

Factors Affecting the Quality of Life for People with Schizophrenia in Saudi Arabia: A Qualitative Study

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Abstract

Background: Quality of life (QoL) for people with schizophrenia has been a focus of concern in order to improve their standard of life to lead to more satisfaction, happiness and well-being. However, a little is known about how Saudi Arabian people with schizophrenia perceive their QoL.

Purpose: This study presents the findings of a qualitative study that explored the QoL for 159 people with schizophrenia.

Method: Structured face-to-face interviews were conducted with people with schizophrenia who live in the community.

Results: A thematic analysis identified two main factors affecting the QoL for people with schizophrenia: 1) the shame of having schizophrenia was a barrier to their QoL and 2) the positive role of religion was a facilitator for their QoL.

Conclusion: This study concluded the following: 1) Religion helps Saudi Arabian people with schizophrenia cope with and manage their mental illness, which improves their QoL, and 2) the shame of having a mental illness negatively affects the social engagement of Saudi Arabian people with schizophrenia, limiting their participation in leisure and work activities and therefore diminishing their QoL. The implications of these results in improving the QoL for people with schizophrenia and other mental illness in Saudi Arabia are discussed.

Keywords: Quality of life; Schizophrenia; Saudi Arabia; Qualitative study; Thematic analysis; Religion; Stigma

Introduction

Schizophrenia is an overwhelming mental illness that affects approximately 1% of the world population. Schizophrenia is recognized as a severe mental illness which characterized by positive symptoms (e.g. delusion, hallucination) and negative symptoms (e.g. blunted affect, emotional and social withdrawal). These symptoms may have a negative impact on a person's social, occupational or interpersonal functioning and his quality (American Psychiatric Association 2014). The Saudi Arabian Ministry of Health reported that 22.4% of mental health services outpatients suffer from mental and behavioral disorders caused by schizophrenia or schizotypal and delusional disorders. In Saudi Arabia, there is no mental health law, and relationships between doctors and patients are organized according to Sharia'a (Islamic law). In Islam, "no responsibility was attributed to a child, a psychotic adult or a sleeping or stuporous person". The welfare and care of people with mental illness under Islam are undoubtedly the responsibility of the family [1-5]. In the Arabic culture, such an illness is viewed as a family issue. Whether or not a person is hospitalized or kept in or discharged from a hospital depends not on what the individual needs but on the desire of the family. Therefore, in Arab culture, the issues of patient consent, autonomy, and decision-making are considered family-centered. Quality of life is a holistic view of health from a bio-psycho-social viewpoint, which emerged during the post-World War II period, to enhance the post-war economic wealth and standards of living. This view arose as a perceived need to enhancement successes of contemporary medicine to improve QoL in case of chronic serious diseases. These broad notions were identified by social scientists, who conduct population-based QoL research that significantly contributes to social indicators. Commonly, QoL has always included several domains related to health and social life such

as work, family, wealth, religion, and environment [7]. According to Foldemo et al., "Quality of life is a complex and multidimensional construct. The majority of definitions include several broad concepts such as well-being, happiness/satisfaction and achievement of personal goals, social relations and natural capacity.." [6,7]. It is important to consider such phenomenon or aspect of one cognitive domain because it can be considered to be part of mental health. And the understanding of such would also result to increase rate or possibility of recovery and better life. While there is no single definition that has been accepted universally for the QoL, it is generally view as a complex and multidimensional construct. The concept of QoL was firstly applied in severe and chronic mental illnesses when the mental hospitals were being closed in many western countries and patients who suffered from chronic severe mental illnesses were being released into the community. The review of the literature on the QoL for people with schizophrenia identified a limitation in the methodology of the previous studies. The previous studies in Arab countries focused only on socio-demographic factors and did not try to investigate other factors associated with QoL in Saudi Arabia, Kuwait and Saudi Arabia and Jordan [8-10]. The limitation on the methodology of the studies of the QoL was firstly and only identified by Bengtsson-Tops and Hansson. The authors

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reported a very important limitation that needs to be investigated in future studies, which is, by using quantitative data only; it was unable to identify other information that would provide a holistic picture of the QoL for people with schizophrenia. Therefore, Bengtsson-Tops and Hansson¹³ recommended that quantitative and qualitative data be combined in order to obtain a comprehensive view of the QoL for people with mental illness. The use of quantitative and qualitative data will help to view people with mental illness from a holistic viewpoint as whole persons involved in daily life. Therefore the purpose of this study was to explore the quality of life for people with schizophrenia in Saudi Arabia. This study addresses the following question:

How do people with schizophrenia in Saudi Arabia perceive their QoL?

Method

Design

The design was a descriptive, qualitative study. The data were collected by semi-structured interview and were analyzed by a thematic analysis method.

Sampling method

A purposive sample was recruited from a psychiatric outpatient department in Saudi Arabia in 2010. The participants of this study were people with schizophrenia. The study inclusion criteria were; Saudi Arabian citizens, aged 18-65 years, and meeting the DSM-IV-TR diagnosis of schizophrenia. The patients were identified as being clinically stable by a psychiatrist. The research aim was described to the potential participants. If the participants decided to participate, they contacted the researcher in order to arrange for the interview.

In cooperation with the head of the Department of Psychiatry, 198 patients who met the study participation criteria were identified. The nurses approached the patients during their regular follow-up visits at the outpatient clinic, and they provided the patients with the research information package along with brief explanations regarding the research project. The patients had the opportunity to decide whether to participate in the study and contact the researcher to arrange for the interview. Of the 198 eligible patients, 159 contacted the researcher and agreed to participate in the study. The consenting patients were interviewed by the researcher on the day of their next visit to the psychiatric outpatient clinic. At the beginning of the interview, each patient was required to sign the consent form together with the researcher. The researcher interviewed the participating patients after they had finished their ordinary consultation sessions in a room in the psychiatric outpatient clinic that was free of distraction [11-15].

Description of the participants

The participants were 159 people with schizophrenia, including 97 male and 62 female. Their ages ranged from 18-65 years, with a mean age of 38.23. Regarding their education level, the majority of the participants completed their secondary school education (72), followed by primary school education (61) and University graduate (26). Concerning employment status, 72 were employed and 87 were unemployed. Most of the participants were married (82), followed by single (62), and divorced, separated or widowed (15).

Data collection

The data were collected through face-to-face interviews, which were conducted in a private room that was provided by the hospital in

which the participants received outpatient treatment. The participants were asked about their view of their QoL, as well as the factors that work as facilitator or barriers to their QoL. Participants were asked the following initial core question and allowed to respond to it as fully as possible: Can you name any things that would improve your life quality? Further questions were added throughout the interviews, which were relevant to the focus and progress of the individual interview process to obtain in-depth information, clarification, and additional details. These questions were as follows: 1) what are the facilitators of your quality of life? 2) what are the barriers to your quality of life? The interviews lasted for 45 minutes and were recorded on a digital voice recorder under agreement from each participant. All the information the patients provided was confidential, and no identifying information was used. Data obtained from the patients were kept under lock [15-21].

Data analysis

Data analysis included two main stages: data preparation and data analysis. In the data preparation stage, the interview recordings were transcribed from verbal data into written form. The transcription was carefully performed by listening to voice tone, breaks, and emotional expression. After the transcription and a careful reading, data were translated from Arabic to English by a bilingual expert. The transcribed data of the interview were provided in a Word document file (.doc) and used for data analysis through the use of the Nvivo software. In the data analysis stage, thematic analysis was used to identify themes related to how Saudi Arabian people with schizophrenia perceive their QoL. Thematic analysis is a method used for analysing qualitative data through organizing and describing it before identifying and reporting themes. This method of qualitative data analysis was used in this study because it is more flexible than other methods because it lacks theoretical restrictions such as, grounded theory. Thematic analysis involves six main phases: 1) reading and re-reading the data until becoming familiar with data, 2) creating preliminary codes, 3) exploring for themes, 4) evaluating themes, 5) defining themes and 6) producing the report¹⁸.

Ethical Considerations

Permission to conduct the study was obtained from the Human Research Ethics Committee of the University of Wollongong, Australia and from a local hospital in Saudi Arabia where the data were collected. Research ethical considerations including the nature and aims of the research, voluntary participation, the right to withdraw from participation, the protection of confidentiality and privacy, the storage of data, and benefits of research were explained in writing to potential participants. Written consent was obtained before participation.

Results

Based on the process detailed in the data's thematic analysis, two main themes emerged; under each theme a group of subthemes was identified. The emerging themes were as follows: (a) shame of schizophrenia and (b) positive role of religion. The findings of the thematic analysis of the data are shown in Table 1. Simple counting (content analysis) was used to identify the number of responses to specific themes to add weight to the importance of themes. Forty-four of the participants, out of a total number of 159, reported that the shame of schizophrenia affected their lives negatively. Within the group that reported feeling shame about their schizophrenia, a group of subthemes emerged. This group of subthemes included keeping "it" secret and the Media exaggerate "it". On the other hand, 110 out of 159 participants reported that the positive role of religion was positively

Codes	Subthemes (no)	Themes (no)
Barriers to QoL	Keeping "it" secret (39) Media exaggerate "it" (5)	Shame of schizophrenia (44)
Facilitators of QoL	Acceptance of illness (15) Religious practices such as prayer and use of the Quran (82) Belief in faith healer treatments (13)	Positive role of religion (110)

Note: no=Number of the study participants who suggested each subthemes and theme. Total number of participants=159

Table 1: Themes and subthemes that emerged based on the thematic analysis of data.

associated with their QoL. Likewise, a number of subthemes emerged in the areas of the positive role of religion including acceptance of the illness; practices (e.g., prayer and reading the Quran); and belief in faith healer treatments (Table 1).

Shame of Schizophrenia

Keeping "it" secret

The issue of keeping schizophrenia a secret matter emerged as a major theme. Thirty-nine of the 159 participants reported that the shame of having schizophrenia affected their lives. Participants indicated that they would prefer to keep their illness secret for two main reasons: (a) family shame of having a family member with schizophrenia; and (b) public shame of having schizophrenia [22-29].

Firstly, participants reported that they preferred hiding their illness because it brings shame to their families and affects their position in the community. Participant no. 27 explained this sentiment in the following statement:

The problem is that our society looks at people with mental illness as a disgrace to their family. Therefore, the patient and family prefer to hide the disease and don't seek professional help [30-36].

(Participant no. 27, 45 years old, male, primary education, unemployed, married)

Participants indicated that they felt punished by their family for having schizophrenia. Participants described the ways that their family punished them as taking the form of misunderstanding, mistreatment, over-controlling them, being treated differently from others in their family, being mistrusted and watched by their family, and being punished for having certain behaviors. For example:

My mum can't understand me. If she will see me nervous or with a very bad mood, she does not know how to deal with me and therefore she starts to ask, "Why are you nervous?" Sometimes I can't tolerate her and I start crying. My mother always tries to break my opinion. She always tries to control me even in the silly things; she treats me like a three-year-old.

(Participant no. 55, 22 years old, female, primary education, unemployed, single)

Secondly, participants talked about consciously trying to hide that they had a mental illness. They indicated that they preferred to hide their illness and keep it a secret matter because they feel shame from the public, uncomfortable and anxious when someone knows about their illness. For example:

The only thing that makes me happy is hiding the fact that I am mentally ill because I feel uncomfortable and anxious when I tell other people about my sickness and that I am on medication. This is a highly sensitive issue for me and and it must be a private and confidential

matter. Only a limited number of my relatives know about my illness because it places a stigma on my family [37].

(Participant no. 9, 44 years old, female, university education, unemployed, single)

Participants reported that having a mental illness impacted on their personal, social, and employment potential. They indicated that due to the shame and negative view associated with mental illness in society, they would not be allowed to get married or to have a job or social relationships. For example:

But because of my illness and negative view of people with mental illness as they are mentally ill. . . people will not allow me to get a job and to get married and to have a little dream like any other human being.

(Participant no. 71, 41 years old, male, primary education, unemployed, single)

Because of the shame and stigma associated with mental illness, participants felt that other people would prefer them to be hospitalized. They believe that the general public is afraid of them and thinks that they should not be in the community, but should rather be kept isolated, away from the mainstream community. For example:

My problem is that all the people who are aware of my condition are afraid of me. At the beginning when I hid my disease, none of them looked at me as a crazy person. But when I was treated for my disease and faced the people, they said that I am mentally ill and I should be in the hospital, not with them in public.

(Participant no. 128, 22 years old, female, secondary education, unemployed, single)

Media exaggerate "it"

Five out of the 159 participants thought that the media has a vital role in demonstrating the lack of knowledge about mental illness, and it adds shame and stigma to those people who diagnosed with schizophrenia. By not understanding mental illness, the media reinforced stereotypes, myths and fear of people with schizophrenia and therefore perpetuated the notion of dangerousness and stigmatizing them more. In term, this increased their feeling of shame. For example:

I found that in the Arabian Gulf TV series, and in Egyptian films, it displays mental illness in an exaggerated and sarcastic way. Usually, all the bad, evil, and dangerous people on TV are people with mental illness.

(Participant no. 16, 34 years old, female, primary education, employed, single)

Not all participants simply accept the idea that media portrayal or broadcast needs to be negative. Providing mental health education by means of the media was suggested as an important way of creating a healthier community, increasing knowledge about schizophrenia, and decreasing myths about the disease, thereby lessening discrimination. For example:

I think it would be better to increase media mental health education for the public to help families and friends to support and take care of those people. And to provide a healthy community that can treat schizophrenia like the flu.

(Participant no. 156, 24 years old, female, primary education, unemployed, single) [38].

Positive role of religion

Religious practices such as prayer and use of the Quran.

The majority of the participants (82) reported that they perform religious practices to improve their lives. Participants stated that they rely on reading and listening to the verses of the Quran. They perform different kinds of worship such as private prayer, prayer at mosques, and praise. The performance of worship helps them to be happy because they will be closer to God and feel that God is with them. They believed that it improves their mental health and find reading the Quran relaxes them, and thereby relieves stress [39-41]. For example:

Continually reading the Quran gives me psychological fulfilment and comfort. Reading verses of the Quran has an influence on my spirit and soul. . . the Holy Quran has a much greater influence in improving my mental health because it relieves stress; satisfies my heart, mind, and soul; and relaxes the psyche. Listening to Quran tapes daily is a great comfort.

(Participant no. 1, 25 years old, male, primary education, employed, married)

Participants experienced a feeling of peace as they concentrated on listening to the Quran or engaged in prayers. They found the process comforting. For example:

Praise and prayers for forgiveness are daily miracles; they give me comfort. Happiness and peace of mind come from listening to the Word of God as the Word of God is at work to break things within the self.

(Participant no. 6, 43 years old, male, secondary education, employed, married)

Positive role of religion

Strong belief in the faith healer treatment of mental illness emerged as an important theme for the improvement of their health. Thirteen of the 159 participants reported that seeing a faith healer helped them to feel better.

Recently, after visiting a faith healer, I began to feel much better, and the hallucinations gradually began to disappear. I continued to see the faith healer . . . I feel much better every time I see the faith healer.

(Participant no. 11, 39 years old, female, university education, employed, widowed)

Faith healers helped participants to be in control of their negative symptoms and encouraged them to trust in God.

I was taking high dose medication because I don't leave my home [sic]. The symptoms were controlling me, until I felt that I have tightness in my chest and heart, and then I visited a well-known faith healer and he advised me to be close to Almighty God and trust him. This was just after Friday prayers.

(Participant no. 28, 43 years old, male, secondary education, employed, married)

The participants cited the most common methods of treatment that were used by the faith healer were as follows: Roqua (reading verses from the Quran), rubbing oil on the body, and drinking water with God's word read over it. For example:

I felt very [much] better when I went to a faith healer. He treated me by Roqua and gave me water to drink from it.

(Participant no. 145, 44 years old, female, university education, employed, married)

Meaning of life

Fifteen of the 159 participants indicated that religion and faith help them to view their illness positively, to accept their illness and improve their life. They view sickness as a test of their belief, and they believe that God will reward them for their patience. They believe that the treatment for their sickness is in God's hands. They insist that they rely on God, have a relationship with God, and find comfort and safety in their religious beliefs and practices. For example:

But my faith in God Almighty is strong, and I believe that what happens to me was decided by God. He decided that I would be sick; I am not mentally ill by chance. And I do not protest what God decided for me. I believe that the only healing for my sickness is in God's hands.

(Participants no. 2, 28 years old, male, primary education, employed, divorced)

Participants believe mental illness to be a challenge sent by God in order to test them. Hope was offered in the form of a story of faith in God. For example:

If you will have the strong belief in God you will say that I am lucky because my God chose to test me in this life. I believe that life is just a test for the believer and my God will reward me in the after life.

(Participant no. 55, 23 years old, female, primary education, unemployed, single)

Discussion

This study involved a qualitative study investigating the QoL for people with schizophrenia in Saudi Arabia. Two themes were identified in relation to the perception of QoL for Saudi Arabian people with schizophrenia; 1) shame of schizophrenia, and 2) the positive role of religion. The discussion will be based on those two themes.

Shame of Schizophrenia

The findings of this qualitative study reveal that Saudi Arabian people with schizophrenia suffer shame from having schizophrenia. This result is supported by other studies undertaken in Morocco and Yemen. These researchers found that people with schizophrenia in traditional Arab countries suffered from stigma. In this study, Saudi Arabian people with schizophrenia reported having two main forms of shame associated with having schizophrenia; 1) family shame of having a relative with schizophrenia, and 2) public shame of having schizophrenia [42].

Firstly, Saudi Arabian people with schizophrenia indicated that the family shame of having a relative with schizophrenia affects their life and how their family treats them. Only a few studies have been published about the family shame of people with mental illness in Arab countries. Arab people prefer to hide that they have a family member with mental illness because they fear a bad reputation if people knew that they have a family member with mental illness. This study was supported by Kadri [19]. Secondly, the public shame of schizophrenia was another factor that negatively affects the QoL for Saudi Arabian people with schizophrenia. Public attitudes toward people with mental illness was studied and assessed in the public, in Yemen 20 and Qatar, in health professionals in Palestine and Jordan, and in non-health providers who work at mental health hospitals in Egypt and Kuwait;

the results showed a negative view of and attitude toward people with schizophrenia.

Another important finding that participants in this study raised is the role of the media in adding to more stigmatization of, and discrimination of people with mental illness. These findings were supported by other studies undertaken in the United Kingdom and New Zealand in regard to the role of the media in generating a negative view of people with mental illness. The interpretations of this qualitative study reveal that the shame of having schizophrenia negatively affected the QoL for people with schizophrenia in Saudi Arabia. This result is consistent with previous studies conducted in the United States of America, Taiwan, and New Zealand that showed that the discrimination and stigmatization of people with mental illness are associated with poor QoL. A possible explanation for this result is that higher levels of stigmatization among people with schizophrenia decreased their self-esteem; thus, they may have had difficulty in seeing their life as important and diminish their ability to enjoy it, which led to a lower QoL [43].

Positive Role of Religion

The results of this study show that people with mental illness in Saudi Arabia believe that mental illness is caused by the will of God. In Islam, health and sickness are perceived as caused by God, and it is believed that health is distributed through his heavenly decisions and power. Therefore, Muslims tend to accept the will of God and face the illness with a strong faith and patience. The findings were supported by other studies [17], undertaken in Arab countries that found that people believe mental illness is caused by the will of God. In addition, Saudi Arabian people with schizophrenia in this study reported using religious practice (e.g., prayer, worship, reading the Quran) as a method to cope with their mental illness. This result was supported by Al-Krenawi et al. as well as Al-Krenawi, Graham, Dean, and Eltaiba. Saudi Arabian people with schizophrenia in this study showed strong personal belief in faith healers. This result is supported by Savaya and by Salem, Saleh, Yousef, and Sabri. In Arab culture, the faith healer has a very important position in the community because he/she belongs to the same culture, background, and community as the patient; they deal with mysterious and supernatural forces in which Arab people strongly believe. The interpretations of the qualitative findings of this study show that religion is found to be positively related to the QoL for people with schizophrenia in Saudi Arabia. This result is consistent with previous studies undertaken in China and the United States of America that show that spirituality and religiousness were positively related to a high QoL for people with mental illness. Therefore, religious faith and practice is an important factor in improving the QoL for Saudi Arabian people with schizophrenia. It is worth noting that none of this study's participants talked about negative religious coping, for example, anger, fear and guilt in their life. A number of studies have focused on investigating the negative and positive effects of religion on the lives of people with schizophrenia. Therefore, a possible reason why Saudi Arabian people with schizophrenia in this study reported only positive religious coping is that Saudi Arabia is a traditional and religious country. The main religion is Islam, which teaches Muslims to accept the will of God and face illness with strong faith and patience. However, a response bias must also be considered as participants might have been reluctant to discuss religion in negative terms in a traditional religious country such as Saudi Arabia. Therefore, in this study the majority of the participants 110 out of 159 were focused in the important role of the religion in the life of people with mental illness. However, only 44 participants reported shame of schizophrenia.

Consequently, the result showed that religion has a stronger impact in the QoL of people with schizophrenia in compare to feeling shame of having schizophrenia [44,45].

Limitations of the Study

There are some important limitations that should be addressed. The first limitation was that the findings may not be generalized to people with schizophrenia who are institutionalized in psychiatric hospitals and are experiencing severe psychotic symptoms because the participants were patients who were receiving outpatient clinic treatment and in a stable mental health condition. A further limitation was a possible response bias, as participants may have been reluctant to discuss religion in negative terms in a traditional religious country like Saudi Arabia.

Recommendations

Mental health services in Saudi Arabia need to integrate professional mental health treatment and religious treatment and provide mutual care for people with mental illness. The study reveals that people with schizophrenia reported that religious beliefs and practices, as well as faith healing treatment, facilitate improvements in their QoL. The stigmatization of people with mental illness in Saudi Arabia needs to be addressed. This study showed that people with schizophrenia in Saudi Arabia are suffering from stigmatization, which serves as a barrier to improving their QoL. Therefore, strategies to de-stigmatize people with schizophrenia in Saudi Arabia should be implemented. Carr and Halpin suggested a number of such strategies educating the media and using it to provide public health education and community awareness, establishing an agency that monitors how the media portray mental illness and provides penalties for inaccurate information, and providing training in psychoeducation for patients and their families. In addition, McGorry et al. suggested that in order to reduce stigma toward people with mental illness people need to share their experience and be open to talk and cope with illness and find the right way to get help.

Mental health providers play a significant role in contacting and dealing with people with schizophrenia in Saudi Arabia. Mental health providers who work with people with mental illness need to pay attention to a number of points that might affect the QoL for the people with schizophrenia in Saudi Arabia. Satorius suggested several interventions that need to be addressed by all mental health professionals who deal with people with mental illness. These actions include 1) examining their personal ability for and attitude toward working with people with mental illness, 2) protecting the rights of people with mental illness, 3) focusing on factors that improve the QoL for people with mental illness, and 4) working effectively with the community to change false perceptions and attitudes toward mental illness.

Conclusion

Saudi Arabian people with schizophrenia identified two main factors that affect their QoL. The first factor is that the stigma of having schizophrenia was identified as a barrier to their QoL. Particularly, they identified family shame, public shame, and the role of the media in creating a negative view of people with mental illness. The second factor that affects their QoL is the positive role of religion in working as a facilitator for their QoL. They highlighted the positive role of religion and religious practice (e.g., prayers and the role of the faith healer treatment) in improving their health and life.

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