

Primary Caregivers of People With Severe Mental Illness Experience of Anti-Psychotic Medication: Findings From the Semi-Structured Interviews

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Abstract

Background: Management of schizophrenia is now shifted to the community setting and family caregivers are the primary caregivers. Managing medications is a complex responsibility of family caregivers caring for patients with mental illness. Medication compliance contributes to improve health outcomes and reduced hospitalization for the care service users; however, little is known about attitudes and perception of family caregivers.

Methods: A purposeful sample of 21 family caregivers were included in the study. Semi-structured interview was employed to collect data from the participants between May and October 2015. Thematic analysis approach was used to identify the common pattern in the data.

Results: Four main themes emerged from the study: insight into illness (poor understanding of illness), treatment factor (thinking about medication, poor guidance for medication compliance), resources and support (availability of medication and cost of medication), health care provider factors (communication gap and poor assessment with follow-up, social dysfunction (social isolation, disruption in life routine).

Conclusions: Responsibility for providing care for patients with mental illness are taken place in the community setting and cared by family caregivers. More information resources are required for this role, which requires specific medication management skills and knowledge.

Keywords: adherence, medication, attitude, beliefs, family caregivers

1. Background

Schizophrenia is one of the most serious psychotic disorder which imposes financial, social and emotional constrains (Stuart, 2014). It has a chronic progression with clinical, cognitive, social deterioration as well as it has a frequent episode of remission and relapse and rehospitalisation (Staring et al., 2011). The main reason for relapse and readmission is medication noncompliance, particularly oral form (García et al., 2006). This explains by fears of medication adverse effect and negligence the importance of daily administration drug (Dean, Wragg, Draper, & McDermott, 2011). There is a relatively small body of literature that is concerned with the family caregivers of people with schizophrenia impacts on medication compliance and found including family relative in the treatment process poses positive clinical outcomes, as reducing relapse (Wilk et al., 2008).

Poor service provision and lack of diversification in mental health care in developing countries (e.g. the restricted availability of beds in mental health hospitals) led to major health reforms (WHO, 2011). As a result, the management of schizophrenia shifted from hospitals towards community care (Chan et al., 2009). Nowadays, families are increasingly fundamental in providing essential needs for affected relatives and between 50-80% of people with schizophrenia live with or have daily contact with their families (Lehman & Steinwachs, 1998). However, families may not have basic skills and knowledge to take on the responsibility of caring for people with schizophrenia and family caregivers may be left alone, unsupported or untrained, which is the leading cause of families' physical and psychological health problems (Macleod, Elliott, & Brown, 2011) as well as recurrent relapse with rehospitalisation among people with schizophrenia (Sharif, Shaygan, & Mani, 2012). This conclusion is applicable to families around the globe, as the majority of the reviewed studies directly stated poor knowledge

levels of schizophrenia among family caregivers (Pitschel-Walz et al., 2001; Sharif, Shaygan, & Mani, 2012).

The number of people diagnosed with mental illness who need an assistance from their family relative are increasing due to core changes in the population life in developing countries. In Jordan, the number of people diagnosed with mental illness has been dramatically growing. Available data is derived mainly from a recent World Health Organization (WHO) report, which stated that 305 individuals per 100,000 of the Jordanian population suffer from mental illness. About 18,300 individuals have been diagnosed with mental illness, out of whom around half have a diagnosis of schizophrenia, making this a significant health care issue. Schizophrenia is considered the most common type of mental illness treated in mental health services. Approximately 52% of mentally ill individuals who are treated in outpatient clinics have schizophrenia and 49% of hospital in-patients with mental health problems are diagnosed with it (WHO, 2011).

Family caregivers of people with schizophrenia are identified as a primary source of support, their roles are essential in optimizing health related outcomes and being adhered with treatment regime (Reinhard, Levine, & Samis, 2012). Additional supports from the front help line (e.g. parents) are recognized to affect patient psychological and physical life and their acceptability of illness and treatment (Allen, Lima, Goldscheider, & Roy, 2012). Similarly, studies suggest that social and familial supports are crucial in increasing medication adherence among patient with chronic disease (Matthes & Albus, 2014). Collaboration and including family caregivers with their ill relative in treatment process, which is a source of social and emotional support, encompasses mutual understanding of medical problem. However, this phenomenon has been insufficiently explored in schizophrenia.

In addition, a limited number of studies supports the role of family caregivers in preventing or reducing medication non-compliance. Wilk, West, Marcus et al. (2008) noted that risk of noncompliance with antipsychotic medication is reduced three times when the family members are involved in treatment process in comparison with those did not receive family support. However, the family members are frequently excluded from being involved in planning treatment by health care professionals (Perkins, 2002). Interestingly, poor understanding of illness by family members restricts family support required for ill relative diagnosed with schizophrenia (Taj, 2008). Consequently, treatments for mental illness are often sought from traditional and spiritual healers and put them to be more influenced by social and cultural myth associated with mental illness. In addition, it poses a risk to alienate medical treatment and look for traditional treatment (i.e. faith healer) to deal with psychiatric illness (H. Lee et al., 2011).

In developing countries, the preference of treatment of mental illness devoted to traditional healers which is less expensive and conforms with social values and beliefs. This delays in seeking appropriate psychiatric helps resulting in deterioration in client psychiatric symptoms. Consistently, a recent studies by Gearing et al. (2013) and Aloud and Rathur (2009) reported that beliefs and values were the main barriers and challenges for Arab individuals in Middle Eastern-Arab countries with mental illness accessing mental health services or participating in psychosocial treatments and service implementation. Likewise, this finding are supported by another studies on Arab-Muslim population which found a lack of understanding magnifies stigma and tend to tolerate mental health problems for long time before considering any formal treatment (Al-Adawi et al., 2002; Okasha, 1999).

Antipsychotic medication is the first line treatment of psychosis for the first episode psychosis; yet 40% of patients do not take medication as prescribed. Previous research in compared healthcare professional and patients' views suggested that health care providers stressed the importance of patient's insight into medication to increase adherence whilst they underestimated the impact of side effect and family support as a leading factor for nonadherence. Reviews of the literature on predictors of psychiatric medication usage and family variables have showed limited and inconclusive findings. Lacro (2005) reported that family involvement in the treatment process with their mentally ill relative was associated with nonadherence. The major weakness of this study was this conclusion reached based on handful number of studies as well as on global indices of "family involvement" and living arrangements. Conversely, Fenton., Blyler, and Heinsen (1997) in his review found that availability of family support or informal family caregivers was linked to higher adherence among outpatient people with schizophrenia. Collectively, these studies examined the presence of family members in treatment process without investigating the role of specific family. Furthermore, family members can be a source of support or conflict when they have exaggerated emotional expression (EE) (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). A study of Kopelowicz et al. (2006) concluded that risk of relapse is three or four times are more likely when family member has high EE compared with family member has low EE.

Medication management has been labelled as one of the major family caregivers task in caring in the community settings (Fortinsky, 2001). For instance, a recent online survey results showed that approximately half of the informal caregivers reported that their major task in caring process devoted to medication management (Brodsky & Green, 2002). This is an essential outcomes as it improves health related outcomes and reduces hospitalization rate

(Arlt, Lindner, Rösler, & von Renteln-Kruse, 2008). However, the importance of this caring increases when the caring receiver diagnosed with cognitive function declines (Cotrell, Wild, & Bader, 2006; Erlen et al., 2013). Consistently, based on the findings of US project on informal caregivers highlighted that informal caregivers role concerning medication management dramatically increased from 54% to 90% when cognitive deficit being sever “advance stage of dementia” (World Health Organization, 2012).

Data from several studies suggest that medication compliance is improved among people with schizophrenia (PwS) who are live with their relative or in close contact with family member (A. Hasan, 2016; Perkins, 2002). Despite this evidence, mental health professionals intend to exclude family caregivers from the treatment process. Little is known about family caregiver’s perception and attitudes towards antipsychotic medication. In a recent qualitative study explored the role of the primary caregivers in management process of schizophrenia treatment and reported primary caregivers had essential role in preventing and managing medication non-compliance (A Hasan, 2016).

The research to date has tended to focus on attitude and perspective of people with mental illness towards antipsychotic medication. In light of this, there is need for an investigation of attitude and perspective of close family member (primary caregiver) towards antipsychotic medication. Indeed, existing research on attitudes towards antipsychotic medication has been predominantly utilized quantitative approach and included patient with mental illness with less attention has been paid for family caregivers (Fisher, Cornman, Norton, & Fisher, 2006; Vervoort, Borleffs, Hoepelman, & Grypdonck, 2007). It thus anticipated that an understanding family caregivers attitudes towards antipsychotic medication may reduce medication noncompliance among people with mental illness (Kelly, McCarthy, & Sahn, 2014). Using qualitative methods, this study purposes to gain insight into the experiences of family caregivers about antipsychotic medication.

2. Methods

2.1 Design

Qualitative design is an approach to understand a person’s experience from his or her perspective (Trotter, 2012). This approach is suited the purpose of this study as a little is known about this phenomenon, therefore, a qualitative design, based on the inductive approach, was used for the data collection and analysis of family relative’s subjective attitudes and perceptions about antipsychotic medication between May and October 2015.

2.2 Participants and Recruitment

Participants were family caregivers of people with mental illness in Jordan. Purposive sampling method was administered to provide diversity in socio-demographic characteristics of interviewees. The inclusion criteria were adult, relative of a people with mental illness, willingness to be interviewed and the ability to talk and explain their experiences. The sampling was based on a maximum variant strategy in terms of levels of education, marital status, and different ages and relationship with mentally ill relative. This sampling strategy enabled the researchers to capture a wide range of views and experiences (Speziale & Carpenter, 2011).

2.3 Data Collection

Semi-structured interviews were employed to elicit participant’s responses. Interviews conducted in private room where participants can express their point of views freely. Each interview lasted up 35 minutes and was audio-taped. A reflective diary was used to support the audiotaped data, to collect non-verbal responses of the interviewees as well as renders the participants feel that author was interested in what they were saying. Simple language was used and technical terms were avoided. The majority of interviews were conducted in Arabic language (mother tongue language of the participants). However, some participants preferred to speak in English. Interviews was carried out on individual basis once. A set of open-ended questions was used to guide responses during interviews (e.g. Would you please share with me your experience about your relative medication? Would you describe the problems that arise from usage of medication?). Probing questions were also used during the interviews to improve the depth of data gathering. After 21 interviews, author noticed data redundancy and information saturation. Thus, decision made to cease interviews.

2.4 Ethical Considerations

Ethical approval was granted by the Ethics and Scientific Committees in the Ministry of Health to conduct the study. Potential participants were approached and informed about the study the purpose, the voluntary nature of their participation, and that they could withdraw from the study at any time without presenting reasons and this would not impact on their ill relative medication. Informants confidentiality and anonymity was assured and maintained, Furthermore, permission for audio-recording of interviews was obtained from each participant. Informed consent was obtained from those who agreed to be involved in the study.

2.5 Trustworthiness

Consolidated Criteria for Reporting Qualitative research (COREQ) was consulted to promote (Tong, Sainsbury, & Craig, 2007; Table 1). Also for building research trustworthiness we have to focus on credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). To address credibility, there is several steps followed to address this point. First, researcher had prolonged engagement with participants to learn the culture and build trust (Lincoln & Guba, 1985). Second, researcher made two transcriptions for each interview by listening to the audio recording on two separate occasions. Then researcher merged the two transcriptions into one final version. Each final transcription was read line by line 2–3 times to identify the main themes. This procedure provided a richer, more meaningful and more credible data set. Moreover, credibility of the current study during data analysis and interpretation was enhanced by showing apparent contradictions in data. Transferability was achieved by selecting a purposeful sample from different psychiatric clinics to illuminate phenomena being studied. In addition, a thick description of the contextual background of the research setting and the participants and credible interpretation is necessary. The dependability of research data is satisfied by using interview guide in order to be consistent. In addition, the transcription strategy was universally similar for all interviews conducted. Digitally recorded interviews were added as another way of enhancing the dependability of obtained data by minimizing any systematic bias and producing plausibility of the account made by interviewees

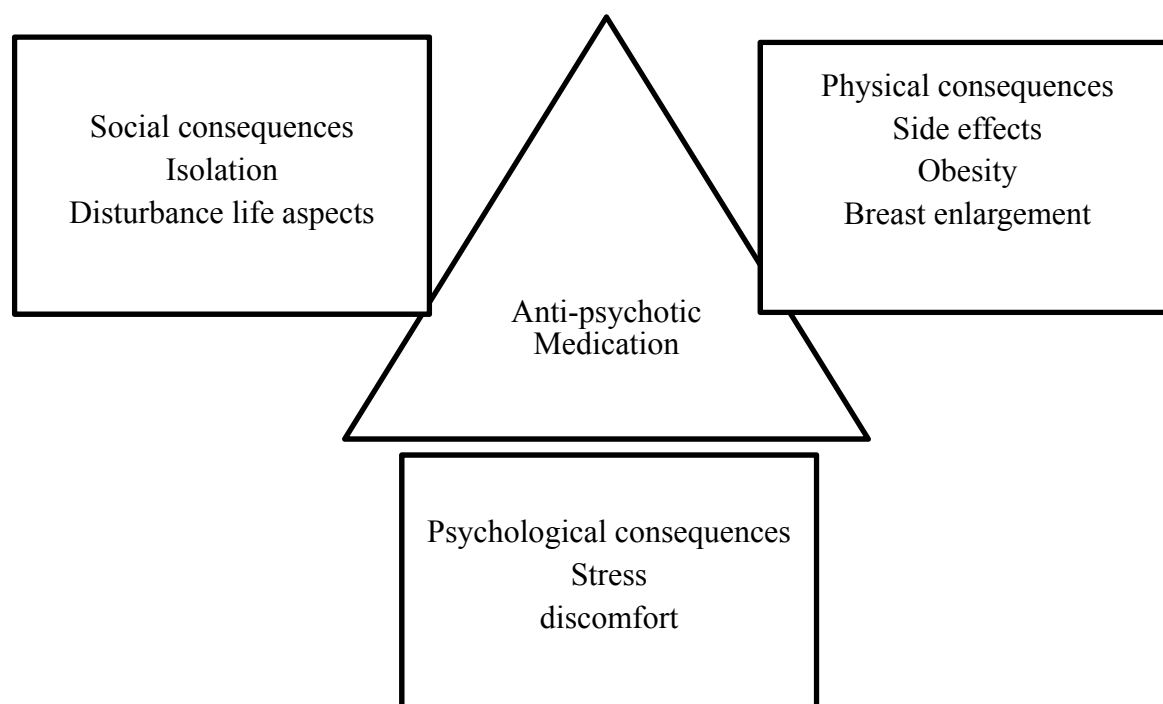


Figure 1. The Impact of Anti-Psychotic Medication on Life Aspects

2.6 Data Analysis

The interviews were audio-recorded and transcribed verbatim, and analyzed using the thematic analysis (TA) approach concurrently with data collection process. This approach was employed as it provides an accessible form of analysis and can be used within different theoretical frameworks (Boyatzis, 1998). TA is extensively used in health research (Braun & Clarke, 2006), by which data is systematically categorised into themes and sub-themes. This approach was employed in this study as it is accessible and flexible within different theoretical frameworks (Braun & Clarke, 2006). Therefore, it is not tied to any epistemological or theoretical assumptions, and can be applied to numerous types of studies. TA can be used to report experiences and to obtain understanding (e.g. regarding interviewees' perceptions) in order to gain the rich (thick) descriptive data. Data analysis in qualitative research is an iterative process from data collection, through interpretation to the writing-up process (Green & Thorogood, 2013). All interviews were analysed manually because the relatively small sample size allowed for this kind of in-depth scrutiny (i.e. due to the small data-set, non-computerised methods were feasible and

appropriate). The first step of analysis was transcribing interviews which assisted author to be familiarized with the data (Pope et al. 2000). Then coding process was performed line by line to generate initial code. The next step included that all similar codes or meanings were collated into potential themes. At the end of this point, all potential themes and sub-themes were identified.

3. Results

The average age of participants were 45 years old and the majority of them were female caregivers. In addition, two third of participants had attained secondary level of education or more. Almost all participants were a primary caregivers and spouse. All interviews were conducted without distraction or repetition. In couple of interviews were the participants invited her husbands to take part due to cultural factors. Five themes emerged: insight into illness, treatment factor, availability of medication and cost of selected brand of medication, health care provider factors and poor instruction about medication.

Table 1. Characteristics of interview participants (Family Members)

Characteristic	Interview Sample
Participants	21
Gender:	
Male	8 (38.1%)
Female	13 (61.9%)
Age (years):	
≤ 20	0 (0)
21-30	2 (9.5%)
31-40	5 (23.8%)
41-50	12 (57.1%)
≥ 51	2 (9.5%)
Education Level:	
Primary School or below	14 (57.1%)
Secondary School	5 (23.8%)
College or above	2 (9.5%)

3.1 Insight into Illness

This theme captures the participants' prior knowledge of schizophrenia which impacts of their understanding, attitudes and perception towards antipsychotic medication.

Poor understanding of illness

This section investigates how the participants' knowledge and understanding of schizophrenia influenced their attitudes towards medication. Data analysis suggested that almost all the participants expressed a limited knowledge of schizophrenia, regardless of age and educational attainment:

"..... Because you know we do not have any educational opportunities from the Ministry of Health in Jordan to answer our questions....." (PC1)

"... He has been getting treatment from the governmental centre for 10-12 years without any educational support from the centre like teaching us or distributing brochures about the illness....." (PC2)

This lack of knowledge around schizophrenia was also evidenced by the fact that more than two-thirds of the interviewees who were interviewed believed that their relative had two personalities and that their interactions with others relied on the predominant personality (aggressive or calm):

"..... I knew about the illness since I was in school. This illness creates two personalities. One is strong and hostile while other is weak and calm and he communicates with others based on these personalities....." (PC1)

"..... We believed that [schizophrenic] patients had multiple personalities....." (PC4, Wife)

Participants' attributed this lack of knowledge about schizophrenia to the social stigma attached with mental illness in Jordanian culture:

"..... I lived in the village for 23 years; the people there have negative views about mental ill person and their families....." (PC18)

"..... It is a difficult topic to talk about in our culture. We live in the village area where people are not educated, hence my father decided to restrict my sister to our home for more than one year, just to protect our family from the stigma....." (PC9)

Moreover, interviewees expressed overwhelming feelings of guilt over their relative's diagnosis with schizophrenia, believing that this was a result of a direct failing on the part of the family:

"..... Furthermore, I have {ah, ah.....} believed the cause of her illness to be due to a mother's neglect, because I {ah} had worked outside the home for a long time previously....." (PC6)

"..... We believed that her poor communication with our mother was one of the causes of her illness {ah, ah.....} because before my mother passed away, she had many arguments with her for unknown reasons [.....]. We also thought this illness stemmed from the jealousy of seeing successful people....." (PC3)

A different group of participants expressed the belief that their relatives' illness resulted from a demonic possession of their relative's mind, prompting them to say or do inappropriate things. These participants attempted to treat their relative by consulting folk exorcists to dispel these spirits:

"..... Previously we thought that this illness [schizophrenia] resulted from the possession of devils inside his body which asked him to perform these behaviours. Also, we {ah} thought this illness stemmed from being nervous, stressed or some unknown fear, but after reading this booklet my view changed (McCauley, McKenna, Keeney, & McLaughlin). This illness is out of his control, we should accept him as he is as well as should avoid asking magicians to treat him....." (PC7)

Similarly, one participant expressed the view that schizophrenia might be the result of charm, which she asked the magician to remove:

"..... In the beginning when he started to behave abnormally or say absurd words, I thought someone had cursed him because he was resourceful and active [.....]. We went to many people for help but it was no benefit to us....." (PC8)

3.2 Treatment Factor

Thinking about medication

This section discusses the participants' views, feelings and thoughts about psychiatric medication and its uses. It seems that participants commonly reported a negative attitude towards medication use. It was noted that this had not been changed over the time which might information attributed as a major cause of relapse.

"..... I kept telling him to stop taking the medication without informing doctor even though he got lead to serious [relapse], and it's so hard to return a patient's status to baseline [.....]....." (PC1)

"..... We know this illness {ah...} can just be treated by herbs [...]. If he doesn't take his medicine [...]......" (PC5)

"..... For instance, my husband had a blood test for depakin level and his result was 77mg, this one time the result arrived at 100mg, and I thought that the depakin medication was discontinued but it caused him to become more distracted and have poor moods....." (PC1)

Similarly, some respondents described that they had previously thought that some of the medication side effects were actually deliberate behaviours exhibited by their relatives. For instance, two respondents said that:

".....I knew the side effects of the medication, but I believed these side effects [...] such as fatigue and muscle spasm were intended behaviour to just sleep...." (PC8)

"..... I would usually say to him that you don't like to do anything because you have everything easily in your life... such as smoking, sleep and food [...]......" (PC9)

Critical analysis of the two preceding quotes reveals that participants reflected on poor understanding of antipsychotic medication information influenced ill relatives in different ways; some of them deduced side effect of using antipsychotic medication is a deliberate behaviour while others utilised their limited knowledge of medication un by attributing their relative's behaviours to normal personal characteristics.

Likewise, in the current study participants noted an acute consequences of medication usage. of these serious side

effects were obesity, enlarge breast which classified to be the most severe and feared adverse effects of antipsychotic medication

“.... When he takes medication {....ah..} after three months his body weight duplicated....”(PC10)

“ His body parts were abnormal {.....} now he is suffering from tremendous change in his body big abdomen and very large breast....”(PC12)

Importantly, the participants mainly spouse in this study identified the negative impact of taking antipsychotic on sexual relationship with their husband. As explained by one participant

“.... Our emotional relationship has changed in a negative way. I didn't know how can he recover and how should I respond to these changes....”(PC10)

Poor guidance for medication compliance

Another view was elicited from a participant interviews were lack of understanding medication mechanism of action and improper discussion with mental health professional results in non-confidence in such medication. In addition, they have stated regarding limited access to obtain valid information about medication and strategies to handle side effects.

“..... We receive medication either with English leaflet or without leaflet. This makes me to be distrust with medication.....”(PC7)

Conversely, improved understanding of medication information might allow some participants to feel that they were an active part of the treatment process in determining the best medication for their relative:

“..... If I observed that the medication is not suitable for him and the illness symptoms such as hearing voices or talking to no one have returned, I can return back to the physician to review this medicine.....”(PC4)

“..... The main problem we face is in shifting psychiatrists [...] {ah...ah} {.....}. There was a lack of original medications. Therefore, they prescribed alternative medication for him [...] but he [relapsed] three times on alternative medication [...]. When I had adequate information about medication, I started to monitor him and knew the suitable medications for his body.....”(PC5)

3.3 Resources and Support

Availability of medication and cost of medication

Almost all the interviewed participant reported that shortage in antipsychotic medications in governmental health center medication were a primary reason for non-adherence with medication. The following quotes reflect this reason

"..... When doctor prescribed Risperdal, we got this medicine from health centre for a nominal price. However, this medicine frequently is out of stock. Its price from the private pharmacy is expensive.... We left him without medication." (PS4)

"..... due to non-availability original medicine, alternative one causes many changes in my body like weight gain and sexual dysfunction....." (PC6)

In the context of medication, some participants reported taking about need to change all medication to be given as a depot which has less side effects and long duration of action:

“..... Sometimes he takes a tablet, but he moves it out when I leave..... when doctor prescribed IM injection she is well now. Previously we had a problem when she used to forget to take her medicine on time, especially as some medicines needed to be taken at different times”(PC4)

In conclusion, the above narrated accounts explicitly highlight that side effects of medication as well as a route of administration have a major role in determining adherence level, which in turn changed some of their views and attitudes towards psychiatric medication in a positive way.

3.4 Health Care Provider Factors

Communication gap and poor assessment with follow-up

The results showed that many participants identified a conflict role for a mental health care provides. More than half of them considered health team discouraged them to have positive influence on improving medication compliance. As illustrated in the comments:

“ We wait doctor in the waiting area {ah.. for calling our name. but, The doctor write prescription immediately based on the last month.....”(PC19)

“ Doctor in the clinic treat many patients every day and they do not have time to chat {...ah...} with everyone(PC7)

“..... Every doctor follows same system, they {...} look at last prescription and write new one accordingly without asking either patient or family any question.....”(PC13)

Conversely, some group of participants stated that mental health care team had a positive role in improving their ill relative compliance with medication by providing certain information regarding specific drugs, which in turn helped to develop their confidence. For example, two participants commented that:

“..... We receive some information on the importance of medication [which] was very useful. Since she started to take [serqual], I did not have confidence in that medicine {...ah} [.....]. This makes me to trust that drug [.....]. It became safer for me. As a result, my view had totally changed and I became more comfortable with medicine.....” (PC16)

“..... For instance, my husband had a blood test for depakin level and his result was 77mg, this one time the result arrived at 100mg, and I thought that the depakin medication was discontinued but it caused him to become more distracted and have poor moods. But when I read the booklet and what it said about medication as well as I had asked you about this, I realised that we cannot suddenly stop taking medication. This has improved my emotional status and I have become less stressed, less depressed and less sad.....” (PC17)

3.5 Social Dysfunction

The participants in this study strongly stressed the negative social effects of medication in disruption the social life of participants. This theme has two subthemes, including social isolation and lack of marriage opportunity.

Social isolation

Many participants, particularly spouses, conveyed a sense of detachment and reported a stressed relationship with family members due to the latter's lack of awareness concerning schizophrenia and its medication's side effects. This is illustrated by comments about the impact of their relatives misunderstanding of schizophrenia on their interpersonal relationships:

“..... My illness caused me to lose my job [.....]. My family, especially my parents blamed me and said I pretended to be lazy and tired just because I did not like to work. However, they changed this view when they read the information in the medication booklet; that the medicine produces these effects.....” (PC1)

“..... I felt {...} like my wife's response has become less defensive when she understood {ah...} the many aspects of the illness.....” (PC4)

Additionally, the major impact of medication on social life was associated with disruption in social life and interpersonal relationship. Many of participants attributed this impact to the negative views linked to the mental illness. In Jordan culture, being diagnosed with mental illness and accepts this diagnosis or take antipsychotic medication means disability.

Disruption in life routine

The negative social effects of using antipsychotic medication were identified by some participants as entire disruption in their ill relative life. For instance, they have problem in getting marriage, continue their study or secure an employment.

“..... in our culture, no one can accept to marry a female diagnosed with mental illness. It looks {ah...ah} like cancer.....”(PC15)

“My son has been dismissed from the university three times... he cannot concentrate... I {ah...} feel he cannot understand as other people....”(PC18)

Another view was noted from the participants in this study that many interviewees, particularly mother stated that their daughters divorced as there was difficulties in playing the role of mother, such as the responsibility of caring for children, or husbands. One participants said:

“.... Her husband divorce her as he noted her aggressive behavior with children....”(PC19)

“.... Now, she is separated from her spouse {...} this occurred three years ago when she started to hear voices and isolate herself....”(PC21)

4. Discussion

This study purposed to understand how family caregivers perceive antipsychotic medications. Two key issues became apparent in this study: the first was the influence of poor understanding illness nature on their attitudes and experience towards mental illness and antipsychotic medications. The second issue is that the influence of poor insight into illness and its influence various life aspects. Perceptions and attitudes of participants in this study identified in three categories, including physical, social and psychological factors, as illustrated in Figure 1.

The evidence that emerged from the qualitative data in the present study demonstrated that the participants' limited knowledge of schizophrenia was influenced by negative public perceptions. Limited knowledge of schizophrenia was also associated with self-stigma, shameful feelings and a pre-occupation with negative psychological feelings (i.e. depression, low self-esteem), all of which have been linked with lower treatment adherence (Vogel, Wade, & Haake, 2006).

The participants reported various reasons for their stressors from their external or internal environments. The former type of stressor is related to the social stigma attached to mental illness in Jordan. Participants stated that negative community attitudes towards the ill relative or their family members was one of the main sources of stress and that they often needed to change their living place to avoid the social stigma.

Previous studies also reported that family caregivers of psychiatric patients experience stigma, much like the sufferers themselves. As a result, they felt ashamed, isolated and guilty by these societal prejudices and in the caring process (Corrigan, 2004). In addition, other interviewed participants revealed that they were afraid of the impact such social stigma had on their family relatives. The impact of stigma is devastating, especially in those developing countries where the influence of collectivistic culture is prominent (Corrigan, 2004b; Fung, Tsang, & Corrigan, 2008). Interestingly, both PCs and published studies reported that this negative view was directed more towards female psychiatric patients as opposed to male psychiatric patients (S. Lee, 2002; Thara & Srinivasan, 2000). PCs who were interviewed also tended to conceal the fact that their relatives had a mental illness in order to prevent any stigma reaction.

Another form of stressor is situational, such as the deterioration of job status after being diagnosed with a mental illness, leading to grief and sorrow from the PCs. In terms of stress responses, PCs during interviews reported a wide range of ineffective physiological (physical illness) or psychological (sadness, worry, panic) responses. Similar results are also evident in the study of McAuliffe, O'Connor, and Meagher (2014), which explored the family caregivers' experience of caring for ill relatives diagnosed with schizophrenia. The study reported high levels of psychological distress among the family caregivers due to three main reasons: (1) having a lack of knowledge about their relative's illness; (2) realising that this led to a considerable change in their ill relative's life.

Moreover, during the qualitative interviews, PCs often referred to the different treatment modalities (herbal or religion faith) they had resorted to in order to avoid fear and worry from their friends and neighbours. This was also supported by Huang et al. (2009), who stated that family caregivers who had misinterpreted the causes of their relative's illness (schizophrenia) were seen to employ various help-seeking behaviours to cope with the illness, such as herbal medicine.

Another key finding in the present study that family caregivers support is linked with higher use of antipsychotic medication. They might be potentially explained by the fact that family caregivers may reinforce medication usage, setting a therapeutic circular chain of events involving medication usage and supportive transactions with loved ones. Notably, this finding of the present study is consistent with earlier study who found family caregivers behaviors are an effective method to increase medication compliance (Dean et al., 2011; Wilk et al., 2008). Our results are very match with prior research, where family is identified as most important resources for people living with mental illness. Families play an important role in providing care and support. Social support is recognized as one of the most important resources in coping with mental illness and compliance with medication (Fisher, Cornman, Norton et al., 2006; Kelly, McCarthy, & Sahn, 2014).

Family caregivers experience social stigma and exclusion from the community as it is reflected in the study as social isolation. This is consistent with Jordanian culture that social stigma prevails in interdependent society and it extends to people with mental illness as well as family members. One coping technique of the family relative to minimize stigma is that using alternative treatment approach or deny problem existence. The findings of this study are in line with those of who reported that in Arab culture the distinction between physical and psychological health is not widely common as has historically been prevalent in Western Cultures. Arab-Muslim literature reveals that Arab-Muslim do not distinguish emotional or psychological distress from physical illness and the majority of populations tend to somatize their illness in which mental ill patient expresses an emotional disorder in

the presentation of physical symptoms (Al-Krenawi, Graham, & Kandah, 2000c; Endrawes, O'Brien, & Wilkes, 2007; Fogel & Ford, 2005). This difficulty in recognizing between illnesses is further increased by the patients' tolerance of their symptoms and their family tolerance of their behavioral problems. Consequently, treatments for mental illness are often sought from traditional and spiritual healers to the exclusion of professional mental health services (Aloud & Rathur, 2009)

In contrast, the results of the interviews conducted in this study suggest that mental health care provider has both positive and negative role on compliance rate. These results are in agreement with those obtained by Chambers et al. (2011) and Henriques, Costa, and Cabrita (2012), who reported a positive impact of health care providers on medication compliance. This is attributed to the fact that this positive role derived from the scientific knowledge being provided by health care professional. However, participants in this study also noted a negative impact health care team. This differs from previous studies conducted in Western countries due to variation in infrastructure in mental health service as the number of psychiatrist and psychiatric nurses in Jordan are so limited in comparison with developed countries. Moreover, the cost of medication was seen as a barrier to medication compliance, especially those who do not cover by medication insurance. The present study results are in accordance with the findings of a recent study by Bajramovic, Emmerton, and Tett (2014) who highlighted that antipsychotic medication is very expensive which leads to noncompliance. Similarly, Orr et al. (2007) noted that cost of medication led to complete or partial noncompliance.

The findings from this study support the following recommendations to enhance compliance in patients suffering from schizophrenia (Puri, Hall, & Ho, 2013). First, mental health professionals need to increase caregiver's involvement and adapt the communication style to make the information more understandable. Second, mental health professionals need to understand the caregivers' perspectives and provide information to correct misconception. It is important to determine the type of non-compliance (e.g. intentional due to beliefs or unintentional due to practical difficulties). Finally, mental health professionals need to monitor non-compliance in a non-judgmental way.

4.1 Limitations of the Study

The limitations of the current review need to be acknowledged is that forward-backward translation process of interview is probable caused loss of the meaning and/or to have the trans-cultural effect bias. In addition, limited number of studies investigated this phenomenon, with the majority conducted in the USA, Canada and the UK. Ideally, transcript has to be returned and checked by interviewees to verify their completeness, accuracy and validity. However, time constraint was a factor restrict authors to return to participants which might affect the internal validity of this study.

5. Conclusion

There are a growing number of people with mental illness and number of family caregivers who care for ill relative in the community setting. Mental illness and antipsychotic medication is the major challenge to the family, patients and health system and community at broader level. So enhance our understanding about family caregivers experience towards antipsychotic medication enables them to provide adequate social and psychological support to ill relative and cope with illness symptoms.

Ethics Approval and Consent to Participate

The ethical approval was obtained from the Ministry of Health in Jordan. In addition, Consent form was sought from all the study participants.

Consent to Publish

I declare that all participants informed and consented such data are subjects for publication in psychiatry journal.

Availability of Data and Materials

Data are available and ready upon request. Data are kept with the research team

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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References

Al-Adawi, S., Dorvlo, A. S., Al-Ismaily, S. S., Al-Salmi, A., Burke, D. T., Shah, M. K., ... Chand, S. P. (2002).

- Perception of and attitude towards mental illness in Oman. *International journal of social psychiatry*, 48(4), 305-317. <https://doi.org/10.1177/002076402128783334>
- Al-Krenawi, A., Graham, J. R., & Kandah, J. (2000c). Gendered utilization differences of mental health services in Jordan. *Community mental health journal*, 36(5), 501-511. <https://doi.org/10.1023/A:1001963714338>
- Allen, S. M., Lima, J. C., Goldscheider, F. K., & Roy, J. (2012). Primary caregiver characteristics and transitions in community-based care. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 67(3), 362-371. <https://doi.org/10.1093/geronb/gbs032>
- Aloud, N., & Rathur, A. (2009). Factors affecting attitudes toward seeking and using formal mental health and psychological services among Arab Muslim populations. *Journal of Muslim Mental Health*, 4(2), 79-103. <https://doi.org/10.1080/15564900802487675>
- Arlt, S., Lindner, R., Rösler, A., & von Renteln-Kruse, W. (2008). Adherence to medication in patients with dementia. *Drugs & aging*, 25(12), 1033-1047. <https://doi.org/10.2165/0002512-200825120-00005>
- Bajramovic, J., Emmerton, L., & Tett, S. E. (2014). Perceptions around concordance—focus groups and semi-structured interviews conducted with consumers, pharmacists and general practitioners. *Health Expectations*, 7(3), 221-234. <https://doi.org/10.1111/j.1369-7625.2004.00280.x>
- Bebbington, P., & Kuipers, L. (1994). The predictive utility of expressed emotion in schizophrenia: an aggregate analysis. *Psychological medicine*, 24(03), 707-718. <https://doi.org/10.1017/S0033291700027860>
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Brodaty, H., & Green, A. (2002). Defining the role of the caregiver in Alzheimer's disease treatment. *Drugs & aging*, 19(12), 891-898. <https://doi.org/10.2165/00002512-200219120-00001>
- Butzlaff, R. L., & Hooley, J. M. (1998). Expressed emotion and psychiatric relapse: a meta-analysis. *Archives of general psychiatry*, 55(6), 547-552. <https://doi.org/10.1001/archpsyc.55.6.547>
- Chambers, J. A., O'Carroll, R. E., Hamilton, B., Johnston, M., Sudlow, C., & Dennis, M. (2011). Adherence to medication in stroke survivors: a qualitative comparison of low and high adherers. *British journal of health psychology*, 16(3), 592-609. <https://doi.org/10.1348/2044-8287.002000>
- Chan, S. W.-c., Yip, B., Tso, S., & Tam, W. (2009). Evaluation of a psychoeducation program for Chinese clients with schizophrenia and their family caregivers. *Patient Education & Counseling*, 75(1), 67-76. <https://doi.org/10.1016/j.pec.2008.08.028>
- Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist*, 59(7), 614. <https://doi.org/10.1037/0003-066X.59.7.614>
- Cotrell, V., Wild, K., & Bader, T. (2006). Medication management and adherence among cognitively impaired older adults. *Journal of Gerontological Social Work*, 47(3-4), 31-46. https://doi.org/10.1300/J083v47n03_03
- Dean, A. J., Wragg, J., Draper, J., & McDermott, B. M. (2011). Predictors of medication adherence in children receiving psychotropic medication. *Journal of paediatrics and child health*, 47(6), 350-355. <https://doi.org/10.1111/j.1440-1754.2010.01985.x>
- Endrawes, G., O'Brien, L., & Wilkes, L. (2007). Mental illness and Egyptian families. *International journal of mental health nursing*, 16(3), 178-187. <https://doi.org/10.1111/j.1447-0349.2007.00465.x>
- Erlen, J. A., Lingler, J., Sereika, S. M., Tamres, L. K., Happ, M. B., & Tang, F. (2013). Characterizing caregiver-mediated medication management in patients with memory loss. *Journal of Gerontological Nursing*, 39(4), 30-9. <https://doi.org/10.3928/00989134-20130220-91>
- Fenton, S., Blyler, R., & Heinssen, K. (1997). Determinants of medication compliance in schizophrenia: empirical and clinical findings. *Schizophrenia bulletin*, 23(4), 637-651. <https://doi.org/10.1093/schbul/23.4.637>
- Fisher, J. D., Cornman, D. H., Norton, W. E., & Fisher, W. A. (2006). Involving behavioral scientists, health care providers, and HIV-infected patients as collaborators in theory-based HIV prevention and antiretroviral adherence interventions. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 43, S10-S17. <https://doi.org/10.1097/01.qai.0000248335.90190.f9>
- Fogel, J., & Ford, D. E. (2005). Stigma beliefs of Asian Americans with depression in an internet sample.

- Canadian journal of psychiatry*, 50(8), 470. <https://doi.org/10.1177/070674370505000807>
- Fortinsky, R. H. (2001). Health care triads and dementia care: integrative framework and future directions. *Aging & Mental Health*, 5(sup1), 35-48. <https://doi.org/10.1080/713649999>
- Fung, K. M., Tsang, H. W., & Corrigan, P. W. (2008). Self-stigma of people with schizophrenia as predictor of their adherence to psychosocial treatment. *Psychiatric rehabilitation journal*, 32(2), 95. <https://doi.org/10.2975/32.2.2008.95.104>
- García, J. I. R., Chang, C. L., Young, J. S., López, S. R., & Jenkins, J. H. (2006). Family support predicts psychiatric medication usage among mexican american individuals with schizophrenia. *Social Psychiatry & Psychiatric Epidemiology*, 41(8), 624-631. <https://doi.org/10.1007/s00127-006-0069-8>
- Gearing, R. E., Schwalbe, C. S., Mackenzie, M. J., Brewer, K. B., Ibrahim, R. W., & Olimat, H. S., ...Al-Krenawi, A. (2013). Adaptation and translation of mental health interventions in middle eastern arab countries: A systematic review of barriers to and strategies for effective treatment implementation. *Int J Soc Psychiatry*, 59(7), 671-681. <https://doi.org/10.1177/0020764012452349>
- Green, J., & Thorogood, N. (2013). *Qualitative methods for health research*. Sage.
- Hasan, A. A., Callaghan, P., & Lymn, Jo. (2016). Qualitative Process Evaluation of a Psycho-educational Intervention Targeted at People Diagnosed with Schizophrenia and their Primary Caregivers in Jordan. *BMC psychiatry* (In press).
- Henriques, M. A., Costa, M. A., & Cabrita, J. (2012). Adherence and medication management by the elderly. *Journal of clinical nursing*, 21(21-22), 3096-3105. <https://doi.org/10.1111/j.1365-2702.2012.04144.x>
- Huang, X. Y., Hung, B. J., Sun, F. K., Lin, J. D., & Chen, C. C. (2009). The experiences of carers in Taiwanese culture who have long - term schizophrenia in their families: a phenomenological study. *Journal of psychiatric and mental health nursing*, 16(10), 874-883. <https://doi.org/10.1111/j.1365-2850.2009.01468.x>
- Kelly, M., McCarthy, S., & Sahm, L. J. (2014). Knowledge, attitudes and beliefs of patients and carers regarding medication adherence: a review of qualitative literature. *European journal of clinical pharmacology*, 70(12), 1423-1431. <https://doi.org/10.1007/s00228-014-1761-3>
- Kopelowicz, A., López, S. R., Zarate, R., O'Brien, M., Gordon, J., & Chang, C., & Gonzalez-Smith, V. (2006). Expressed emotion and family interactions in mexican americans with schizophrenia. *Journal of Nervous & Mental Disease*, 194(5), 330-334. <https://doi.org/10.1097/01.nmd.0000217880.36581.6b>
- Lacro, J. P., Dunn, L. B., Dolder, C. R., Leckband, S. G., & Jeste, D. V. (2002). Prevalence of and risk factors for medication nonadherence in patients with schizophrenia: a comprehensive review of recent literature. *The Journal of clinical psychiatry*, 63(10), 892-909. <https://doi.org/10.4088/JCP.v63n1007>
- Lee, H., Kane, I., Sereika, S. M., Cho, R. Y., & Jolley, C. J. (2011). Medication-taking behaviours in young adults with schizophrenia: a pilot study. *Journal of Psychiatric & Mental Health Nursing*, 18(5), 418-424. <https://doi.org/10.1111/j.1365-2850.2011.01689.x>
- Lee, S. (2002). The stigma of schizophrenia: a transcultural problem. *Current opinion in psychiatry*, 15(1), 37-41. <https://doi.org/10.1097/00001504-200201000-00007>
- Lehman, A. F., & Steinwachs, D. M. (1998). Translating research into practice: the Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations. *Schizophrenia Bulletin*, 24(1), 1-10. <https://doi.org/10.1093/oxfordjournals.schbul.a033302>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75): Sage.
- Macleod, S. H., Elliott, L., & Brown, R. (2011). What support can community mental health nurses deliver to carers of people diagnosed with schizophrenia? Findings from a review of the literature. *International journal of nursing studies*, 48(1), 100-120. <https://doi.org/10.1016/j.ijnurstu.2010.09.005>
- Matthes, J., & Albus, C. (2014). Improving Adherence With Medication. *Deutsches Aerzteblatt International*, 111(4).
- McAuliffe, R., O'Connor, L., & Meagher, D. (2014). Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study. *Journal of psychiatric and mental health nursing*, 21(2), 145-153. <https://doi.org/10.1111/jpm.12065>
- McCauley, C. O., McKenna, H., Keeney, S., & McLaughlin, D. F. (2015). Concept analysis of recovery in mental illness in young adulthood. *Journal of Psychiatric and Mental Health Nursing*, 22(8), 579-589.

<https://doi.org/10.1111/jpm.12245>

- Okasha, A. (1999). Mental health in the Middle East: an Egyptian perspective. *Clinical psychology review, 19*(8), 917-933. [https://doi.org/10.1016/S0272-7358\(99\)00003-3](https://doi.org/10.1016/S0272-7358(99)00003-3)
- Orr, A., Orr, D., Willis, S., Holmes, M., & Britton, P. (2007). Patient perceptions of factors influencing adherence to medication following kidney transplant. *Psychology, health & medicine, 12*(4), 509-517. <https://doi.org/10.1080/13548500701294556>
- Perkins, D. O. (2002). Predictors of Noncompliance in Patients With Schizophrenia [CME]. *The Journal of clinical psychiatry, 63*(12), 1121-1128. <https://doi.org/10.4088/JCP.v63n1206>
- Pitschelwalz, G., Leucht, S., Bäuml, J., Kissling, W., & Engel, R. R. (2001). The effect of family interventions on relapse and rehospitalization in schizophrenia—a meta-analysis. *Schizophrenia Bulletin, 27*(1), 73-92. <https://doi.org/10.1093/oxfordjournals.schbul.a006861>
- Puri, B., Hall, A., & Ho, R. (2013). *Revision notes in psychiatry*. CRC Press. <https://doi.org/10.1201/b13188>
- Reinhard, S. C., Levine, C., & Samis, S. (2012). *Home alone: Family caregivers providing complex chronic care*. AARP Public Policy Institute Washington, DC.
- Sharif, F., Shaygan, M., & Mani, A. (2012). Effect of a psycho-educational intervention for family members on caregiver burdens and psychiatric symptoms in patients with schizophrenia in Shiraz, Iran. *BMC psychiatry, 12*(1), 48. <https://doi.org/10.1186/1471-244X-12-48>
- Speziale, H. S., & Carpenter, D. R. (2011). *Qualitative research in nursing*. Lippincott Williams & Wilkins.
- Staring, A. B. P., Gaag, M. V. D., Duivenvoorden, H. J., Weiden, P. J., & Mulder, C. L. (2011). Why do schizophrenia patients who have poor insight still take antipsychotics? memory deficits as a moderators between adherence belief and behaviour. *Journal of Psychiatric Practice, 17*(5), 320-329. <https://doi.org/10.1097/01.pra.0000405362.95881.48>
- Stuart, G. W. (2014). *Principles and practice of psychiatric nursing*. Elsevier Health Sciences.
- Taj, F., Tanwir, M., Aly, Z., Khowajah, A.A, Tariq, A, Syed, F. K., ... Shahzada, K. (2008). Factors associated with non-adherence among psychiatric patients at a tertiary care hospital, Karachi, Pakistan: a questionnaire based cross-sectional study. *Journal of Pakistan Medical Association 58*, 432-436.
- Thara, R., & Srinivasan, T. (2000). How stigmatising is schizophrenia in India? *International journal of social psychiatry, 46*(2), 135-141. <https://doi.org/10.1177/002076400004600206>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care, 19*(6), 349-357. <https://doi.org/10.1093/intqhc/mzm042>
- Trotter, R. T. (2012). Qualitative research sample design and sample size: Resolving and unresolved issues and inferential imperatives. *Preventive medicine, 55*(5), 398-400. <https://doi.org/10.1016/j.ypmed.2012.07.003>
- Vervoort, S. C., Borleffs, J. C., Hoepelman, A. I., & Grypdonck, M. H. (2007). Adherence in antiretroviral therapy: a review of qualitative studies. *Aids, 21*(3), 271-281. <https://doi.org/10.1097/QAD.0b013e328011cb20>
- Vogel, D. L., Wade, N. G., & Haake, S. (2006). Measuring the self-stigma associated with seeking psychological help. *Journal of Counseling Psychology, 53*(3), 325. <https://doi.org/10.1037/0022-0167.53.3.325>
- Wilk, J. E., West, J. C., Marcus, S. C., Countis, L., Regier, D. A., & Olfson, M. (2008). Family contact and the management of medication non-adherence in schizophrenia. *Community Ment Health J, 44*(5), 377-380. <https://doi.org/10.1007/s10597-008-9139-6>
- World Health Organization. [WHO] (2011). *Mental Health System in Jordan*.
- World Health Organization. [WHO] (2012). *Alzheimer's disease International. Dementia: a public health priority*, 112.

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