicidal impulses (13). It has been said that service users with bipolar disorder need to recover from the symptoms, the trauma and maladaptive coping (6). The service users also need to recover beyond that, as they experience spiritual issues, particularly in stressful circumstances, often manifested as 'giving-up' and self-blame (8). Most research in bipolar disorder focused on the clinical symptoms and left the other recovery aspects unattended (9).

Looking into the global context, spirituality has been integrated into healthcare services set up by chaplain services and multi-faith centres for religious practices in Western countries such as in the UK, as it is person-centred (10). Moreover, a story on the spiritual form of strength was brought into attention by Conroy (2004), who wrote about a real sense of recovery in a profoundly spiritual sense of self through constantly seeking strength from God (11). However,

most mental health practitioners as the front-liners in mental health service only likely to offer medical interventions when such practices fail to recognise spirituality as part of a person's holistic care (12) to explore the phenomenon of spiritual distress and its recovery approach, as experienced by people living with bipolar disorder.

MATERIALS AND METHOD

This study took a qualitative study design using the one-to-one in-depth and semi-structured interview as guided by the Constructivist grounded theory approach that prefers the predetermined interview topics (refer to Table 1).

The study samples were 25 people diagnosed with bipolar disorder, recruited from two psychiatric outpatient clinics in Kuala Lumpur, Malaysia. All participants met the inclusion criteria as follows: 1) adults over 18-year-old, 2) diagnosed with bipolar disorder by a psychiatrist, 3) able to speak in Malay or English, 4) not presented with severe symptoms, and 5) have a religious affiliation.

All interviews were audio-taped and transcribed verbatim by the researcher. All interview data conducted in Malay were translated into English for the presentation of results. Ethical approval was obtained from the National Medical Research Registration (NMRR), Malaysia prior to data collection. The researcher used the thematic analysis to derive the understanding of the theme. Direct quotations were used throughout the themes to illustrate the findings being presented. After a direct quotation, the participant can be identified by their alias, and religious orientation; "I" for Islam, "H" for Hindu, "C" for Christian, followed by page and line numbers.

RESULTS

The age of participants varied from their 20s to their 60s, with a balanced gender distribution (48% males, 52% females). The ethnic representation in this study was dominated by Malays

(n=16, 64%), which was expected in Malaysian society. The other participants were Chinese (n=4) and Indian (n=5) Malaysians. The Malay and Chinese participants were all Muslim and Christian, respectively (of the four Christians, three were converts from Buddhism). The Indians comprised four Hindus and one Christian. Slightly more than half of the sample was married (56%), while the others were single, divorced or widowed. The majority of the sample (21 out of 25) view themselves as middle class based on their household income. All participants had been diagnosed with bipolar disorder for at least two years, and 14 out of the 25 people had lived with bipolar disorder for more than ten years.

This paper presented the theme 'Restoring hope, meaning, and purpose', with three subthemes; 1) experiencing spiritual despair, 2) engaging in spiritual meaning-making, and 3) orienting the spiritual life.

Experiencing spiritual despair

The majority of the participants (19 out of 25) experienced having despair in God and of a "fated experience" (i.e. *takdir*) by God in the sense of suffering, loss or losses in changing and challenging life circumstances. The term "loss" in the subjective accounts was used to refer to various setbacks, deficits, and negative impacts that participants encountered in their lives, particularly during the early stage of having bipolar disorder. An excerpt from Ahmad contains the metaphorical language of an "empty soul" about the loss of identity:

> I had lost a lot of things – my friends, focus on studies, and I was disrespectful to my parents. I even lost myself. My soul felt empty. I didn't know who I was (Ahmad; I; 7: 7–9).

The similar number of participants (19 out of 25) expressed how their negative thoughts and emotions dominated their states of mind, bringing a loss of hope, meaning and direction in life.

The following example is an excerpt from Melati, who expressed the loss of control and sense of hopelessness:

> I do not see any other reason or a way to get out of here. I just do the same thing over and over again. I got loss of control. The only thing that I could control is to think about whether I want to live or not (Melati; I; 2: 4–7).

In this study, slightly more than half of the group (14 out of 25) expressed thoughts of suicide in the sense of life despair. Negative thoughts and emotional expression towards God for their life circumstances were predicated on a belief in their preordainment by God, as seen in the following excerpt:

> My heart says, "it is not fair that God has put me in this kind of situation". That is a possible reason for me to not perform my solah (Mahmud; I; 3: 9–11).

The notion of faith is deployed in a way not directly indicating spiritual despair. Here, the participants undermined the religion once they questioned the fated event and abandoned the religious practice.

Engaging in spiritual meaning-making

In this subtheme of "engaging in spiritual meaning-making", the participants began to understand their fated experiences in terms of spiritual interpretations, which suggest the potential transition from the state of despair into spiritual recovery. The majority of the participants (18 out of 25) adopted a positive view towards God in making a spiritual meaning of bipolar disorder itself, or the preordained or the fated experience. Nora provided her opinion on the positive view of being tested in the mind of God:

> We know that Allah is giving us a test. Hence, there must be something special that He stores for us afterwards. Besides that, He would also elevate our status in the Hereafter (Nora; I; 16: 17–19).

Sofia expressed her need for support from others as well as a general context of positive religious ideation:

> The patient needs a backup regarding religion. She needs a strong religious thought, followed by the support from the family to keep her moving (Sofia; I; 4: 15–16).

This cited narrative conveyed the importance of a "close" family in which may well be necessary to advance the direction of religious-spirituality in people with bipolar disorder. For most of the participants, positive emotional resources such as love, care, and happiness were channelled by supportive family members, particularly spouses. Nora, with a loving and supportive husband, pointed out that "support" could be a form of treatment for participants with bipolar disorder:

> When you have all the support from all of them [i.e. families and friends], you will feel that you are being loved, appreciated, needed, and you have the strength to continue living (Nora; I; 18: 10–13).

Here, Nora referred to the social support form of treatment from all close family members, friends, and colleagues as a mean of elevating her sense of self-worth and belonging. Here, the term "strength" could refer to support from others, primarily with a sense of love and the feeling of belonging and appreciation. In this sense, support has essentially become a strong factor for living with bipolar disorder.

Orienting the spiritual life

This subtheme uncovered articulations of life goals, aims, and purpose set against the experience of losses and despair associated with bipolar disorder. In this study, a sizable minority of participants (9 out of 25) expressed their life goals concerning a religious aim to live. Umar, in the following excerpt, was quite direct in accounting for the best route to a positive recovery in identifying the fundamental challenge of "spiritual illness", effectively an alienation from God that requires a "return" to "righteousness":

> When I was into negative things - I was spiritually sick. So, how do we treat our sick spirit? We need to return to God's path of righteousness. This is as the Spirit acts as our bridge to God (Umar; I; 8: 26–29).

Similar sentiments were expressed by nine of the participants concerning a religious aim underpinning their secular endeavours. However, the majority (n=16) did not mention this aspect, and indeed their life goals varied, including a commitment to families, individual careers, and development. Ahmad pointed out the need to have life goals:

> You have got to decide in the future what you want to do and who you aspire to be. You've got to have a vision and ambition (Ahmad; I; 14: 17–18).

The narrative excerpt illuminates Ahmad's perception of the need to have self-determination which he highly recommends as the first step in moving forward with bipolar disorder. Sofia highlighted the need for a balance between reliance on spiritual-religious practices and medical assistance for controlling mood:

> I think I am ok with my spiritual aspect. Alhamdulillah. It's balance of course. Being balanced means that I can control my mood, I take my medication. I have to discipline myself starting from my Suboh [i.e. morning] prayer until night time (Sofia; I; 22: 14–18).

As illustrated by the above quote, the perception of the "spiritual aspect" comes into balance with the participant's ability to control her mood or emotion. It could be that emotion corresponds to anxiety about the effects of bipolar disorder, reflecting the dedication demonstrated by taking medication. In not taking medication for treating bipolar disorder, this subjective account suggests that being self-centred might limit both the spiritual self-efficacy of the individual and their access to sources of help and guidance from others.

> With having bipolar and you're not taking your medication, you just don't care for God; you don't care about anything. You become very self-centred, very selfish. And all you think is to kill yourself (Robert; C; 17: 1–3).

From this example, it is perhaps more interesting to explore how the maintenance of emotional and indeed spiritual well-being is coupled with the use of modern medicine; a preferred intervention in many contemporary services for mental health, especially in Malaysia.

DISCUSSIONS

As demonstrated in the finding, participants' religion, the families, and medication appeared salient to the participants concerning the meaning and values within the Malaysian worldview. The religious meaning system itself provides a concrete functional structure for these Malaysian participants, which helps to understand the phenomenon of spiritual despair. The religious meaning system is defined by Silberman (2005, p. 644) as the personal beliefs or theories of individuals regarding themselves, others, the situations they encounter, and their relations to it as they go about their everyday lives. These beliefs or theories form idiosyncratic meaning systems that allow individuals to give meaning to the world around them and their experiences (13).

Nearly half of the participants in this study experienced a 'loss of faith in God' when facing life adversities in which they highlight their negative appraisal towards their religion. Levin (2009) uses the terminology 'distorted faith' and suggests it as part of the symptomatology in people with mental disorders (14). Rather than seeing people with bipolar disorder have distorted faith because of the symptoms, this study proposed that the religious meaning system in Malaysia give way for 'negative religious reframing' of adverse events in the participants' lives.

One of the explanations that support our finding of spiritual despair is spiritual intelligence or quotient (SQ), which can decline regarding an individual's consciousness in every aspect of life (15). Another explanation is sought through describing spiritual despair or struggle as an impairment of one's ability to transcend oneself (2). Maladaptive coping could also be the case in this Malaysian research sample when voicing the emotional distress as mentioned by previous studies (8).

The spiritual meaning-making was portrayed by the participants as the coping mechanism. Spiritual meaning-making can indicate growth in the aftermath of spiritual distress (16), and it is the strongest predictor for resolving spiritual distress (17). This study argues the need to look at the context of the study population in Malaysia, where this reveals the symbolic meaning of relationships with family members perceived by the participants as supportive and meaningful to their recovery. Relational qualities within families and communities could serve as a spiritual resource for the attachment system aside from religion (18).

Meanwhile, the advantages of medication is related to their spiritual conditions as it intervene to mitigate the distress associated with the symptoms. It is crucial to consider the fact that the participants are in favour of scientific explanations of its symptoms and the hierarchical position of psychiatrists (in Malaysia) in authorising medication. Viewed conventionally,

medicine is the first line of treatment for bipolar disorder (7), and some scholars have highlighted the medicinal benefit of promoting spirituality in people with health problems (52). Hence, it can be clearly stated that medicine can be part of an integrated repertoire of spiritual resources, which justifies that spirituality is beyond the coherence of subjectivity as related to being compliant to medication.

Implications and limitation

This research explores the concept of spiritual distress and its rehabilitation from misery in coping with bipolar disorder. This study invites the mental health professionals to look into resolving spiritual distress, and the spiritual care approach for people with bipolar disorder. This study did not provide the demographic representativeness of the actual people with bipolar disorder in Malaysia with only a small number of participants. This study imposes a limit within the Malaysian group living with bipolar disorder with a religion, and those attending to the mental health services only.

CONCLUSION

To conclude, this study favourably highlights the role of mental health service in promoting spiritual recovery within the context of living with bipolar disorder and concerning loss events. In this study, spiritual recovery for the event of spiritual distress is not limited to religion but involved the fundamental role family members and their psychiatrist. This study, therefore, places the importance of the individual's access to spiritual resources that are necessary to resolve struggles before they become chronic and before they lead to significant damage. To do that, we need to learn much more about how struggles evolve and how we may best help people amid their spiritual conflicts.

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