A GROUNDED THEORY OF PERSONAL RECOVERY AMONG PEOPLE WITH MENTAL ILLNESS IN QATAR

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

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Abstract


Background. Personal recovery in mental illness refers to a person’s ongoing journey to find meaning in their life despite the limitations caused by mental illness. This concept arose through the published narratives of mental health service users in Western countries and has gained increasing popularity over the past three decades. Many national mental health strategies and services have incorporated a recovery-based approach into service planning and delivery. However, recovery is a personal journey and there is not a one-size-fits-all approach. Limited investigations of personal recovery in non-Western contexts reveals the importance of factors not commonly cited in the predominant recovery literature. Further examining recovery in non-Western contexts may increase the capacity of mental health services to support recovery for diverse service user populations. The aim of the main empirical study for this thesis was undertaken to develop a theoretical understanding of mental illness self-management in Qatar. Self-management was chosen over a more specific focus on personal recovery in order to expand the potential scope of participants’ concerns and to avoid forcing Western-centric concepts of personal recovery into the study.

Methods. The empirical study was conducted in Qatar between February 2016 and June 2017. Classic grounded theory was chosen to address the objectives. Recruitment occurred on inpatient psychiatric units and through word-of-mouth. In-depth, unstructured interviews were conducted in English or Arabic with service users who had a range of nationalities and psychiatric diagnoses. In total, 28 interviews were conducted with 21 service users. Constant comparison was used for analysis.

Results. Participants’ main concern was reciprocity membership; they wanted to feel a sense of belonging to a group of others and they wanted there to be reciprocity in those relationships. Reciprocity membership becomes balanced when an individual is satisfied with their contribution to the group, the acknowledgement from other group members, the expectations of the group, and their alignment with the values and interests of the group. This satisfaction is appraised by a sub-process called valuing. If reciprocity membership is appraised as being unsatisfactory or unbalanced, two sub-processes, managing relationships and positioning, are sometimes used to achieve or restore balance.

Conclusion. Knowledge created through work undertaken for this PhD provides new understanding of service users’ experiences of mental illness in an Arabic context. Further research is needed about the topic. However, the grounded theory of reciprocity membership provides a potential starting point that mental health professionals can use to support personal recovery.
Declaration

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I am forever grateful for the ongoing support from my student research assistants who volunteered many hours to help me recruit and interview participants, and then to transcribe/translate the data. Special mention to Icra Elwadia, Mona Saleem, Amna Ahmed, Eiman Ahmed, Shamsa Jama and Suad Nur for sticking with the project until the end. Our team would not have worked as effectively without the additional support and mentorship provided by Professor Annie Topping and Mr. Mohamoud Adam.

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Finally, I am extremely grateful that my family still loves me after all the ups and downs that comes with five years of PhD studies!
Personal statement

My first journey through a foreign culture began 20 years ago. I was leaving my home in Canada, after completing an undergraduate degree in psychology, to reunite with my future wife in Australia. Some aspects of the culture were different, but for the most part, things were similar. After spending a year in Australia, we moved back to Canada, with a two-month stopover in Thailand along the way.

My experience in Thailand was much different. After the initial excitement and romanticism wore off, I starting criticizing many aspects of everyday life because of the differences. Luckily, I was in the country long enough to develop some critical reflection on the differences between Thai and Western culture. And I learned a very important lesson: Just because people do things differently, it does not make them wrong, foolish, or uninformed. I discovered that there were important lessons to be learned in people’s differences.

After about six years of travelling back and forth between Canada and Australia, I decided to enrol in a Masters of Nursing program. My travels had re-kindled a long time interest in healthcare and Nursing seemed like a career that would give me the flexibility to work in diverse settings and the skills and knowledge to make a meaningful contribution to the communities where I would eventually work.

I had an interest in mental health before nursing school, which continued to develop throughout my studies. Experiencing the different ways in which people with mental illness perceive the world and react to the things around them was one of my most powerful learning experiences during my studies. This led me to a job as a staff nurse in a psychiatric hospital.

I found that hearing patients’ stories reminded me of travelling. Some of the stories were different from conventional views, but very real in the context of their experiences. My interest in patients’ stories helped me to understand that the hospital is just a small part of their lives.

I enjoyed my job as a psychiatric nurse, but I began looking for a new adventure. After two years, I took a job teaching nursing in Doha, Qatar. During my time in Qatar I have had the opportunity to teach a mental health clinical course each year. I noticed that while the people may be different, some of their experiences seemed essentially the same. Just like in Canada, mental illness makes it difficult for many people to manage their day-to-day lives.

I also believe that mental health services and treatments should not be dictated by people with formal training (i.e., professionals) and that the people who use these services should have a say in what is and what is not appropriate. As far as I know, this is a recent Western ideal, and did not seem to be happening in Doha. This gap in service development, combined with my interest in hearing others’ stories and experiencing new ideas led me to the topic of my PhD studies. The vast majority of the work for this thesis was completed during the five years I spent working in Qatar.
Use of the alternative format
This thesis is in the alternative format as I have included two published articles and one in progress article in the body of the thesis. This format has allowed me to develop publication skills under the guidance of my supervisors simultaneously as I worked on the thesis. It also means I will not have to rewrite sections of my thesis after completion in order to publish them in journals. The downside of using this format is the necessary overlap and repetition between traditional thesis sections and the included articles. I have tried to minimize this overlap as much as possible.

I have adhered to the University’s guidance on alternative format theses, namely the requirement that it represents a coherent original contribution to the literature. Chapter 1 begins with an introduction to the context of the study and the contribution it makes. This is followed by a background section composed of two published literature reviews. Chapter 2 describes and justifies the study methodology. Results are presented in Chapter 3 through a third article in journal format. Chapter 4 contains a discussion of key findings. Chapter 5 presents implications for research and service development and a conclusion.

As required, author contributions for the papers included in this study are described below:

Study 1 (published)

All authors made substantial contributions to the conception and design of this study. JH was responsible for article retrieval, study screening, data extraction and analysis, and manuscript preparation. SP and HW participated in study screening, data extraction and analysis, and critical review and revision of the manuscript.

Study 2 (published)

JH was responsible for the literature review and manuscript preparation. SP and HW were responsible for critical review and revision of the manuscript.

Study 3 (submitted)

JH was responsible for design of the study with feedback and guidance provided by HW and SP. JH led recruitment and data collection with frequent guidance provided
by HW and SP. HW and SP reviewed all study documents and provided revisions. JH conducted data analysis. HW and SP provided feedback during analysis. JH drafted the manuscript, which was revised by SP and HW.
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1.1 Introduction

This chapter provides background for the primary empirical study in the form of two published review articles. These articles contain the majority of content for the chapter but are followed with some additional discussion aimed at reviewing the context for the study, tying the articles together and explaining how both have informed the research objectives for the empirical study. The first article (1.2.1) is a scoping review of mental illness research in the Gulf Cooperation Council (GCC), a socio-politico-economic union of six Arab countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates). It synthesizes published literature about people’s experiences of mental illness in the region. The results of this review led to a second review (1.2.2) examining the concept of personal recovery in mental illness through an Arabic sociocultural lens. Subsequently, section 1.3 reviews some of the context that was discussed in the articles and adds additional information, section 1.4 explains my motivation for choosing mental illness in Qatar as a broad area to focus my PhD studies, section 1.5 clarifies my impetus for undertaking the literature reviews, section 1.6 summarizes the results of the reviews and links these to the development of the research aims for the empirical study, and section 1.7 outlines the unique contributions of this project to the body of knowledge.

1.2 Literature Reviews

This section contains the two published literature reviews that were conducted as part of the thesis.
1.2.1 Study 1 - Mental illness in the Gulf Cooperation Council: A scoping review
Mental illness research in the Gulf Cooperation Council: a scoping review

Jason E. Hickey1,2*, Steven Pryjmachuk2 and Heather Waterman3

Abstract

Rapid growth and development in recent decades has seen mental health and mental illness emerge as priority health concerns for the Gulf Cooperation Council (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, and the United Arab Emirates). As a result, mental health services in the region are being redefined and expanded. However, there is a paucity of local research to guide ongoing service development. Local research is important because service users’ experience of mental illness and mental health services are linked to their sociocultural context. In order for service development to be most effective, there is a need for increased understanding of the people who use these services. This article aims to review and synthesize mental health research from the Gulf Cooperation Council. It also seeks to identify gaps in the literature and suggest directions for future research. A scoping framework was used to conduct this review. To identify studies, database searches were undertaken, regional journals were hand-searched, and reference lists of included articles were examined. Empirical studies undertaken in the Gulf Cooperation Council that reported mental health service users’ experience of mental illness were included. Framework analysis was used to synthesize results. Fifty-five studies met inclusion criteria and the following themes were identified: service preferences, illness (symptomology, perceived cause, impact), and recovery (traditional healing, family support, religion). Gaps included contradictory findings related to the supportive role of the Arabic extended family and religion, under-representation of women in study samples, and limited attention on illness management outside of the hospital setting. From this review, it is clear that the sociocultural context in the region is linked to service users’ experience of mental illness. Future research that aims to fill the identified gaps and develop and test culturally appropriate interventions will aid practice and policy development in the region.

Keywords: Arabs, Mental disorders, Mental health, Mental health services, Middle East, Qatar, Scoping review

Background

The Gulf Cooperation Council (GCC) is a union of six Arabic states in the Persian Gulf, including Bahrain, Kuwait, Oman, Qatar, Saudi Arabia and the United Arab Emirates (UAE). These countries share many cultural, political, religious, economic, and geographical similarities [1]. The aim of the union is to promote regional development through coordination, cooperation and integration among member countries [2].

The GCC has benefited substantially in recent decades from large reserves of oil and natural gas. Qatar, for example, is a small, peninsular country that was once mainly utilized by coastal fishermen, pearl divers and nomadic Bedouin tribes [3]. Now, its capital city, Doha, is being transformed into an ultra-modern metropolis and the country has the highest GDP per capita in the world [4]. The UAE provides another example of rapid economic development; in less than 10 years it went from being one of the least developed countries in the world to a modern industrialized nation [5].

Islam is the foundation of cultural and social customs in the GCC [6]. It infuses nearly all aspects of life, from architecture, food choice, daily routine, social interactions, education, healthcare and more. Tolerance, hospitality and modesty are highly valued [7]. However, social customs also result in strict guidelines for what is considered appropriate behaviour in certain circumstances. For example, in Saudi Arabia, it is illegal to publicly practice any religion other than Islam, and women are required to wear a gown (i.e. Abaya) and headscarf in...
public [8]. In other Gulf countries, these rules are often relaxed for foreigners. However, social and cultural norms sometimes clash with ongoing modernization and the influx of foreign workers. Because of this, some feel that traditional values are being threatened [9].

The recent and rapid changes in the region and the pressures or strains that have been mentioned above have seen mental health and mental illness emerge as priority health concerns for all countries in the GCC. In Kuwait, mental health was identified as one of six strategic priorities through a consultation with WHO [10]. As part of this agenda, mental health services are being integrated into primary healthcare, and community and home-based services are being developed. Oman also acknowledges the need to scale-up mental health services, particularly by increasing the number of available beds, providing training for primary care workers, and implementing a school health program [11]. In Qatar, a National Mental Health Strategy was recently developed [12]. This strategy focuses on system-wide change to reduce stigma, improve treatment seeking, increase availability of resources, scale-up the workforce, provide services in a variety of locations, and develop standards and guidelines. Bahrain, Saudi Arabia and the UAE have also emphasized mental health as a national priority and service development is underway in these counties as well [13–15].

Research on mental illness from GCC countries suggests that sociocultural factors influence people’s experience of mental illness in the region. For example, causal attribution of mental illness to demons (Jinn) prompts people to seek traditional or religious healers frequently [16]; shame can cause families to impose social isolation on a sick family member [17]; extended family structures can promote increased levels of family support and housing [16]; and religious (Islamic) influences have been linked to non-Western presentations of illness [18]. Hence, for service planning to be most effective, it cannot necessarily rely on international best practices and evidence from other countries. However, it is widely acknowledged that there is limited local research available to guide contextually-appropriate development of mental health services in the region [11, 12].

The current article aims to systematically review and synthesize regional literature that reports service user perspectives on mental illness in GCC countries, identify major gaps in the literature, and suggest directions for future research. This information will facilitate the development of mental health services in the GCC. It will also provide information for mental health practitioners in non-GCC countries who provide services for Arabic people.

**Theoretical framework**

Arksey and O’Malley’s [19] framework was used to develop the review protocol. According to one of the most commonly cited definitions, a scoping study “aims to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available” ([20] as cited by [19], emphasis in original). Scoping studies tend to be inclusive of a range of research designs regardless of where the research sits on the ‘evidence hierarchy’ [21, 22] and seek to provide greater conceptual clarity [23].

Arksey and O’Malley [19] identify four possible reasons to conduct a scoping study: to examine the extent, range and nature of research activity; to determine the value of undertaking a full systematic review; to summarize and disseminate research findings; and to identify research gaps in the existing literature. Most reports on scoping studies tend to incorporate a combination of these objectives, and outcomes typically include identification of themes in the literature, gaps that have yet to be addressed, and tangible recommendations for practice and research [24–27]. These characteristics make a scoping study well-suited for the aims of the current review.

**Methods**

**Inclusion criteria**

Articles covering one or more of the following common or clinically relevant illnesses [28, 29] were included: mood disorders, alcohol and substance use disorders, schizophrenia, Alzheimer’s and other dementias, anxiety disorders, obsessive compulsive disorder (OCD), personality disorders, and phobias. Additionally, studies had to be empirical (i.e. based on observed and measured phenomena and deriving knowledge from actual experience rather than from theory or belief), published in English, and conducted in the GCC (Qatar, Saudi Arabia, Kuwait, Bahrain, the UAE, Oman). Only studies that reported subjective data from participants were included because the perspectives and lived experiences of service users are critical for informing a recovery-oriented understanding of mental illness. Subjective data was defined as opinions or experiences collected directly from participants. Articles not meeting these criteria were excluded from the review.

**Identifying relevant studies**

First, several databases (CINAHL, Anthropology Plus, MEDLINE, SocINDEX, PsycINFO, Embase, and NCBI PubMed) were searched. The following search string was developed with the assistance of a librarian: ((MM “Mental Health”) OR (MM “Mental Disorders +”) OR (MM “Mentally Ill Persons”)) AND (Cooperation Council for Arab states of the Gulf OR CCASG OR Gulf Cooperation Council OR GCC OR Qatar* OR Emirat* OR Abu Dhabi* OR Bahrain* OR Kuwait* OR Saudi Arabia* OR Oman*). Second, several regional journals (Arab Journal of Psychiatry, Eastern Mediterranean
Health Journal, Avicenna, Journal of Local and Global Health Science, Journal of Local and Global Health Perspectives, QScience Connect, and Qatar Medical Journal) were hand searched. Databases and regional journals were searched from inception to December 2013. Finally, reference lists of articles identified in the previous two strategies were searched.

**Study screening**

Figure 1 illustrates the study identification and screening process. The first author screened titles from the initial database results \( (n = 2449) \) and removed duplicates and irrelevant articles. Inclusion criteria were then applied to full abstracts for the remaining articles \( (n = 655) \) by the first author. The other two authors (SP, HW) each screened a 5% random sample of abstracts to ensure consistent application of inclusion criteria. Full papers for the articles that passed abstract screening \( (n = 80) \) were obtained and read in full by two authors. An additional 36 articles were excluded at this stage. Eleven articles were included from the hand search of regional journals and reference lists. Fifty-five articles were included in the final data analysis. Table 1 demonstrates how each of these 55 studies met the inclusion criteria.

**Data extraction**

The first author (JH) extracted data from all 55 articles using a structured extraction template. This template was developed and piloted by the review team. Two authors (SP, HW) each extracted data from half of the final set, meaning data was independently extracted from each article twice. The two extractions were compared and discrepancies resolved through group discussions between the three authors.

Data were extracted from each study under the following categories: general information (e.g. year, profession of primary author), methodology (e.g. design, study location), sample characteristics (e.g. gender, diagnosis), results (e.g. main outcome, subjective outcome), and discussion (e.g. limitations, conclusions). Strengths and weaknesses
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<td>Bahrain</td>
<td>Obsessive compulsive disorder</td>
<td>Characteristics of obsessions and compulsions</td>
</tr>
<tr>
<td>Suleiman et al. (2002) [45]</td>
<td>Cross-sectional</td>
<td>Bahrain</td>
<td>Depression</td>
<td>Symptomology</td>
</tr>
<tr>
<td>Al-Ansari et al. (1989) [51]</td>
<td>Cross-sectional</td>
<td>Kuwait</td>
<td>Schizophrenia</td>
<td>Characteristics of hallucinations and delusions</td>
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<tr>
<td>Al-Ansari &amp; Negrete (1990) [36]</td>
<td>Comparative cross-sectional</td>
<td>Kuwait</td>
<td>Alcohol abuse/dependence</td>
<td>Perception drinking patterns and associated impacts</td>
</tr>
<tr>
<td>Al-Kandari et al. (2001) [81]</td>
<td>Cross-sectional</td>
<td>Kuwait</td>
<td>Substance dependence</td>
<td>Reasons for initiating drug use</td>
</tr>
<tr>
<td>Al-Kandari et al. (2007) [37]</td>
<td>Cross-sectional</td>
<td>Kuwait</td>
<td>Substance dependence</td>
<td>Preferences for illicit drugs, craving/withdrawal patterns, related problems</td>
</tr>
<tr>
<td>Al-Saffar et al. (2008) [82]</td>
<td>RCT</td>
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<tr>
<td>Bilal (1988) [83]</td>
<td>Cross-sectional</td>
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<td>Substance abuse</td>
<td>Perceived problems</td>
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<tr>
<td>Bilal et al. (1987) [64]</td>
<td>Cross-sectional</td>
<td>Kuwait</td>
<td>Alcoholism</td>
<td>Reflections on illness</td>
</tr>
<tr>
<td>Bilal et al. (1987) [64]</td>
<td>Cross-sectional longitudinal</td>
<td>Kuwait</td>
<td>Alcohol dependence</td>
<td>Problems associated with drinking</td>
</tr>
<tr>
<td>Chaleby (1985) [57]</td>
<td>Cross-sectional, chart review</td>
<td>Kuwait</td>
<td>Mixed*</td>
<td>Perceptions that marriage was related to psychiatric disorder</td>
</tr>
<tr>
<td>Demerdash et al. (1981) [66]</td>
<td>Comparative cross-sectional</td>
<td>Kuwait</td>
<td>Substance abuse</td>
<td>Reasons for drinking, reasons for combining substances</td>
</tr>
<tr>
<td>El-Islam et al. (1988) [84]</td>
<td>Cross-sectional</td>
<td>Kuwait</td>
<td>Depression</td>
<td>Timing of onset and symptomology of hypochondriasis</td>
</tr>
<tr>
<td>El-Islam et al. (1988) [43]</td>
<td>Cross-sectional</td>
<td>Kuwait</td>
<td>Depression</td>
<td>Core depressive symptoms</td>
</tr>
<tr>
<td>Suleiman et al. (1989) [85]</td>
<td>Comparative cross-sectional</td>
<td>Kuwait</td>
<td>Mixed*</td>
<td>Reported negative life events</td>
</tr>
<tr>
<td>Suleiman et al. (1986) [47]</td>
<td>Cross-sectional</td>
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<td>Provoking factors for attempted suicide</td>
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<td>Zahid et al. (2010) [86]</td>
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<td>Satisfaction across nine life domains</td>
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<td>Zahid &amp; Ohaeri (2010) [53]</td>
<td>Cross-sectional</td>
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<td>Schizophrenia</td>
<td>Perceived caregiving burden</td>
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<tr>
<td>Zahid &amp; Ohaeri (2010) [87]</td>
<td>Qualitative interviews</td>
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<tr>
<td>Zahid &amp; Ohaeri (2013) [88]</td>
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<tr>
<td>Zahid et al. (2010) [89]</td>
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<tr>
<td>Zaidan et al. (2006) [42]</td>
<td>Cross-sectional</td>
<td>Oman</td>
<td>Alcohol abuse</td>
<td>Impact of alcohol abuse</td>
</tr>
<tr>
<td>Bener et al. (2013) [90]</td>
<td>Cross-sectional</td>
<td>Qatar</td>
<td>Mixed*</td>
<td>Reasons for non-compliance</td>
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Table 1: Inclusion data for all articles included in final review (Continued)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Design</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bener &amp; Ghuloum (2013)</td>
<td>Cross-sectional</td>
<td>Qatar</td>
<td>Mixed*</td>
<td>Satisfaction with psychiatric consultation, important topics to include in consultation</td>
</tr>
<tr>
<td>El-Islam (1994)</td>
<td>Cross-sectional</td>
<td>Qatar</td>
<td>Mixed*</td>
<td>Phenomenology of various phobias, perceived cause of illness</td>
</tr>
<tr>
<td>Ghuloum et al. (2010)</td>
<td>Prospective cross-sectional</td>
<td>Qatar</td>
<td>Mixed*</td>
<td>Satisfaction with psychiatric consultation</td>
</tr>
<tr>
<td>Chaleby (1986)</td>
<td>Retrospective</td>
<td>Saudi Arabia</td>
<td>Alcohol/substance abuse</td>
<td>Frequency of stressors</td>
</tr>
<tr>
<td>Chaleby &amp; Raslan (1990)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Social phobia</td>
<td>Perceptions of childhood, parents, work environment</td>
</tr>
<tr>
<td>Shahin &amp; Daly (1999)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Mixed*</td>
<td>Knowledge, attitudes and beliefs about psychiatric medications</td>
</tr>
<tr>
<td>Abalkhail (2001)</td>
<td>Prospective, comparison group</td>
<td>Saudi Arabia</td>
<td>Substance dependence</td>
<td>Symptoms experienced during detox</td>
</tr>
<tr>
<td>Al Sughayir (2000)</td>
<td>Case-control</td>
<td>Saudi Arabia</td>
<td>Mixed*</td>
<td>Possession beliefs</td>
</tr>
<tr>
<td>Al-Habeeb et al. (2013)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Depression</td>
<td>Components of suicidal ideation, frequency/duration of suicidal ideation, control over suicidal thoughts, reasons and deterrents for attempting suicide</td>
</tr>
<tr>
<td>Alshowkan et al. (2013)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Schizophrenia</td>
<td>Perceived quality of life</td>
</tr>
<tr>
<td>Al-Solaim &amp; Loewenthal (2011)</td>
<td>Qualitative interviews</td>
<td>Saudi Arabia</td>
<td>Obsessive compulsive disorder</td>
<td>Encounters with traditional healers, supernatural beliefs, impact of religion, impact of illness</td>
</tr>
<tr>
<td>Al-Subaie (1994)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Mixed*</td>
<td>Perceived outcome of traditional healing</td>
</tr>
<tr>
<td>Chaleby (1988)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Mixed*</td>
<td>Factors perceived to be associated with marital discord</td>
</tr>
<tr>
<td>Qureshi (1992)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Substance abuse</td>
<td>Reasons for using, symptoms associated with craving, methods to obtain drug</td>
</tr>
<tr>
<td>Qureshi et al. (1998)</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Mixed*</td>
<td>Reasons for seeking, and perceived outcomes of, traditional healing</td>
</tr>
</tbody>
</table>
Table 1 Inclusion data for all articles included in final review (Continued)

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Location</th>
<th>Condition</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zarrouk (1975) [54]</td>
<td>Cross-sectional</td>
<td>Saudi Arabia</td>
<td>Schizophrenia</td>
<td>Characteristics of hallucinations</td>
</tr>
<tr>
<td>Al Zarrad &amp; Abu-Mugaiseeb (2002) [100]</td>
<td>Prospective</td>
<td>UAE</td>
<td>Mixed&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Attitudes and satisfaction towards service</td>
</tr>
<tr>
<td>Amin &amp; Hamdi (1995) [32]</td>
<td>Retrospective chart review, prospective follow-up</td>
<td>UAE</td>
<td>Mixed&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Symptomology</td>
</tr>
<tr>
<td>Daradkeh &amp; Karim (1994) [60]</td>
<td>Cross-sectional</td>
<td>UAE</td>
<td>Schizophrenia</td>
<td>Negative impacts of illness</td>
</tr>
<tr>
<td>Hamdi et al. (1997) [44]</td>
<td>Cross-sectional</td>
<td>UAE</td>
<td>Depression</td>
<td>Characteristics of depressive symptomology</td>
</tr>
<tr>
<td>Salem et al. (2009) [33]</td>
<td>Cross-sectional</td>
<td>UAE</td>
<td>Mixed&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Outcomes after consultation with traditional healer, perceived cause of illness</td>
</tr>
</tbody>
</table>

<sup>a</sup>Includes one or more targeted disorders
of individual studies were assessed and recorded during the extraction process.

Data analysis
Descriptive statistics were compiled to illustrate the “extent, nature and distribution” [19] of the literature identified. A thematic analysis of the subjective data was also conducted. The purpose of this analysis was to identify and elaborate on the main concepts addressed by the literature. One of the main criticisms of scoping studies is that there is a lack of transparency and rigour in synthesizing and presenting thematic results. Framework analysis [30] was chosen as an analytic approach in order to address these issues.

Framework analysis proceeds through a series of logical steps to reach a narrative summary of the results. Data extraction forms were read and re-reread to increase familiarity, then codes were applied to identify key concepts within the data. Once all extraction forms had been coded, the initial codes were reviewed and revised to create a conceptual framework. The conceptual framework was then applied back to the extraction form to assess its fit. When the extraction forms had been recoded according to the conceptual framework, the data was entered into a matrix where results could be examined across themes (columns) or article (rows). The majority of analysis was conducted by one author (JH). However, initial codes and a draft of the conceptual framework was reviewed and discussed by the entire team, and the matrix was reviewed to ensure logic and consistency.

Results
Figure 2 displays the publication timeline. The oldest included study was published in 1975 and there are three notable peaks in publication frequency in 1988, 2001–2002, and 2010–2013. There is an upward trend in publications over the entire period.

The greatest number of studies were conducted in Saudi Arabia ($n = 21, 38\%$) followed by Kuwait ($n = 18, 33\%$). Five studies (9\%) were conducted in each of Qatar, Bahrain and the UAE. One study (2\%) was conducted in Oman.

Psychiatrists acted as first author on the majority of publications ($n = 39, 70\%$) followed by researchers from medicine (specialty unspecified) and nursing, who authored four papers each (7\%). Professions of other first authors included epidemiology ($n = 2, 4\%$), psychology ($n = 2, 4\%$), the behavioural sciences ($n = 1, 2\%$), and pharmacy ($n = 1, 2\%$). The profession of the primary author was unspecified in two cases.

Figure 3 displays which diagnoses were investigated. The most common target was a mixed sample ($n = 16, 28\%$), comprising individuals with a range of diagnoses. This was followed by studies examining exclusively schizophrenia ($n = 14, 25\%$) and alcohol or substance use disorders ($n = 13, 23\%$). None of the included articles targeted Alzheimer’s or other dementias.

Table 2 displays sample size by gender and diagnosis. Overall, males outnumber females by a ratio of 2.2 to 1. The largest gender imbalance occurred for alcohol or substance use disorders where males outnumbered females by a ratio of 72.6 to 1. The only disorder where females were over represented was OCD, where females outnumbered males by a ratio of 2.6 to 1.

The vast majority of studies ($n = 42, 84\%$) recruited participants from public psychiatric treatment centres. Of these, half recruited from inpatient or detox units, while half recruited from outpatient departments. Two studies (4\%) recruited from private clinics, and only one study (2\%) recruited participants from the community. Twelve studies (24\%) were unclear about recruitment location.

Several themes and sub-themes emerged during analysis, including service preferences, illness (perceived cause, symptomology, impact), and recovery (traditional healing, family support, religion). The following section, which

![Publication Timeline](image-url)
critically synthesizes the results of this review, is organized according to these themes and sub-themes.

**Service preferences**

Gender seemed to influence service preferences in several studies. For example, Bener and Ghuloum [31] found that patient gender affected the type of topics seen as most important when receiving treatment from a psychiatrist. In that study, males viewed discussions with a doctor about treatment options as being most important, while females prioritized explanations of the condition and the underlying cause. Surveyed preferences were limited to interactions with a psychiatrist; thus, it is not possible to determine preferences across other professional groups. Additionally, the results were collected using a brief questionnaire, which limited choices and did not explore the underlying reasons for observed differences. However, the study suggests that gender is an important consideration for service delivery in this region.

The importance of gender is reinforced by Amin and Hamdi [32], who found gender to have an influence on where participants preferred to seek treatment. The authors found that females in need of psychiatric care tend to present at the emergency department, while males were more often seen in the outpatient department. Amin and Hamdi [32] suggest several reasons for their observed difference but these were conjecture and not grounded in the results. Additionally, this study is now 20 years old and with the recent modernization in the region, results may no longer be accurate. Thus, there has been no recent research to examine service users’ preferences across a range of services within the healthcare system.

Other studies, however, have demonstrated a preference for services outside of the healthcare system. Salem et al. [33] found that nearly half of the sample went to a faith healer prior to seeking psychiatric care. The majority of these participants continued to see a faith healer even after engaging with psychiatric services. Because convenience sampling was used in this study it is difficult to generalize results to the wider population. However, the participants originated from various countries in the Gulf region, had a range of diagnoses, and included nearly equal proportions of men and women. This diverse sample adds to the generalizability of the study. The author concludes that mental health professionals need to be aware of patient preferences for traditional healing and understand the reasons why they sometimes refuse medical treatment.

A comparable study conducted by Al-Solaim and Loewenthal [34] in Saudi Arabia demonstrated that psychiatric services seem to be seen as a last resort when other options (e.g. faith healers) are not successful. This reinforces Salem et al.’s [33] argument that mental health professionals should not ignore the contribution of traditional healers to service users’ treatment. However, Al-Solaim and Loewenthal’s [34] results are drawn solely from the experiences of 15 women. It is possible that they may not represent the majority view. Men, in particular, as demonstrated earlier, may have different preferences.

**Illness: symptomology**

Symptomology was one of the most commonly occurring themes in the included articles. Clinical presentation of mental illness was described for alcohol and

<table>
<thead>
<tr>
<th>Diagnosis of Interest</th>
<th>Male</th>
<th>Female</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol or substance use disorders</td>
<td>1452</td>
<td>20</td>
<td>72.6 to 1</td>
</tr>
<tr>
<td>Depression</td>
<td>668</td>
<td>263</td>
<td>2.5 to 1</td>
</tr>
<tr>
<td>Obsessive compulsive disorder</td>
<td>27</td>
<td>70</td>
<td>1 to 2.6</td>
</tr>
<tr>
<td>Phobias/anxiety disorder</td>
<td>165</td>
<td>65</td>
<td>2.5 to 1</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>1111</td>
<td>413</td>
<td>2.7 to 1</td>
</tr>
<tr>
<td>Mixed sample</td>
<td>2704</td>
<td>1958</td>
<td>1.4 to 1</td>
</tr>
<tr>
<td>Total</td>
<td>6127</td>
<td>2789</td>
<td>2.2 to 1</td>
</tr>
</tbody>
</table>
substance abuse [35–42], depression [32, 43–45], suicide [46, 47], panic disorder [48], OCD [34, 49, 50], schizophrenia [51–55], smoking behaviour [56], and hypochondriasis [18]. Several of these articles emphasized the unique presentation of certain illness within the Arab context.

For example, Shooka et al. [50] demonstrated that religious and blasphemous thoughts were the most common obsessions in patients with OCD, while repeated prayer-related cleaning and washing was the most common compulsion. The authors suggest that there are higher levels of religious content in participants from a strict religious context. These findings were reinforced by Mahgoub and Abdel-Hafeiz [49], who found an Islamic focus for obsessions and compulsions in OCD. In particular, prayer and body washing were the most common obsessions and religious repeating and religious washing were the most common compulsions. Both these studies are quite old; however, the Islamic influence on symptomology was also apparent in Al-Solaim and Loewenthal’s [34] more recent study on OCD. An additional finding in this more recent study was that symptoms in the religious domain were the most disturbing for patients and their families. Despite their limitations, these studies suggest that the content and focus of OCD symptoms are culturally influenced.

Research on other disorders has also demonstrated a contextual influence. For example, a study by Kent and Wahass [52] on schizophrenia in Saudi Arabia found that hallucinations had more religious and superstitious content compared to a sample from the United Kingdom. Zarrouk [55] found that delusions also differed from non-Arabic samples, with Saudi patients more frequently believing they were being ‘made’ to do things. In a study on depression by Hamdi et al. [44], four main types of symptom variation (compared to non-Arabic studies) were identified, namely variations in idioms (e.g. heavy/tense vs. depressed/sad), use of somatic metaphors (e.g. ‘my body is shattered’), influence of religion (e.g. denying acts considered haraam/forbidden), and behavioural alterations (e.g. going into desert to stare at nothing). Several of these variations clearly reflect the local context.

Taken together, these articles demonstrate a contextual influence on symptomology in the GCC. It should be noted that religion is also associated with symptoms in non-Arabic contexts. However, the religious content of symptoms in this review are clearly shaped by the Islamic context. This finding has appeared repeatedly over a considerable period of time (1978–2011), which suggests that this is a somewhat stable phenomenon. Many of these authors reasonably suggest that an understanding of local variations in clinical presentation is important for accurate diagnosis and treatment of service users.

Illness: perceived cause

The perceived cause of mental illness was often external. For example, participants with a diagnosis of nosophobia attributed the cause to over-investigation of minor complaints by physicians [48]. Similarly, over one-third of women in polygamous marriages attributed their illness to their marriage [57], the majority of caregivers attributed the cause of illness to social stressors [58], and those with thoughts of self-harm attributed these thoughts to the devil [48]. Taken individually, the design weaknesses (e.g. convenience sample, bias, cross-sectional design) in these articles prevent reliable conclusions from being made. However, the consistent external causal attribution across studies lends credibility to the findings.

One particular class of perceived external cause, the supernatural (e.g. black magic, jinn, evil eye), seems particularly common. For example, Salem et al. [33] found that about one-third of participants attributed their illness to supernatural factors, while one-third attributed them to psychiatric problems and one-third were unsure. Similarly, Al-Solaim and Loewenthal [34] and Al-Sughayir [59] found that the majority of patients attributed their illness to possession by jinn (i.e. evil spirits). This external attribution to supernatural forces can be protective as certain symptoms may not be as stigmatized and may not produce such strong feelings of guilt [34, 48]. In fact, those with the evil eye may see themselves as having some positive attribute worthy of envy, which boosts their self-esteem [34]. Again, there are design weaknesses (e.g. bias, unrepresentative samples), but the consistent findings on supernatural attribution warrant further, more rigorous investigation.

Illness: perceived impact

Most of the data under this theme come from studies on alcohol and substance abuse, which limits applicability to people with other diagnoses. Additionally, there was a certain amount of heterogeneity in impact outcomes. For example, Al-Ansari and Negrete [36] surveyed people undergoing treatment for alcohol abuse. Participants felt guilty about drinking, that it caused their family/friends to worry about them, that it sometimes created interpersonal problems, and caused them to neglect personal responsibilities. In contrast, Zaidan et al. [42] found that the majority of their sample never felt guilty about their drinking. Based on the information presented, the samples in the two studies seem comparable, aside from country of residence. Hence, the reasons for the observed differences are unexplained. Additionally, both studies enrolled males only and therefore results are further limited.

Daradkeh and Karim [60] and Al-Solaim and Loewenthal [34] offer limited information on illness impact among people with schizophrenia and OCD, respectively. These included barriers to social inclusion (schizophrenia) and
interpersonal problems with family members (schizophrenia and OCD). However, the small sample size used in these studies means that further investigation is needed before reliable conclusions can be made.

Another major limitation in the majority of the studies on alcohol and substance abuse is their almost exclusive reliance on questionnaires to collect data. This limits the depth and richness of information collected and prevents participants from sharing relevant information that is not covered on the questionnaire. Thus, despite the relatively large number of studies on this topic, understanding remains limited.

**Recovery: traditional healing**

As mentioned above, a large proportion of psychiatric patients visit a traditional healer prior to seeking medical help [32–34, 58, 61]. This practice was perceived to contribute to recovery in a variety of ways. However, there were mixed perceptions on the effectiveness of traditional treatment.

Qureshi et al. [62] found that some participants with depressive or catatonic symptoms reported a temporary improvement from traditional treatment but that most were unsatisfied. Similarly, Salem et al. [33] found that about half of participants with a range of diagnoses experienced only a temporary benefit, with others experiencing no benefit at all. Both studies interpreted ‘benefit’ as a reduction in symptoms.

While most authors exploring the effectiveness of traditional healing seem to assume that symptom reduction is of primary importance, this may not necessarily be the case for service users. For example, Al-Subaie [61] found that, even those who did not perceive their symptoms to be reduced, reported feeling that God would reward them for having faith in traditional healing methods, which are primarily based on religious beliefs. This finding suggests that service users may place value on treatment benefits other than a reduction of symptoms. However, these other potential benefits are largely ignored in the studies reviewed, as is the relative importance of various benefits to participants.

A further limitation in the studies included in this section is selection bias. Since participants were selected from the population of people seeking psychiatric treatment, it is possible that others received longer lasting benefit from traditional treatments and did not subsequently access services. A broader sampling strategy (e.g. including people with mental illness who do not make regular use of psychiatric services) would be necessary for a more accurate investigation.

**Recovery: religion**

Committing acts that were incongruent with the teachings of Islam led to feelings of guilt and lower self-esteem [34, 48]. The more compliant a person was with the values of their faith, the more pride they felt [34]. However, compulsive religious acts relating to mental illness sometimes interfered with daily life and led to treatment seeking. Religion, however, particularly prayer, was still seen as one of the main ways to cope with mental illness and related stress. For example, being religious was associated with lower levels of death anxiety [39] and alcohol abuse [64, 66].

The majority of the studies included in this section incorporated religion as a minor variable that was a small part of a larger study. Thus, a systematic, in-depth investigation of religion has not been undertaken. Despite a lack of direct evidence, many of the reviewed studies argued that religion had an impact on certain aspects of participants’ illness, including symptomology (e.g. [43]), treatment seeking (e.g. [37]), etc. However, these claims and their underlying assumptions are currently unsubstantiated by the literature. In other words, broad assumptions were sometimes made, based solely on the

**Recovery: family support**

The extended nature of the Gulf Arab family was frequently addressed as being a source of support for service users. Potential supportive roles of the family in one study included medication supervision, being tolerant of short periods of withdrawal, helping to find acceptable ways to describe and understand the illness, not expecting anything in return for their help, and assistance in filling leisure time [63]. While these caregiving themes make sense intuitively, the author introduces subjectivity and bias into the analysis and does not consider alternate or contradictory views. Additionally, the study was conducted over 20 years ago and no similar studies have been conducted to support or refute the author’s findings. It is also possible that the supportive role of families has changed in the ensuing period of rapid socioeconomic development.

Studies also suggested that support is more common in extended families compared to nuclear families and that those living in extended families had more social contact, better personal hygiene, less active symptoms, and better treatment outcomes [63, 64]. Conversely, the extended family was also perceived to have a negative impact; tension or stress within the family were cited as reasons for substance abuse [65] and attempted suicide [47], and were associated with higher disease severity [53]. Unfortunately, only the study by Zahid and Ohaeri [53] was recent enough to consider these influences within a modern context, and even this study did not examine the issue in depth. Hence, while it seems likely that the family plays a role in service users’ recovery from mental illness, the nature of this role in a modern context remains unclear.
authors’ own personal beliefs or professional understanding about the value of religion. Thus, while it seems likely that religion plays a role, it is difficult to objectively interpret the impact of religion based on the literature included in this review.

Discussion
This systematic scoping review was undertaken in order to synthesize regional literature on service users’ experience of mental illness, identify gaps in the literature, and identify opportunities for future research; 55 articles were included in the review.

The included studies offer a small glimpse into service preferences, including a preference for initial consultations with faith healers. The use of faith healers to treat mental illness has also been documented in other developing countries. For example, a study conducted in rural India reported that faith healing is widely used and that many people seek traditional services before medical psychiatric services [67]. Services of faith healers are also commonly used in Ghana. This is because traditional healers offer more culturally appropriate models of understanding illness, higher levels of psychosocial support, and easier accessibility [68]. A study in Zimbabwe found that three quarters of people sought both traditional and medical treatment for mental illness; however, in this study, biomedical care providers were the most common point of first contact [69].

The frequent use of traditional healers has implications for government-run psychiatric services. The title of the article by Ae-Ngibise et al. [68] summarizes these implications quite well: ‘Whether you like it or not, people with mental health problems are going to go to them [faith healers]’. While some collaboration currently occurs in Qatar, ongoing service development efforts should aim to identify opportunities to incorporate safe, appropriate traditional healing as part of a comprehensive service.

External stressors, particularly the supernatural (i.e. jinn, black magic, evil eye) were frequently seen as the root cause of mental illness. This indicates a need to address cultural beliefs and social factors when treating mental illness. A recently published review found that psychiatric symptoms are commonly attributed to the supernatural among Muslims worldwide [70]. The authors claim that this external attribution has diagnostic and treatment implications. For example, biomedical treatment may not be accepted if underlying cultural beliefs about the supernatural are not addressed [71]. Therefore, practitioners should foster an awareness of traditional beliefs and be open to incorporating these as part of the therapeutic process.

Symptomology was described for most major mental illnesses and several similarities and differences were identified compared to typical presentations in the West. Variations in presentation of mental illness across cultures has been widely reported and debated in the literature [72]. Variations create difficulties in applying standard diagnostic criteria such as the DSM-5 or the ICD-10 in cultural contexts that differ from the West. This provides fuel for an argument that the dichotomous nature of diagnostic categories are unhelpful in the treatment of people with mental health issues [73, 74]. Unlike physical illness, mental illness is predominantly subjective (i.e. unmeasurable); interpretation and explanation of symptoms by the patient is influenced by sociocultural understanding [75, 76]. Attending to a person’s subjective experience of their illness and the overall impact of the illness on their life can lead to a more holistic understanding of the patient and better treatment outcomes [77]. It is worth noting that this practice aligns well with recovery-oriented care.

Other sociodemographic and sociocultural factors, such as family support, marriage, religion, education, financial status, gender, birth order, and nationality/ethnicity, were also investigated. However, the relationship of these factors to mental illness was difficult to assess due to limited data and weaknesses of the included studies. These areas provide fertile ground for future research.

The articles included in this review add important, contextually-relevant data to our understanding of mental illness in the region. However, despite nearly 40 years of research addressing the impact of sociocultural factors on people’s experiences of mental illness, a limited understanding of these issues remain. For example, the Arab extended family is widely acknowledged in having a key supportive role for those with mental illness. However, it has also been reported as a source of stress and conflict. Religion influences all aspects of life in Arab society and provides a source of strength and support for people with mental illness. However, forbidden acts, such as alcohol and substance abuse and suicide, still occur, and cause guilt and worry for patients and their families. Widespread belief in the influence of the supernatural on mental illness has been documented. These beliefs fall within the scope of modern mental health practice, but there is little evidence of how they can be incorporated successfully into a contextually-relevant model of psychiatric care and recovery. Research into the interplay between psychiatry and traditional healing is also lacking; service users place value on consultation with faith healers, but it is unclear how these services might be incorporated into a cohesive system of mental health service in the region, or even if they should be incorporated. The concept of stigma is conspicuously absent from the articles and little effort has gone into measuring or describing stigma towards mental illness in the GCC. Also absent from the literature are investigations into service users’ self-management of their
illness. Most service users spend the majority of their lives outside of the healthcare system. Yet, virtually nothing is known about the strategies and resources they use to minimize the day-to-day challenges of mental illness.

**Strengths and limitations**

This review is the first of its kind to be conducted in the Gulf region. Two other reviews of mental health research have been published [78, 79]. However, the scope of these reviews is limited to the frequency, distribution and topics of publications. This review is the first to synthesize the results of research on mental illness in this region. Additionally, the systematic approach undertaken for this review facilitated a relatively objective synthesis that was rigorously conducted. Finally, the use of Framework Analysis overcomes a major criticism of scoping studies by providing a transparent method of analysis where thematic results can be clearly linked to individual studies.

This review is limited by the general weaknesses in the body of literature. For example, most of the research included in this review seems to be unfunded. This implies that proposals may not have been subjected to peer review. While lack of funding does not necessarily imply low quality, many of the papers reviewed here would have benefitted from additional peer review during the planning stage. Increasing the funding available for mental health research could help to improve the overall quality of the research (e.g. through the scientific review process) and guide the focus of future research to ensure it is ethically sound and relevant for the development of practice and policy.

The evidence base consists primarily of cross-sectional studies aimed at developing foundational knowledge. This type of evidence does not allow for causal inferences to be made and only provides a snapshot of a phenomenon at one point in time. This means that the relationships between sociodemographic factors and illness experiences are still not well understood. Longitudinal research would help to increase understanding of illness trajectory outside of the hospital setting, while interventional research would help to improve the transformation of knowledge into practice. Additionally, the vast majority of included research was quantitative, meaning that results of the review lack depth. Incorporating more qualitative research has the potential to clarify important issues, help to develop a better understanding of service users’ perspectives, and build contextually relevant mental health theory that can be applied and tested through subsequent research. Qualitative research would also facilitate development of contextually valid measurement scales and questionnaires.

Underrepresentation of women in the studies highlights the need to look beyond convenience samples in psychiatric research at ways of identifying more representative samples. The gender imbalance implies that review findings are more relevant to the male psychiatric population. Finally, very few studies include family members or caregivers, even though most acknowledge the contribution of social support to recovery. Thus, understanding of caregivers’ potentially supportive role in the region remains limited.

**Conclusion**

Despite the limitations of the reviewed literature, we can conclude that the sociocultural context in the Gulf region is linked to people’s experience of mental illness. However, service users’ perceptions and understandings about the nature of the context-illness experience relationship have not been systematically explored. This is particularly true for the process of self-management of illness outside the hospital setting. Interventions that are developed based on this limited understanding may have limited effectiveness and acceptability. While many questions can be derived from the identified knowledge gaps, two seem prominent:

1. What strategies do service users in Arabic countries use to self-manage their mental illness outside of the hospital setting?
2. What treatments and interventions would be most effective and acceptable to support this self-management?

Future research that attempts to address these two questions will increase the capacity of Arabic mental health services to provide efficient and culturally appropriate support to service users.

**Authors’ contributions**

All authors made substantial contributions to the conception and design of this study. JH was responsible for article retrieval, study screening, data extraction and analysis, and manuscript preparation. SP and HW participated in study screening, data extraction and analysis, and critical review and revision of the manuscript. All authors read and reviewed the final manuscript.

**Authors’ information**

JH has been working as a Nursing Instructor in Qatar since 2012. His research focuses on service users’ self-management of mental illness in the Middle East. This article was undertaken as a part of JH’s PhD studies at the University of Manchester.

**Competing interests**

The authors declare that they have no competing interests.

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1.2.2 Study 2 - Exploring personal recovery in mental illness through an Arabic sociocultural lens
Essays and Debates in Mental Health

Exploring personal recovery in mental illness through an Arabic sociocultural lens

Introduction

Arabic culture in the Gulf region (i.e. Qatar, Kuwait, Saudi Arabia, Bahrain, Oman) is characterized by traditional values and beliefs. Islam guides nearly every aspect of life for the majority Muslim population. At the same time, development and globalization in the Gulf region is occurring at such a rapid pace that traditional values are under threat (Teller 2014). This situation sometimes creates tension between various stakeholders regarding what is understood to be good practice (Al-Subaiey 2010).

One example where the potential for tension exists can be found in the concept of personal recovery in mental illness. During the last three decades, personal recovery has become generally understood as an ongoing process that emphasizes hope, identity, meaning and personal responsibility (Ralph et al. 2002, Spaniol et al. 2002, Andresen et al. 2003). However, this understanding has been developed primarily in Western countries, and it is likely that it has inherent Western values that may not be appropriate in non-Western settings.

In the following sections, we discuss definitions of personal recovery, examine selected Western and non-Western recovery models, and debate the potential fit of recovery-oriented services in a traditional Arabic context.

It should be noted that the evidence available to support our discussion is generally low level and based mainly on authors’ descriptions and opinions of recovery. Moreover, since the authors are Western health professionals, the viewpoint on Arabic culture is from an outsider looking in (Merton 1972).

Empirical concepts and models of personal recovery

Anthony (1993) developed one of the first models of personal recovery in mental illness. He based this model on a recovery vision: ‘any person with severe mental illness can grow beyond the limits (Davidson et al. 2005a,b). However, while full recovery is possible in many cases, there are those whose symptoms will persist throughout their lives (Lacro et al. 2002, McEvoy et al. 2006, Chapman & Horne 2013). Thus, a goal of clinical recovery is neither adequate nor appropriate for many people with a diagnosis of mental illness (Slade 2009).

Pioneering accounts from service users in English-speaking countries have resulted in an alternate conception of recovery in mental illness, that of personal recovery (Houghton 1982, Lovejoy 1982, Leete 1987, Deegan 1988, Unzicker 1989). These accounts describe the ongoing impact of mental illness outside of the hospital setting and share insights on how to overcome or mitigate day-to-day challenges.

The goal of personal recovery is for the individual to learn to live well within the limitations of symptoms, rather than trying to eliminate the symptoms (Anthony 1993). However, despite a general consensus on the potential value of a recovery approach to services, considerable debate exists as to the nature and universality of the concept of personal recovery.

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imposed by his or her illness’ (Anthony 1993, p. 9). At that time, Anthony (1993) suggested a potential framework, but also put forward a call to develop empirically based models of personal recovery.

This call has been taken up by many in the field, resulting in the development of numerous concepts, models, and frameworks over the ensuing decades. Some of these are outlined in the following paragraphs. We do not attempt a comprehensive review of recovery models. This information can be found elsewhere (Leamy et al. 2011, Slade et al. 2012). Instead we will discuss select exemplars to highlight the similarities and differences between the models as well as the strengths and weaknesses across the models.

**Western models**

Jacobson & Greenley (2001) describe a conceptual model of recovery from the United States. The main concepts, decided upon in consultation with a diverse stakeholder group, include: hope, healing, empowerment and connections. These concepts were drawn from ‘an analysis of numerous accounts…’ (Jacobson & Greenley 2001, p. 482). However, the reader is given no further information about these accounts. Thus, it is difficult to make judgements about for whom this model might fit.

Repper & Perkins (2003) describe six concepts of personal recovery. They also recognize the hazards in promoting a universal model, which would ultimately set many people up for failure (Deegan 1988). The concepts include: restoring hope; the importance of relationships; spirituality, philosophy, understanding; taking back control; coping with loss; and, the quest for meaning and value. Instead of recovery from illness, Repper and Perkins emphasize the recovery of a meaningful and valuable life.

Andresen et al. (2003) developed a set of concepts based on a literature review of 50 articles containing the personal narratives of people with schizophrenia. The concepts include: finding hope, re-establishment of identity, finding meaning in life, and taking responsibility for recovery. While the model’s simplicity is helpful for guiding professional care, it also suggests that the process itself should be simple (Larson 1999). However, recovery is a complex process that is different for everyone and not easy to achieve (Drake & Whiteley 2014).

Slade (2009) offers a personal recovery framework, which confusingly, is based on a slightly modified version of Andresen et al.’s (2003) model. The concepts that form the foundation of his recovery framework are hope, identity, meaning, and personal responsibility. These have been modified from Andresen et al.’s (2003) original model based on a report published by the National Institute for Mental Health in England (National Institute for Mental Health in England, 2004). However, they remain so similar to those identified by Andresen that it creates a question about the generalizability of Slade’s (2009) framework to service users with a diagnosis other than schizophrenia.

One of the main limitations of our current knowledge is that recovery models are based on a relatively uniform population, mainly Western Anglophones. Even within Anglophone populations, differences in personal recovery are emerging: Australian models tend to emphasize personal strengths, models from the UK and USA emphasize community integration and participation, and the importance placed on meaning in life is higher in Canada and the UK (Slade et al. 2012).

If differences exist in these relatively similar Anglophone populations, what should be expected in contexts that are socially and culturally dissimilar? A small body of literature that documents recovery in diverse populations has emerged in recent years. We will now turn to this body of work to examine the fit of the recovery model from a more diverse perspective.

**Non-Western models**

Song & Shih (2009) examined the factors and processes associated with recovery in a sample of 15 Taiwanese participants with a diagnosis of mental illness. The authors identify three cornerstones for recovery. First is ‘symptom remission or gaining control’. This first component is somewhat in contrast to Western models. For example, Taiwanese participants discuss being ‘cured’ and the importance of medication in this process. In the West, medications are acknowledged as being important for many but they are more often viewed as a necessary evil rather than as a foundation (Slade 2009).
Self-reliance, hardiness and resilience is the second foundation identified by Song & Shih (2009). Taiwanese participants often referred to having the courage to face challenges and never giving up. This foundation aligns well with the concept of hope from Western models.

The third foundation was family support, which provided both motivation and a sense of duty to overcome the challenges imposed by mental illness (Song & Shih 2009).

Sung et al. (2006) investigated recovery among eight Korean university students with a diagnosis of schizophrenia. Similar to some Western models, successful social engagement was a key factor in for recovery. However, it seems that social engagement in this Korean sample is not so much about being successfully engaged in meaningful activity and relationships, as it is about the quality of relationships with others and how high quality relationships provide a sense of inclusion.

A final, hybrid example is a narrative study conducted in New Zealand of 20 Maori (indigenous) and 20 non-Maori individuals with a diagnosis of mental illness (Lapsley et al. 2002). While non-Maori participants would be considered ‘Western’, the Maori people are an indigenous population with unique culture, language and customs (New Zealand Ministry for Culture and Heritage, n.d.). The authors of this study identified several aspects of Maori’s recovery experiences that differed from their Western counterparts.

First, the extended family played a major supportive role for Maori’s with mental illness. Second, Maori’s cultural interpretations influenced how they perceived the cause of current signs and symptoms, and also whether or not a psychiatric diagnosis was accepted. Finally, the majority of Maori participants reported using traditional healing practices.

Recovery-oriented mental health services

Despite the confusion, debate, and potential risks, Anthony’s (1993) original vision remains strong, and in fact, it is been increasingly incorporated into international practices and policies (Gagne et al. 2007). However, it is often unclear how these services should be organized. This is likely due to the lack of evidence available to support recovery-oriented services.

To our knowledge, only one experimental study has examined the effectiveness of a recovery-approach. Slade et al. (2015) conducted a cluster, randomized, controlled trial to evaluate the effectiveness of a standard care plus a recovery-oriented intervention versus standard care alone. Findings indicated that there was no difference between the control and experimental groups on a primary outcome measure (Questionnaire about the Process of Recovery). Lack of significant findings in this study markedly contrast with the rising popularity of recovery-oriented services over the past 20 years.

At least one Arabic country has begun to incorporate concepts of personal recovery into service development. Qatar’s National Mental Health Strategy outlines a vision for the redevelopment of services based on people’s potential to lead meaningful lives despite their illness (Supreme Council of Health, 2013). It does not rely solely on recovery as a model but does incorporate several key concepts. The report also acknowledges that the lack of local knowledge creates a barrier to efficient service development. The following sections outline several contextual factors in Arabic countries that may be incongruent with Western concepts of personal recovery.

Autonomy vs. community

Islamic ethical principles highlight the importance of the collective over the individual. For example, benefit to society can supersede autonomy in Arabic countries (Abdur Rab et al. 2008, Fadel 2010). The guiding ethical principles of Islam place the community before the individual in order of importance. One could hypothesize from this position that recovery-oriented services in an Arabic society might emphasize the long-term needs of the community as well as, or even ahead of, the individual.

Similarly, group membership is valued above individualism in traditional Arabic countries, such as Saudi Arabia, Kuwait and the United Arab Emirates (Hofstede 2001, Hofstede et al. 2010). In these collectivist countries, groups (e.g. the extended family) assume caregiving responsibility in return for loyalty. While many Western recovery models do emphasize the importance of social connections and support, the individual is seen to have primary responsibility for their recovery (Deegan 1988, Mind, 2008). Emphasizing individual responsibility alone would not be appropriate in a collectivist society.

However, limited evidence suggests that group membership in Gulf countries can be both a source
of support and tension. Extended families can facilitate social contact, improved treatment outcomes, and better coping (El-Islam 1982, Bilal et al. 1987). Conversely, tension in the extended family has also been cited as a precipitating factor for substance abuse, attempted suicide and increased disease severity (Suleiman et al. 1986, Al-Nahedh 1999, Zahid & Ohaeri 2010). Additionally, anecdotal evidence suggests that family members are often reluctant to participate in the care of a relative with mental illness. Any Arabic recovery model must take this complex social support mechanism into account. However, there is limited evidence available to guide service development in this area.

**Doctor–patient relationship**

The doctor–patient relationship is another area where a recovery model may not fit well with mental health services in Arabic countries. Within a recovery model, professional expertise is seen as a resource that may or may not be used, or helpful to, all patients. Patients decide what is helpful and what is not and are considered experts by experience. Rashad et al. (2004) describes a health care system in Egypt where the doctor is the authority and the patient does, or is supposed to do, what the doctor instructs. While Rashad et al. (2004) seems somewhat critical of the system, El-Islam (2008) suggests that Arabic patients prefer an authoritative approach. He describes how patients want their psychiatrists to remove (i.e. cure) their illness, and will accept little personal responsibility for their treatment. Rather, it is the Arabic family who often works with the psychiatrist to enable treatment (El-Islam 2008). It is worth noting that paternalism is not unique to the Arabic health care system and has been well documented worldwide (Cody 2003). However, there has been a slow shift in developed countries to a more collaborative approach over the past several decades (Nys 2008).

**Supernatural beliefs**

The majority of Arabic people believe that many mental illnesses occur as the result of jinn (demons), black magic and the evil eye (Salem et al. 2009, Al-Solaim & Loewenthal 2011). Like indigenous New Zealanders (Lapsley et al. 2002), this belief system influences treatment-seeking practices of people with psychiatric symptomology. Many Arabs first seek treatment from a traditional (faith) healer prior to seeking psychiatric care (Al-Subaie 1994, Al-Sughayir 2005). Those who do seek psychiatric treatment often continue to see the faith healer while concurrently receiving psychiatric treatment. Health professionals with a Western orientation to psychiatric treatment might try to convince these service users that supernatural attribution is incorrect and that the actual causative factors relate to brain chemistry. This biomedical understanding may be helpful for some, but for others, it is an instance where tension between Western and non-Western beliefs can be created. This tension also creates potential for a collaboration or partnership between biomedical and traditional healing that is rarely seen. Regardless of the ‘real’ reason underlying someone’s mental illness, recovery oriented services should acknowledge and explore this traditional belief system and discuss experiences/preferences for non-medical treatment (Ae-Ngibise et al. 2010).

**Personal recovery in an Arabic context**

Very little research has been conducted that could inform a model of personal recovery in an Arabic context, particularly in the Gulf region. Most recovery models in the West are underpinned by qualitative studies of service users’ recovery experiences. The only comparable study from the Gulf region was conducted in Saudi Arabia with eight female service users with a diagnosis of obsessive compulsive disorder (Al-Solaim & Loewenthal 2011). Participants in this study felt pride when they were able to be compliant with the teachings of Islam. The importance of religion is also suggested by other studies that demonstrate frequent use of traditional (religious) healers in the Gulf region (Al-Subaie 1994, Al-Faraj & Al-Ansari 2002, Salem et al. 2009). One study in particular demonstrated that the people who access traditional healers may receive spiritual, rather than clinical, benefits from these treatments (Al-Subaie 1994).

Given the importance of religion and traditional healers, it stands to reason that a recovery-oriented mental health service in the Gulf region should consider non-medical understanding of mental illness and actively explore these beliefs with service users. We acknowledge that it may sometimes be difficult to reconcile medical and non-medical beliefs about mental illness; however, recovery for
many in the Gulf region may rely on non-medical interpretations of their experience. Additionally, increased coordination between medical services and traditional healing may provide a more holistic approach to recovery in Arabic countries. This collaboration could simultaneously address clinical recovery and also offer service users the opportunity to (re)connect with, and draw strength from, their faith. Admittedly, there are certain risks associated with traditional healing practices (World Health Organization, 2013). However, formal collaboration between traditional healers and mental health services would make it easier to regulate these practices and prevent potentially harmful outcomes.

In addition to the importance of faith in personal recovery, Al-Solaim & Loewenthal (2011) also found that participants were able to cope more effectively with stressors when they had strong family and social networks. This finding mirrors all three non-Western recovery studies described above. However, there is little understanding of how mental health services in Arabic countries can support these networks.

If we look to the international literature on family and social connectedness, we find that this is primarily seen as an individual responsibility (Tew et al. 2012). In this regard, services aim to support the service user to make positive connections. However, another approach, which moves away from individual responsibility, is for services to work with families and communities with the aim of fostering connections and mobilizing resources (White 2009). It seems likely that both approaches (i.e. individual and social) are important in an Arabic context.

Unfortunately, it is not clear how mental health workers should best engage in work with families and communities. Research in the area shows that educating families does not seem to be adequate; mental health workers also need to provide training on coping and stress management (Macleod et al. 2011). In terms of social connectedness, working with communities seems to have received less attention than working with families. This may be because community engagement is sometimes outside of the scope of practice for some health care professionals (Thornicroft et al. 2010). However, one area that shows promise is facilitating the development of supportive communities where service users are experts by expertise. For example, mental health professionals have provided training for service users to act as peer support workers, service development consultants, and advisors on research projects (Tew et al. 2012, Simpson et al. 2013). This creates a role in healthcare and research communities for service users to make a valuable contribution.

In Arabic countries, it may be helpful to examine the scope of practice for mental health service providers and consider including working with families and communities as a part of these roles, if it is not already included. Importantly, staff members should be provided with training on how to teach coping and stress management to families. Community engagement initiatives that locate responsibility with the community and not the individual service user should be piloted and evaluated. Additionally, creating opportunities in certain community groups for service users to contribute as experts by experience has promise. This work will be challenging due to stigma, lack of resources, and a myriad of other factors. However, increasing the capacity of families and communities to provide support for service users seems to fit well within the context of a collectivist society. Additional qualitative studies in the region would help to clarify the main aspects of recovery in an Arabic context.

Summary

It is widely accepted that personal recovery is an individual process and that what works for one person may not work for someone else. Because of this, we caution that one size does not fit all. The fact that recovery-oriented services are being increasingly implemented worldwide does not necessarily mean that the practice is appropriate or effective. Personal recovery is an easy ‘sell’ because the concepts are straightforward, responsibility is partially shifted to the service user, and a focus on the positive can be reassuring. From the many service user narratives and descriptive research articles that have been published, we know that recovery undoubtedly happens for many people. However, there is very limited evidence to support the development of recovery-oriented services in contexts where recovery has not been studied. Additionally, current conceptualizations of personal recovery may not even be transferrable to non-Western contexts. Perhaps more importantly, an uncritical incorporation of a Western-biased recovery model into non-Western mental health ser-
vices may lead to the imposition of inappropriate values on people receiving treatment (Cross et al. 2000). This means that recovery concepts need to be modified to incorporate the values, customs and beliefs of service users in non-Western contexts. These modifications then need to be carefully evaluated. Continued research into the strategies that people use to manage their illness, as well as what services can do to support this self-management, is needed in a range of sociocultural contexts. This will help to identify culturally appropriate ways to improve services and contribute to the global discussion on personal recovery in mental illness.

Competing interests

The authors declare that they have no competing interests.

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Authors’ contributions

All authors made substantial contributions to the conception and design of this article. JH was responsible for the literature review and manuscript preparation. SP and HW were responsible for critical review and revision of the manuscript. All authors read and reviewed the final manuscript.

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1.3 Context

Qatar is a small (11,571 km²) country in the Middle East bordered by Saudi Arabia and the Persian Gulf. Historically, the area was inhabited by nomadic Bedouin traders and coastal Arabs, who were fishermen, pearl divers, and pirates (Kronfol, Ghuloum, and Weber 2013). However, the country is undergoing a period of rapid development, sparked by the discovery of vast amounts of oil and natural gas in 1939. Data from 2016 places Qatar as having the highest GDP per capita in the world (Central Intelligence Agency 2016).

The large-scale development that has occurred over the past 20 years has led to a boom in the country’s population, which rose from 340,000 in 1984 (World Bank 2015) to 2.68 million as of April, 2017 (Ministry of Development Planning and Statistics 2017). Qatari citizens number around 250,000 making them a minority in their own country (Doherty 2012). The remainder of the population (e.g., long term residents, skilled expatriates, and unskilled labour migrants) are considered non-nationals and constitute the majority of the population. According to the 2004 census (note: the more recent 2015 census does not include figures on religion), 77.5% of the population were Muslim (Pew Research Center 2009).

Hamad Medical Corporation (HMC), the main provider of psychiatric services, spends 1.95% of its total budget on these services (World Health Organization 2011a). This seemingly indicates a disparity for mental health services, considering that mental disorders constitute three of the top six most burdensome diseases in the country, and three of the top five causes of disability (Institute for Health Metrics and Evaluation 2013).
The only public adult psychiatric treatment centre in the country has four inpatient units, three for males and one for females, and an outpatient department. It is acknowledged that in-patient facilities are currently inadequate. This is largely because the number of inpatient beds (63 as of January 2017) has not kept pace with rapid population growth. Specific information on the past development of the mental health system was unobtainable. However, in 2005, there were .97 beds for every 10,000 people in the country (World Health Organization 2005). If we divide the current population by the number of inpatient beds (63/2.68 million) we arrive at a figure of .24 beds for every 10,000 people in the country. This equates to a 75% decrease in the number of beds available per capita.

During the period from October 2012 to August 2014 (most recent data available at the time of writing) there were 2,374 inpatient admissions. The majority of these patients were Arabic and approximately 23% were Qatari Nationals. Other common nationalities included Indian (13%), Nepalese (8%), Pilipino (6%), Egyptian (5%), and Pakistani (5%). It is not possible to compare these numbers with census data because the necessary statistics are not made publicly available. Two thirds of all admissions were male and the average length of stay in 2014 was 17.29 days.

1.4 Motivation for studying mental illness in Qatar

Publication of Qatar’s National Vision 2030 (General Secretariat for Development Planning 2008) and the associated National Health Strategy (Supreme Council of Health 2011) outlined a plan for major upscaling of health services. Mental health services were listed as a priority area. When I moved to Qatar in 2012 to work as a nursing instructor/lecturer in a Canadian undergraduate nursing
program, it was apparent that much of this work was getting underway. As part of my service to the community, I joined the National Mental Health Research Workstream. Through my role as a faculty member at a local university, I also began to network with individuals involved in these service developments. Basically, I was interested in contributing to the change.

One thing that surprised me about the approach to service development was the lack of focus on what the individuals who use the services want, or what their opinions were. International best practice evidence was compiled, experts in the field were brought in to consult and advise, and experienced Western policy and practice experts were hired as members of the National Mental Health Implementation Team to lead these changes. These individuals intended to consult with service users in Qatar. However, they told me through informal discussions that they found it difficult to connect with locals. The team led development of the National Mental Health Strategy, which states that “research into the specific experience of different population groups will be essential to building effective, targeted interventions…” (Supreme Council of Health 2013, 14).

During this time, I had been accompanying nursing students to the local psychiatric hospital for their clinical course in mental health nursing. My experience with local service users was different than those of the implementation team; I found that service users were interested to share their stories with me and my students. This led me to believe that exploring and sharing service users’ concerns would be an area where I could make a contribution to service development.
1.5 Impetus for undertaking the literature reviews

My professional interest in mental health and illness and my experience teaching nursing students in Qatar helped me to decide on the general area of focus for my PhD. However, I recognized that I was in a foreign context and that my experiences working as a psychiatric nurse in Canada, and the knowledge I had gained from doing so, may not transfer to Qatar. This led me to undertake a scoping review of mental health research in the region. I hoped that by doing so I would familiarize myself with the literature, develop a better understanding of the contextual influences on mental illness in the area, and identify gaps in the literature that would help me to narrow the focus for my PhD studies. I was able to achieve these outcomes and decided to study the concept of recovery in mental illness. However, my knowledge of recovery was limited, so under direction from my supervisors, I decided to conduct a second review. I hoped this would allow me to engage with the body of literature on recovery, develop a sense of what recovery was like for Arabic people, and investigate whether the literature was applicable in an Arabic setting. The review helped me to develop my knowledge about recovery, but I discovered a large gap in the literature with respect to recovery outside of a Western setting. This second review helped me to finalize my research objectives and confirmed that a study on recovery in Qatar would result in a beneficial addition to the body of knowledge.

1.6 Summary of review findings leading to research aims

Two reviews were undertaken to inform development of an empirical research project. The first was a scoping review of mental illness research in the GCC (Hickey, Pryjmachuk, and Waterman 2016). This article aimed to
“systematically review and synthesize regional literature that reports service user perspectives on mental illness in GCC countries, identify major gaps in the literature, and suggest directions for future research” (p.2). The review identified 55 studies conducted in the GCC and synthesized service user experiences into several themes. These themes are described on pages 8-11 of the article and include ‘service preferences’, ‘illness’, and ‘recovery’. One unique finding from this review was the contextual influence on people’s experience of mental illness, particularly in regard to recovery (see article, p.15/10). More specifically, traditional healing, religion, and family support all seem to be important for the recovery journey of service users in the region. This is unique because these factors do not prominently feature in the dominant discourse on recovery. Gaps in the reviewed literature (see p.15/11-12) include unclear and contradictory findings related to the presumed supportive role of the extended family and of religion, underrepresentation of women in study samples, biomedical treatment of mental illness in the context of widespread beliefs in supernatural causation (e.g. jinn, black magic), an absence of research on stigma despite frequent discussion of its impact, and low knowledge of the strategies and resources service users employ outside of the hospital setting to manage the day-to-day challenges.

Findings from the scoping study suggested several directions for future research (see article p.15/12). First, additional qualitative research on mental illness in the GCC is needed to provide depth to our understanding of service users’ experiences. Second, underrepresentation of women in study samples necessitates more gender equity in future research. The scoping study does not specifically address a need for future research on recovery, however, considering the
seemingly unique aspects of recovery in the GCC context, a reasonable implication is that future research on recovery in that region would add to the international discussion on that topic. The scoping review also raised two primary questions:

1) What strategies do service users in Arabic countries use to self-manage their illness outside of the hospital setting?

2) What treatments and interventions would be most effective and acceptable to support this self-management? (Hickey, Pryjmachuk, and Waterman 2016, 12)

The potential directions for research that were identified led me to undertake a second review article which critiqued common models of recovery through an Arabic sociocultural lens (Hickey, Pryjmachuk, and Waterman 2017). This review uses exemplars to highlight similarities and differences between predominant Western models of recovery and conceptualizations of recovery developed in non-Western contexts (p.16/164-165). The article identifies three contextual factors that may lead to different experiences of recovery in an Arabic context (p.16/165-166). These include a focus on community rather than autonomy, a more authoritarian doctor-patient relationship, and widespread supernatural beliefs and use of religious healers. The article argues that certain components of recovery models, in particular, self-determination and personal responsibility may not be applicable or appropriate in an Arabic context (p.16/165 and 168). The rationale behind this argument is that the majority of recovery models have been developed based on data from Anglo-Caucasian service users from individualistic cultures. The collectivist nature of Arabic culture suggests that values inherent in existing models may not be a good fit in an Arabic context. The
article concludes that contextualized research is needed in order to develop culturally appropriate recovery models and services in non-Western contexts (p.16/167-168).

These reviews, combined with the lack of service user consultation on local mental health service development described in section 1.4, provided further support for an empirical study of recovery in Qatar. Because so little is known on the topic of recovery in an Arabic context an exploratory inquiry was chosen with an aim to develop a theoretical understanding of mental illness self-management in Qatar. For the purposes of this study, illness self-management was defined as, “the actions taken by people to recognise, treat and manage their own health” (NHS n.d.). As discussed earlier in Study 2 (p.16), common (i.e., Western) recovery concepts may not be appropriate or applicable in an Arabic context. Therefore, self-management was chosen over recovery so as not to force concepts of recovery into the study. Additionally, self-management may encompass components of recovery, but does not imply or require that recovery is taking place. Therefore, a focus on self-management potentially expands the scope of the study. The following specific objectives were developed:

1. Explore service users’ experience of mental illness in an Arabic context.
2. Identify service users’ main concern(s), related to mental illness self-management.
3. Identify and describe the actions service users take to address their illness self-management concerns.
4. Develop a substantive theory of mental illness self-management.
The substantive theory developed from this project will contribute to a better understanding of mental illness in the region, has potential to guide service and policy development, and may ultimately facilitate people’s ability to live a meaningful life despite any limitations imposed by their mental illness.

1.7 Contribution of the project

This project contributes to the body of knowledge in two ways. First, there is no published study that broadly explores people’s experience of mental illness in the GCC using a qualitative methodology. One study examining obsessive-compulsive disorder in Saudi Arabia provides insight into the cultural influences on this disorder and demonstrates the value of an in-depth qualitative study on mental illness (Al-Solaim and Loewenthal 2011). However, no other similar literature exists. Thus, my study adds in-depth understanding of mental health service users’ concerns and experiences.

Secondly, this project adds to the growing international literature on recovery. No previous study on this topic undertaken in the GCC has been published. Thus, it adds a new perspective about people’s quest to develop meaning in their lives, which is at the core of the recovery process. The project adds new perspective on recovery in a non-Western context and also provides a potential reinterpretation of some mainstream recovery concepts.

1.8 Summary

This chapter has provided the background and literature reviews that support the work undertaken for the empirical study. The unique context and dearth of regional research combined with my personal and professional interest in the topic of service users’ experiences of mental illness provides a fertile area for
research. The lack of specific knowledge about people’s experience of mental illness and personal recovery in an Arabic context presents an opportunity for a unique contribution to the literature. The following chapter reviews the rationale for the empirical study, restates the study aim and objectives and critically discusses methodological development for the empirical study.
Chapter 2 Contents

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2.1 Introduction and rationale for empirical study

The previous chapter describes how rapid development and population increases in Qatar have put strain on mental health services in the country. To respond to these changes, and with the aim of developing a world class health care system, substantial resources are being directed towards scaling up mental health services in the country. However, there is a lack of information regarding the needs and preferences of service users. My PhD topic was developed to address this gap.

As a first step, I (in collaboration with my supervisors) conducted a scoping review of mental health research conducted in the Gulf Cooperation Council (GCC). The main themes that were identified included service preferences, illness, and recovery (Hickey, Pryjmachuk, and Waterman 2016). The recovery theme was further subdivided into traditional healing, religion, and family support. After doing some exploratory reading about the concept of personal recovery in mental illness – basically, the process of finding meaning in life in spite of one’s illness – I began to realize that these three sub-themes differed from the majority of recovery conceptualizations in the existing literature.

Simultaneously, the Qatar National Mental Health Strategy was being implemented (Supreme Council of Health 2013). The strategy is based on international best practices and consultations from international experts and incorporates an emphasis on recovery. However, the scoping review led me to believe that recovery in Qatar might differ from recovery as described in the existing literature. I undertook a second review to address this concern.

The second review examined the predominant concepts of recovery through an Arabic sociocultural lens (Hickey, Pryjmachuk, and Waterman 2017). It also
examined differences between Western and non-Western literature on recovery. In
the review we conclude that predominant (Western) conceptualizations of recovery
may not be appropriate in the GCC. It also highlights a gap in knowledge about
conceptualizations of recovery in the region. In fact, other than the scoping review
we conducted, nothing had been published on recovery in an Arabic context prior
to undertaking this project.

2.2 Aims

This study was designed to develop a theoretical understanding of the
illness self-management strategies used by people with mental illness in Qatar. As
discussed in the previous chapter (1.6), self-management was chosen over recovery
to broaden the scope of the study and to avoid forcing concepts of recovery. No
literature could be located that studied mental illness self-management or recovery
within an Arabic context. The specific objectives of the study were to:

1. Explore service users’ experience of mental illness in an Arabic
   context.
2. Identify service users’ main concern(s), related to mental illness self-
   management.
3. Identify and describe the actions service users take to address their
   illness self-management concerns.
4. Develop a substantive theory of mental illness self-management.

2.3 Methodology

During my literature reviews, I discovered that very little had been published
about people’s experiences of mental illness in the GCC. This led me to choose an
exploratory, qualitative, methodology. Qualitative research allows an in-depth
exploration of a topic (Ritchie and Lewis 2003). I felt this approach would help to fill a gap in regional literature. Qualitative research can also give voice to populations who normally do not have one (Jack 2010). Thus, a qualitative methodology would allow me to give voice to some of the unheard concerns of mental health service users in Qatar.

There are many different approaches to qualitative research, so I examined several to find the best fit. Phenomenology would allow me to gain an in-depth understanding about the nature of service users’ day-to-day experiences (Van Manen 1990). However, it also has two drawbacks in relation to the goals for this project. First, phenomenological studies do not encompass the wider social, political, and economic context of culture (Ploeg 1999). Since culture seems to be linked to recovery in this context, it did not seem appropriate to use a methodology that may not be inclusive of this factor. Second, phenomenology is a descriptive methodology (Moustakas 1994). I did not want to limit myself to a description of mental illness experience. I also hoped to develop new ideas and hypotheses that could indirectly benefit people with mental illness.

Ethnography initially seemed well suited to my evolving interests because of its focus on culture. It encourages rich descriptions of people and places (Spradley 1979) and also facilitates the inductive development of theory (Wilson and Chaddha 2009). This would allow me to analyse service users’ stories as I had originally intended and also develop hypotheses that might benefit people with mental illness (e.g., better ways to organize services).

Ethnography requires the examination of social phenomenon (Hammersley and Atkinson 2007), which struck me as an exciting approach to studying mental
illness in Qatar. It would give me the opportunity to explore how cultural aspects of life in the GCC affect service users’ experience of mental illness. Additionally, the methodology has been well established as a useful approach for researching mental health and illness (e.g., Cleary et al. 2011; Kaye 2013; Scheper-Hughes 2001).

One potential downside for using ethnography is its emphasis on field observation (Willis and Trondman 2002). In Qatar, it is likely that stigma and a cultural aversion to publicising family life would create a substantial barrier to undertaking prolonged engagement in the field in the traditional sense. But because ethnography has a certain amount of methodological flexibility it could still be a useful approach. I could potentially make observations during interviews (Schensul, Schensul, and LeCompte 1999), and some types of ethnographies, such as interpretive ethnographies, do not rely on prolonged observations in the field (Blaikie 2010; Maggs-Rapport 2000).

However, ethnography is essentially a study of culture and how meaning and understanding is developed between groups of people. I was more interested to study illness management, and possibly recovery, in an Arabic context, rather than focusing exclusively on the culture of mental health service users. Because recovery is a social process, I found a better fit with grounded theory.

Using grounded theory enables service users to provide data through interviews. However, the focus is on the main concerns of participants and the process(es) by which the main concerns are continually resolved (Christiansen 2007). This approach fits better with my professional philosophy (e.g., patient-centeredness). It also aligns with my interest in health promotion; the grounded theory that is developed using this methodology should be useful for practitioners.
(health professionals in this case) in helping them to assist participants (mental health service users) to resolve their main concerns (Glaser 1998).

Grounded theory enables the development of a substantive theory, essentially a interrelated set of concepts and their properties, that is relevant and useful to lay practitioners in a particular topical area (e.g., mental illness) (Glaser 1998). Thus, it provides an opportunity to identify strategies that could be useful for guiding the work of mental health practitioners. Such a theory would fill a gap in current understanding and provide a contextually relevant basis for service and policy development.

There are several different approaches to grounded theory. Since the method was first published (Glaser and Strauss 1967), three popular approaches have developed. Barney Glaser, one of the two originators of the method, has maintained a preference for the original methods, with very little modification over the past 40 years (Hernandez 2008). His method is often referred to as ‘classic’ or ‘Glaserian’ grounded theory. The pillars of his method are 1) theory generation based on the emergence of concepts that are grounded in the data, 2) comparative analysis (i.e., constant comparison) of data to facilitate the emergence of concepts and their properties, 3) and theoretical sampling of participants that is guided by emergent theory. The two main questions that this method seeks to answer are, 1) what is the main concern of the population under study? And, 2) How is this issue continually resolved by participants (Christiansen 2007)?

Glaser’s approach has been criticized for its objectivist stance and for not recognizing the effects of the researcher on the research (Bryant 2009; Charmaz 2003). However, many grounded theorists argue that these criticisms are
unfounded (Breckenridge 2012; Charmaz 2003; Glaser 2002). The goal is not about finding and describing an objective truth. Rather, it is about developing hypotheses about people’s concerns and actions that make sense, are useful, and are modifiable (Glaser 1998).

Corbin and Strauss (2007) offer a second approach to grounded theory that is more purposefully aligned with qualitative research. Their variation continues to incorporate constant comparison, theoretical sampling and theory development. However, it differs in several ways. These include a stronger emphasis on the researcher’s prior experience to identify concepts for investigation, a greater role of the literature (at all stages of the research) to increase theoretical sensitivity, several research ‘tools’ to facilitate theory development, and a different approach to categorization in analysis.

One common critique of Corbin and Strauss’ approach is that it is not actually grounded theory (Charmaz 2006; Glaser 2002). Their use of the literature, and purposeful incorporation of the researcher’s perspective to identify hypotheses and subsequent searching of the data to confirm or refute these has created a variation of theory development through verification. This takes the focus away from the participants and places equal importance on the literature and the researcher’s perspective (Hernandez 2008). There is nothing fundamentally wrong with this practice. However, it is essentially different from the original conception of grounded theory because it no longer employs an emergent approach to theory development.

A third approach has been developed by Kathy Charmaz (Charmaz 2014, 2006). Charmaz emphasizes symbolic interactionism and social constructivism in
her approach to grounded theory. She stresses that data collection, analysis, and the writing process are all “created from shared experiences and relationships with participants and other sources of data” (Charmaz 2006, 130). Charmaz purposefully reflects on and acknowledges her own contributions to the theory development process. She also advocates for the inclusion of multiple voices and perspectives in order to illustrate a complete picture of participants’ situation (Charmaz 2003).

Charmaz’s (2006) incorporation of constructivism leads her to place primary importance on “learning how, when and to what extent the studied experience is embedded in larger and, often, hidden positions, networks, situations, and relationships” (p.130). This emphasis takes the focus of inquiry away from the participants’ concern (Breckenridge 2012) by placing a framework on the analysis. By doing this, it allows the researcher to develop a better understanding of how social and cultural factors impact participants’ concerns.

In Qatar at present, the concerns of service users often go unheard. Practitioners, administrators, researchers, and the government all have a strong voice in how services are organized and delivered. It is also common practice to seek advice from international ‘experts’ who have minimal knowledge of the local community or culture. Of the three approaches to grounded theory, only Glaser’s approach gives exclusive priority to the participants’ concerns. As outlined above, Corbin and Strauss rely on the literature and the researcher to develop hypotheses to be verified in the data, and Charmaz utilizes constructivism to determine priorities for analysis. While constructivist grounded theory may be better suited to examining how culture affects recovery, Glaser’s (classic) grounded theory has the strongest chance of giving voice to the primary population (i.e., people with mental
illness). For this reason, I chose classic grounded theory to address my research problem.

2.3.1 Philosophical Orientation and Reflexivity

Glaser (2015) emphatically warns his students not to engage in the ‘rhetorical wrestle’. He argues that grounded theory is a ‘general concept-indicator method’ and not based on a particular philosophical underpinning. Glaser (2015) also states that the method ‘works’ regardless of the researcher’s philosophical stance, so long as this stance does not lead the researcher to preconceive the outcome.

I agree with interpretivists that meaning in research is created through interactions between the researcher and the participant. And despite Glaser’s pronouncements about rhetoric, classic grounded theorists acknowledge reflexivity as a fundamental aspect of the research process (Evans 2013). Even Glaser (1978) argues that a researcher’s prior experience should be utilized to increase ‘theoretical sensitivity’.

Reflexivity, defined as “critically examining one’s effect as a researcher on the research process” (Reay 1996; as cited in Hall and Callery 2001, 262) was employed throughout the research process to help ensure I was not ‘forcing’ (Kelle 2007) my own ideas, attitudes and beliefs on the data. Of particular concern was the potential to ‘force’ the concept of recovery into the analysis. Glaser (1978) advises strongly against the pre-data collection literature review that is standard practice in all other empirical research. He takes this position in order to avoid forcing predefined concepts, identified during the literature review, on the data. Glaser (1998) acknowledges, however, that in some situations (e.g., doctoral studies) researchers are required to demonstrate their ability to provide rationale
for a study using a literature review. In these cases, Glaser (2015) warns that the researcher must remain open to the possibility that their study may be about something else entirely than what the literature review points towards. Thus, I began this study with an understanding of, and interest in recovery, but an awareness that the concerns of study participants may lead me in another direction. As mentioned in chapter 1 (p.23), this is one of the reasons I chose the topic of self-management over recovery per se.

Throughout the study, I continually assessed (i.e., constantly compared) the ‘fit’ of emergent concepts with subsequent data. Theoretical memos further helped me assess my potential impact on the analysis and track the development of concepts (Glaser 2014). Discussions with my supervisors also helped me remain aware of my influence on the data. These three tools helped to ensure I did not force my own interests on the data.

2.4 Methods

2.4.1 Sampling

Sampling in grounded theory consists of two stages, purposive sampling and theoretical sampling (Holton 2010). Purposive sampling is used to recruit initial participants and focuses on individuals most likely to share a broad range of opinion and experience with the research team (Glaser 1978). In this study, initial participants from both genders with differing diagnoses were selected. Broad inclusion criteria were developed in order to be inclusive of a diverse range of participants. However, some limits were put in place to ensure the study aligned with service development priorities:
• 18 years or older. The study focuses on the adult psychiatric population in order to be of most relevance to the adult psychiatric service, which was the focus of service development when study development began.

• Able to converse in either English or Arabic. These two languages allow for inclusion of the largest proportion of potential participants; the majority of service users with an ongoing need for services speak one or both of these languages.

• Not repatriating after admission. Many labour migrants who develop mental health problems in Qatar repatriate to their home countries for treatment. However, service development is currently aimed at improving services for those who have potential ongoing need for local services. Including individuals with an ongoing need for local services helps to ensure that the substantive theory has most relevance for service development.

• Current diagnosis of one of the following: Mood disorders (dysthymia, cyclothymia, depression, bipolar), alcohol and drug/substance use disorders, schizophrenia, bipolar disorder, anxiety disorders, obsessive-compulsive disorder, personality disorders, Alzheimer’s/dementia, and phobias. This list was based on the most common and debilitating mental illnesses worldwide (World Health Organization 2011a) and includes other mental illnesses identified as being clinically relevant in Qatar (Ghuloum, Bener, and Abou-Saleh 2011, Ghuloum 2013 personal communication).

• Capable of providing informed consent. Potential participants were assumed to have the capacity to provide informed consent if they were able to understand relevant study information, retain that information, weigh the
risks and benefits in order to make an informed decision, and communicate that decision (Department of Health 2005).

- Willing and physically able to participate in an hour-long interview.

Note: participants who did not meet at least one of the inclusion criteria were excluded from participating. No other exclusion criteria were applied.

The second phase, theoretical sampling is one of the defining features of grounded theory and should begin once concepts begin to emerge (Glaser 1978, 1998). The purpose of theoretical sampling is to extend understanding of emergent concepts and their properties (Glaser 1978); participants are selected who are thought to have information about, or experience with an emergent concept.

A common concern of novice researchers is that concepts will not simply emerge (Glaser 1998). This was a concern during development of the current study, but was quickly mollified when concepts became apparent while analysing the first few transcripts. However, an issue with theoretical sampling did arise. Initial concepts (e.g., improving, contributing, connecting) were somewhat ‘invisible’ and it was not possible to identify participants who had experience with these prior to selecting them. This experience may relate to the criticism of ambiguity that is sometimes ascribed to theoretical sampling (Breckenridge and Jones 2009). Glaser (2015) acknowledges this potential issue and suggests verifying prior experience with concepts after recruitment. In this study, I assumed that any inpatient would have potential experience with one or more of the concepts. Thus, I continued to recruit a broad sample, but began to focus interviews more on emergent concepts rather than general discussion. In effect, theoretical sampling was replaced with theoretical interviewing. This involved asking focused questions related to
participants’ experiences of emergent concepts (e.g., “Others have mentioned the importance of feeling productive. Is that important to you?”). In this way I was able to gain in-depth information and alternate perspectives on concepts that had emerged during previous interviews, essentially the goal of theoretical sampling (Glaser and Holton 2004). I discussed this approach with Dr. Glaser at a grounded theory workshop and he confirmed it as an appropriate solution (Glaser 2015, personal communication). See Appendix 1 for an early and late interview schedule.

2.4.2 Gaining Access

Inpatient sampling took place at the only inpatient facility in the country. Formal permission to undertake the study was required from the Medical Chair of the psychiatry department and from the Director of Nursing for psychiatry. Contact with other gatekeepers (i.e., people who will facilitate access to the participant population) was also extremely valuable. Maintaining contact and building rapport throughout the life of the project can help to ensure the success of recruitment and follow up (Van Manen 1990). However, sometimes gatekeepers may choose not to cooperate (Davies and Peters 2014). This was not the case in this study, as gatekeepers (e.g., staff nurses, unit psychiatrists, social workers) were consistently supportive. One reason behind this may have been my professional relationship with these individuals through my work as an instructor at a local university.

2.4.3 Stakeholder consultations

Access to my participant population was also facilitated through stakeholder consultations. This has occurred in two main ways. The first was practical access. Stakeholders (See Table 3 below) granted formal approvals, liaised with others who needed to provide formal approval, and communicated on my behalf with the local
institutional review board on several occasions when initial or continuing reviews were delayed. The second way in which stakeholders facilitated access was to ensure my project was culturally appropriate and had relevance for the local community (Hubbard, Kidd, and Donaghy 2008). Since I was a foreign researcher, this aspect of public involvement was particularly important.

Table 3. PhD project advisory group

<table>
<thead>
<tr>
<th>Position*</th>
</tr>
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<tbody>
<tr>
<td>Acting Medical Director for Psychiatry, service provider organization</td>
</tr>
<tr>
<td>Chair for Psychiatry, service provider organization</td>
</tr>
<tr>
<td>Chair of Research Committee, Psychiatry Dept., service provider organization</td>
</tr>
<tr>
<td>Senior Consultant Psychiatrist, service provider organization</td>
</tr>
<tr>
<td>Dean &amp; CEO, health professional university in Qatar</td>
</tr>
<tr>
<td>Mental Health Nursing Instructor, health professional university in Qatar</td>
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<tr>
<td>Assistant Executive Director Nursing – Psychiatry, service provider organization</td>
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<tr>
<td>Assistant Executive Director Nursing – Research, service provider organization</td>
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<tr>
<td>Assistant Executive Director Nursing – Education, service provider organization</td>
</tr>
<tr>
<td>Nursing Educator – Psychiatry, service provider organization</td>
</tr>
<tr>
<td>Assistant Executive Director of the National Mental Health Implementation Team, government</td>
</tr>
</tbody>
</table>
Lay members of the local community: A Qatari Family, a Qatari service user; an non-national Arab service user

*names removed to protect privacy

I identified and contacted these stakeholders early in the conceptualization of this project. Stakeholders represented mental health professionals and administrators, government mental health officials, and mental health educators. I met directly with all of these individuals at certain points in the project in order to seek feedback, advice, and assistance. In addition to facilitating access, this raised the profile of the project, developed collaborative relationships with these individuals, facilitated implementation of the project, and ensured the project was relevant from a service and policy perspective.

I have also engaged the public in this project, via inclusion in the stakeholder group (see Table 3). Public involvement in research (PPIR) is defined as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them ("INVOLVE Strategy 2012-15 Putting People First in Research" 2012, 1). The term ‘public’ refers to actual or potential service users who are not involved in the research in a professional role. Public involvement can range from consultation to collaboration to consumer control (Boote, Telford, and Cooper 2002).

However, while PPIR has benefits, it can also cause difficulties and require resources. Since this is the first time I have involved the public in a research project their role has remained at the consultative level (Caress et al. 2012). Additionally, the concept of PPIR is rare in the research and decision making culture in Qatar. This may be due to the authoritative role of the physician in Arab healthcare systems (Rashad, Phipps, and Haith-Cooper 2004) and the related expectation that
the doctor will take responsibility for treatment decisions (El-Islam 2008). These aspects of the health care system refer to clinical contexts but may extend to other areas of healthcare and health research. However, there is no previous research that looks specifically at PPIR in Qatar or nearby countries.

Based on my experiences with consultation, health care professionals were at ease giving feedback and advice, while the public were unsure of what was expected. This may have been due to limited previous exposure to, and understanding of, research (Boote, Telford, and Cooper 2002). It may also have been related to a potential power imbalance between lay members of the advisory team and the biomedical system (Green 2016), which as mentioned in the previous paragraph, holds authority in the healthcare system in Qatar. Two key areas where these consultations were successful however were in confirming the importance of and need for the study, and helping to ensure that a culturally sensitive approach to participant interactions was taken. These are perhaps areas where lay members felt they had a higher degree of experience and expertise.

2.4.4 Recruitment

The majority of participants were recruited from inpatient psychiatric units as close as possible (i.e., within 48 hours) to their discharge. It could be argued that inpatients may not be able to offer much wisdom on self-management of mental illness since they were not able to do so without intervention from mental health services. However, this population were chosen because it was assumed that most would be thinking about what they needed to do to manage their illness post-discharge and to avoid relapse. For most participants this turned out to be true.
I visited inpatient units accompanied by a bilingual research assistant (RA). RAs were student nurses who had completed two mental health nursing courses (note: this is the full extent of mental health nursing education in their generalist program) and received extensive training in recruitment, consent and data collection as part of their involvement in the project. A diverse group of RAs was chosen so that the characteristics of the team would match a large number of potential participants. This was done with the aim of putting participants at ease, increasing trust, and facilitating in-depth data collection (Aponte et al. 2015; Whitmore 1994). However, it can be difficult for students to commit the time needed for extra-curricular research activity (Taber et al. 2011) and several withdrew from the team throughout the year-and-a-half recruitment period. Two of these were replaced but it was difficult for them to catch up on the knowledge needed to undertake recruitment and data collection (Wells and Cagle 2009). These RAs were instead assigned to other study activities (e.g., planning dissemination activities). RAs received a stipend for their contributions to the project. Table 4 below lists the gender, nationality, and language spoken for the initial team of RAs.

Table 4. Research assistant characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Nationality</th>
<th>Languages spoken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>Somali, born in Qatar</td>
<td>Arabic, English</td>
</tr>
<tr>
<td>Female</td>
<td>Somali</td>
<td>Urdu, Hindi, Arabic, English</td>
</tr>
<tr>
<td>Male</td>
<td>Pilipino</td>
<td>Togalog, English</td>
</tr>
<tr>
<td>Female</td>
<td>Palestinian/Canadian</td>
<td>Arabic, English</td>
</tr>
</tbody>
</table>
During the first step of recruitment, an RA and I spoke to the Head Nurse or Charge Nurse on each unit and asked if there were any service users who met inclusion criteria for the study. Direct (personal) introductions are important in Arabic culture (Williams 1999). Hence, after potential participants were identified, a member of staff was asked to provide an introduction. This also provided a buffer for the service users so that they would not feel intimidated by a direct approach from people they were unfamiliar with. It also caused a slight issue initially, as I discovered staff were telling service users they had to talk to me. To correct this issue I spent more time educating staff nurses about the study and its requirements/intentions. In particular, I discussed voluntariness and coercion with them. This additional explanation seemed to remedy the problem. When I revisited inpatient units, I attempted to engage staff nurses who had already provided introductions during past visits. This part of the recruitment process improved over time.

After the introduction was made, the RA and I informed the service user that we were interviewing people for a research study and asked if we could sit with them for a few minutes to explain the study. If the service user consented to receiving this information, we sat together in a private location on the unit (e.g., office, family room), and provided a copy of the patient information sheet. This was
explained in either English or Arabic, depending on the preference of the service user. Similar recruitment strategies have been used with success in other local studies (Donnelly et al. 2015; Killawi et al. 2014).

After the study was explained, the RA and I assessed the service user’s interest in participating. Some were immediately not interested in participating. This was usually due to the person being under a court order and feeling reluctant to talk about their case, or discomfort with the idea of being audio-recorded. Killawi (2014) also found that potential participants in Qatar were reluctant to have interviews audio recorded and recommended that hand-written notes are taken if possible. I initially considered conducting unrecorded interviews with these participants and recording data in memos. However, this approach fell outside of my protocol and the RAs did not feel they would be able to accurately record data in field notes for the interviews conducted in Arabic. My desire to more accurately record participants’ experiences (Patton 2002), combined with the added benefit of becoming more familiar with the data through transcription of audio files (Rapley 2007) led me to insist on audio recording interviews. To address participants’ concern, we explained the data protection policy in detail, offered reassurance about privacy, and emphasized voluntariness of participation. Service users who felt uncomfortable at this point were thanked, given our contact information in case they changed their mind, and the interaction was ended.

A few service users acted inappropriately towards the RAs during the recruitment phase (e.g., making lewd remarks, making paranoid accusations). In these cases, the RAs informed me using a predetermined code phrase, and I terminated contact with the service user. While it is possible that these service
users may have been able to provide informed consent given adequate time
(Fischer et al. 2013), they were excluded from the study to maintain safety. Missing
out on these few participants was not a major concern as I was consistently on
target for a typical sample size in grounded theory studies (Mason 2010), and it was
more important to get rich data, which I was, than high numbers of participants
(Sandelowski 1995). However, it is possible that those who declined because of my
decision to audio record or were excluded because of safety concerns may have
offered a different perspective on the emerging theory.

Service users who seemed interested after receiving study information were
invited to participate and offered 24 hours to make their decision. This 24 hour
window was a requirement from one of the institutional review boards that
approved the study in order to avoid potential coercion. Coercion was also a
concern for the research team, due to the vulnerable nature of the participant
population (Shivayogi 2013). This concern was addressed by emphasizing
voluntariness and the option to take the 24 hour period to consider participation,
by having a member of staff act as an intermediary to provide introduction, and
taking adequate time to explain the study (Chiang, Keatinge, and Williams 2001;
Carpenter et al. 2000). The majority of service users who seemed interested after
receiving initial information requested to be interviewed immediately. In these
cases, participants were required to answer a list of questions relating to the main
aspects of the study (e.g., benefits/risks, purpose, confidentiality, etc.) (Sugarman
and Paasche-Orlow 2006). If the service user was able to answer these questions,
informed consent was obtained.
A minority of participants were recruited through word-of-mouth. Bryant and Charmaz (2010) view this approach as an “attribute of theoretical sampling” (p.158) as it facilitates the identification of potential participants who have experience with theoretical concepts. I distributed my contact details and brief study information through my personal and professional networks and enrolled participants, requesting that potential participants contact me (Groger, Mayberry, and Straker 1999). This did not result in a large amount of recruitment, possibly because of the level of privacy typically maintained by Arabic families (Abudabbeh 2005) and stigma preventing people from self-identifying as having a mental illness (Corrigan, Larson, and Rusch 2009). However, it facilitated access to participants who were not currently engaged with psychiatric services. These participants offered additional perspectives on the study topic and enabled recruitment of a more diverse sample (Bryant and Charmaz 2010).

2.4.5 Consent

The Helsinki Declaration recommends obtaining written informed consent to protect patient autonomy (“WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects” 2013). However, in Arabic society, a person’s signature is usually associated with major life events, such as, purchasing property, legal matters, and marriage. Past studies have reported difficulty in obtaining a signature as part of the consent process for Arabic research participants (Killawi et al. 2014; Rashad, Phipps, and Haith-Cooper 2004). Lay members of the stakeholder group were consulted regarding consent procedures and they agreed that seeking written consent would be inappropriate. Instead, verbal informed consent was audio-recorded.
Additionally, there is sometimes debate about whether or not people with mental illness have the capacity to provide informed consent. An examination of the literature on this topic (Carpenter et al. 2000; Fischer et al. 2013) led us to conclude that given adequate time, the majority of mental health service users have this capacity. However, additional safeguards were put in place. These are discussed in section 2.5.

2.4.6 Data Collection

The most common source of data in grounded theory research is unstructured interview data (Glaser 1998). Rather than using a pre-determined set of questions, the interviewer asks ‘grand tour’ questions and shows interest in hearing the participants’ stories and concerns (Nathaniel 2008). Unstructured interviews give the participant more control over the content and direction of interviews (Corbin and Morse 2003). This was useful considering that I was interested in participants’ main concerns rather than their perspective on a predefined set of issues. For this study, I asked participants to tell me about themselves and their illness and then encouraged participants to talk about whatever they felt to be relevant. Simple prompts (e.g., “tell me more about that”) were particularly effective at eliciting rich data. Participants were sometimes unsure of where to start but usually, after they began, information started to flow freely.

Major concepts began to emerge after the first few interviews. At this point I began the second phase of recruitment, theoretical sampling. However, as mentioned earlier, it was not possible to identify whether potential participants had prior experience with the concepts or not. Therefore, I continued to sample a broad
range of participants but implemented ‘theoretical interviewing’ to increase understanding of emerging concepts.

Once I began theoretical interviewing I continued to use ‘grand tour’ questions to start the interview but also included more specific questions related to emerging concepts (e.g., “Other participants mentioned a desire to be productive, is that the same with you?”). Using a combination of grand tour questioning and focused questions based on emergent concepts allowed participants to both communicate their own stories and concerns and add perspective to emerging concepts. In many cases, participants’ own dialogue addressed emerging concerns without the need for leading questions.

One to four follow-up interviews were conducted with selected participants (i.e., key informants). This was done to clarify previously collected information, gain perspective on the emerging theory, and assess the temporality of the illness-management process. Key informants were chosen for two reasons. First, because they provided particularly rich information during their initial interview and were open to continuing participation. Second, to allow investigation of hypotheses that emerged from the theory. For example, several participants were anticipating significant life changes in the near future. Follow up interviews enabled me to assess the impact of these changes on theoretical concepts. All interviews were audio-recorded. Table 5 lists displays the key informant interviews. Demographic information has been omitted to protect the privacy of participants.

Table 5. Key informant interviews

<table>
<thead>
<tr>
<th>Participant</th>
<th>Diagnosis</th>
<th>Number of interviews</th>
<th>Time span (months)</th>
</tr>
</thead>
</table>

Because of my inability to speak Arabic and my position as a cultural outsider (Hammersley and Atkinson 2007), RAs who share language and culture with participants were chosen in order to facilitate the culturally nuanced exchange of information (Freed 1988; Sturge 1997). In addition to facilitating information exchange, RAs that share characteristics with the participant population can offer additional insights that might not be obvious to a researcher who is unfamiliar with the local culture (Peacock et al. 2011). Employing local students as RAs also may have contributed to the openness and comfort I experienced from participants.

More specifically, initial consultations with stakeholders suggested that local people (i.e., Qataris), especially local females, would not be willing to participate. However, most service users that were approached seemed open and comfortable, enabling me to recruit and collect in-depth information from a range of service users, including women.

Despite these benefits, several potential issues may arise when using translators in qualitative research. For example, translators may not fully understand English questions and may misinterpret these questions to participants (Kapborg and Berterö 2002). This was addressed through extensive piloting with RAs to ensure that questions were being appropriately translated (Squires 2009). For example, RAs practiced interviewing each other during role plays. They also
interviewed standardized patients and reviewed video-recordings of these interviewers. After data collection began, initial transcripts were reviewed in a group setting and interview style was critiqued. Finally, the use of grand tour questions meant that very few questions had to be asked of participants.

Kapborg and Berterö (2002) also highlight the difficulty faced by interviewers when translating participant responses back to a non-native speaker during the interview. Different interpreting styles have been discussed in the literature, each with their own strengths and weaknesses (Wallin and Ahlström 2006). I chose to let the RA take responsibility for the interview, rather than have questions and answers translated back and forth. This was a team decision and based on an intent to allow rapport to develop between the RA-interviewer and participant, preserve the flow of the interview, and reduce potential for confusion and/or paranoia in participants. This strategy seemed effective, possibly because the RAs had prior training on interviewing this service user population during their studies and because of the extensive piloting.

Interviews were conducted in two general locations where confidentiality could be maintained (Easton, McComish, and Greenberg 2000). One was a room (e.g., office) on the inpatient unit where the service user was admitted. The other was an office at my place of employment (a university). Participants were offered the choice of these two locations, or to identify an alternate location if that is preferable. However, as the majority of participants chose to do their interview immediately after providing consent, the inpatient location was most frequently used.
English interviews were transcribed by either myself or an RA. I double-checked all transcriptions after they were completed to ensure that all identifiers had been removed and to correct any errors or omissions. Interviews in Arabic were transcribed and translated into English by an RA. These were double checked by another RA for errors or omissions. I completed a further check to ensure identifiers had been removed.

Kvale (2008) suggests that having the research team transcribe interviews can provide a positive learning experience and facilitate the enhancement of interviewing skills. This certainly seemed to be the case during this study. The RAs’ immersion in the data encouraged reflection and allowed in-depth debriefing. Using this process, the quality of interviewing (e.g., flow, rapport, depth of data) seemed to increase throughout the project.

The interpretation involved in translating a text from one language to another can also be seen as a threat to data validity (Hunt and Bhopal 2004; Kapborg and Berterö 2002). Interpretations have to be made about meaning when words do not translate directly from one language to another, and these interpretations are culturally mediated (Massimiliano 2013). Even when translators share a similar cultural background, independent interpretations of the same text may differ (Twinn 1997). RAs were trained to expect this difficulty and indeed, they did have difficulty translating concepts on occasion. To deal with these situations, RAs discussed difficult-to-translate concepts and came to a consensus on the best translation.

Despite these potential threats, translating within grounded theory can be seen as a positive process, as it can lead to a better understanding of the data.
(Massimiliano 2013). It can also facilitate conceptual analysis of the data by “intertwining” translation and analysis (Shklarov 2009). I was not able to personally transcribe the Arabic interview data, so I was not able to make full use of these benefits. However, this may have been one of the factors that contributed to the researcher assistants’ increasing proficiency with interviews. Transcribing the English interviews and discussing concepts with the translator(s) was beneficial for me as well in developing an in-depth understanding of the emerging concepts.

One key aspect of grounded theory that protects against the threats of translation is constant comparison. Shklarov (2009, 1), for example, writes that the technique of constantly comparing emerging concepts and theory with new data ensures that theory development “[transcends] cross-language boundaries”. She also emphasizes that the goal of this process is to develop a deeper understanding of emergent ideas. In other words, completely accurate translations of an individual’s data are not absolutely necessary since concepts are being developed by comparing one incident to the next. If a concept is developed based on a mistaken translation, it will be corrected through comparison with subsequent data.

2.4.7 Constant Comparative Analysis (CCA)

One of the key features of CCA in grounded theory is that data collection and analysis occur simultaneously (Glaser and Strauss 1967). Concepts and theory that emerge from one interview guide subsequent recruitment and data collection. Subsequent analysis involves comparing the new data against the previous concepts in order to refine and increase understanding of them. Therefore, it is vital that periods of data collection are interspersed with periods of analysis.
The process of theory building using grounded theory methodology relies on the conceptualizing of empirical indicators (Glaser 1978). Processes and action that occur in the data are abstracted and labelled by the analyst through open and selective coding. For example, an analyst might label a participant’s discussions of the past as ‘reminiscing’. These labels (i.e., codes) become the emergent theoretical concepts and properties (i.e., the multiple dimensions of a concept).

I began analysis after the first two interviews had been transcribed. Open coding was used to ‘fracture’ the story and group similar ideas and occurrences into overarching categories (Glaser 1992). Open coding was done ‘line-by-line’ so that all data was initially coded. This allowed the emergence of a large number of categories and properties that are grounded in the data (and not preconceived). Action words (verbs or gerunds) were used for the majority of codes to ensure a focus on process. The following table shows a participant response from the first interview and the codes that were assigned to each line.

Table 6. Line-by-line, open coding.

<table>
<thead>
<tr>
<th>Data</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant:</strong></td>
<td></td>
</tr>
<tr>
<td>Ummm, I am *name, patient case of bipolar disorder.</td>
<td>Identifying with illness</td>
</tr>
<tr>
<td>I received this diagnosis 2009.</td>
<td>Timelining</td>
</tr>
<tr>
<td>Ahh, first I refused that there is mental health or I have something like this.</td>
<td>Delaying acceptance</td>
</tr>
<tr>
<td>I did not go for the doctor.</td>
<td>Delaying acceptance</td>
</tr>
<tr>
<td>I was going for emergency to take the injection clorazapine to sleep because I was sleepless.</td>
<td>Testing the waters</td>
</tr>
</tbody>
</table>
But ah, later on I found I need this help and I went by myself to the psychiatry department. There I got first admission and it helped me a lot. I stayed there for one month and now after one month and a half. After, I did not continue my study, I did not continue grade 12. But I will continue next year I hope so. What else? I work also at *a hospital and ah only that. You want to ask me any questions?

*indicates where identifying information was removed

As incidents begin to repeat, constant comparison is used to compare them with similar occurrences. This process leads to the development of categories to account for the data in a way that ‘fits’ and is ‘relevant’ (Glaser 1998). Some of the initial categories that emerged from the data in this study are listed in Figure 4 section A below (p.59). During open coding three main questions were repeatedly asked of the data:

1) What is this data a study of?
2) What concept does this incidence indicate?
3) What is actually happening in the data?

(Glaser 1978).

Theoretical Memoing is an important procedure for grounded theory analysis, coincides with coding, and captures a researcher’s analytic thoughts and insight (Glaser 2014). There is no predetermined structure or content for memos and they can take many forms depending on the analyst. Memoing throughout the entire process can help to add analytic depth to a theory up until the time it is
submitted to be published (Glaser 2014). I began to write theoretical memos when coding and continued until the analysis and discussion chapters were finalized. The majority of my memos were attempts to elaborate emergent concepts and functioned to describe the nature of the concept or its relationship to another concept. These often left me with questions to investigate through constant comparison or identified weaknesses in my current conceptual understanding (i.e., areas where additional data was needed). The following is an excerpt of a memo related to the initial development of valued contributory membership as a potential core category:

Mental illness is seen as a major threat to valued contributory membership and much of the day-to-day behaviour of people with mental illness can be seen as an attempt to ameliorate the impact of their illness on the value of their member contribution. This is particularly true around times of acute illness acerbations. However, mental illness is not the main focus of the observed social patterns. In fact, it forms one of many concerns that are constantly resolved, with the ultimate focus being on maintaining or increasing potential contribution.

When a core category becomes clear, the research shifts to selective coding (Glaser 2015). Some of the selective codes that were used in the current study are listed in Figure 4, Section B (p.59). Selective coding refers to the process of coding only empirical indicators that relate to the core category and are helpful in organizing the developing theory (Draucker et al. 2007). This allows the research to focus on relevant data and ignore data that is unrelated to the emerging theory.
(Holton 2010). This increased focus allows more in-depth development of relevant concepts and speeds up the coding process.

As more becomes known about the core and sub-core categories they are developed and refined through further memoing. In my case, this development was possible because additional data and comparisons allowed me to more clearly elaborate concepts and their properties, and as the analysis proceeded, my memos produced fewer gaps and questions to follow up on. The statements below are exerts from a series of memos that detail my evolving understanding of the core category.

July 14. Recently I changed, or thought about changing valued contributory membership to satisfied contributory membership...

July 20 Today, I am wondering if esteemed contributory membership is more appropriate....

Sept 13. Core category is contributory membership. Basically, this means being part of a group in which some kind of contribution is made....

Through constant comparison, selective coding, theoretical interviewing, and memoing, I eventually labelled the core category as reciprocity membership. Three sub-core categories were also identified, managing relationships, valuing and positioning. These will be discussed further in the results chapter. However, it is worth noting that once these concepts are identified, it is the researcher’s job to look deeper and identify the properties of these concepts. There are many possibilities for properties, depending on the nature of the core and sub-core
categories. Types, stages, conditions, and sub-processes are all potential areas for category development. An example given by Glaser (1998) is the core concept of celebrity. Different types could include musician, actor, philanthropist, etc. In this study, the core concept had four associated conditions, contribution to, expectations of, acknowledgement from and alignment with.

Theoretical saturation occurs when no further concepts or properties of concepts are being identified during CCA. At this point, analytic focus shifts to developing theoretical codes (Glaser 1978). Theoretical codes are also grounded in data, but function to conceptualize the relationship between substantive codes. To clarify, substantive codes conceptualize the empirical data while theoretical codes conceptualize the relationships between concepts (Holton, 2010). Theoretical coding in the current study highlighted several cause/effect relationships in among the core and sub-core categories (See Figure 5 p.88). For example, when reciprocity membership is unbalanced it leads to action through managing relationships or positioning. This action may result in a balancing or rebalancing of reciprocity membership. Theoretical coding is generally done during the sorting phase (Glaser 1978; Holton 2010).
A. Initial concepts identified (some examples listed)

- Open coding; comparison of incident to incident
  - 1. Participant contribution
  - 2. Contributory membership
  - 3. Valuing
  - 4. Improving
  - 5. Envisioning
  - 6. Connecting
  - 7. Synapsing
  - 8. End of the denying line
  - 9. Catastrophising

B. Concepts refined (final concepts listed)

- Selective coding; comparison of concept to incident
  - Reciprocity Membership (creating by combining 1, 2 and several other concepts from the open coding stage)
  - Valuing (remained consistent with open coding stage)
  - Positioning (created by combining 4, 5 and several other concepts from open coding stage)
  - Managing Relationships (created by combining 6, 7 and several other concepts from open coding stage)

C. Grounded theory developed*

- Theoretical coding; comparison of concept to concept

*See Figure 5, p.88 for accurate representation of theory
Sorting refers to the process of arranging and rearranging memos in various ways until a coherent theory has been formed. Much of the sorting had been done in my head before I physically printed my memos, cut them into pieces and arranged them in folders in my office. I initially created four folders, one for the core category and three for the sub-core categories. I created subfolders as I grouped memos into properties of concepts. These were inserted into each main folder. I also created new folders (e.g., implications) to hold memos that did not fit directly within the main theory.

As I was sorting, I found that I had already identified the relationships between categories (i.e., theoretical codes) prior to sorting. Unlike Holton (2010), I had unwittingly theoretically coded my data while memoing. The following excerpt provides an example of how a memo was used to capture the relationship between categories.

*Valuing* is closely linked to *positioning*. The *valuing* process seems to prompt action in both the *positioning* and probably the *connecting* (later changed to *managing relationships*) processes. Particularly when value is deemed to be less than ideal and when new opportunities are identified.

Finally, the sorted memos were used to guide the final stage of the analytic process, writing (Holton 2010). The organization of folders was used to create an outline for the results chapter (Glaser 2014). Theoretical concepts were written up verbatim from sorted memos (Glaser 2012) or sometimes edited for grammar and flow. Because a great deal of content had already been written into the memos, there was very little additional writing to do for the results. The most time
consuming process was going back to the data to find quotes I could use to illustrate concepts in the theory. Writing continued until all sorted piles of memos (i.e., concepts) had been integrated into a coherent theory (Glaser 2012).

2.5 Ethical considerations

There is an apparent debate regarding the universality of ethical guidelines for human subjects research (Abdur Rab et al. 2008). Some authors assert that international guidelines are based on Western values and principles and do not provide appropriate guidance for research in other cultural contexts (Rashad, Phipps, and Haith-Cooper 2004; Rathor et al. 2011). However, international guidelines acknowledge that local cultural, religious, and social contexts, as well as regulations and policies, should be taken into account (Council for International Organizations of Medical Sciences and Islamic Organization for Medical Sciences 2004; “WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects” 2013; World Health Organization 2011b).

This project was reviewed and approved by the University Research Ethics Committee at the University of Manchester. My employer at the time of the study (University of Calgary) also required an ethical review, so a second review and approval was undertaken. Stakeholder consultations and a third ethical review by the local institutional review board (Hamad Medical Corporation’s Medical Review Council) helped to ensure that local research regulations were met and that ethical principles had been integrated into the research protocol in a way that was culturally appropriate.
2.5.1 Autonomy and informed consent

As a Caucasian, male, Western, relatively young (37-38 at the time of the study) researcher, it would have been impossible for me to effectively explain the study to potential Arabic participants. Language and cultural barriers can create a challenge for ensuring informed consent (Betancourt and Jacobs 2000). I expected that this would be especially true for Arabic women, whom it would be inappropriate for me to approach directly without a male relative present. To address these issues, a female, Arabic RA was always with me during inpatient recruitment. This seemed to help alleviate participants’ potential feelings of mistrust and overcome cultural barriers (Yancey, Ortega, and Kumanyika 2006).

Participants’ openness during interviews may also have been due to the fact that this interaction was seen as professional in nature rather than social. In Qatar, male-female and local-foreigner social interaction is extremely restricted. However, the cultural norms for formal or structured interactions (e.g., going to see the doctor or working for a boss of a different gender) are much more open. Thus, participants seemed comfortable to discuss sensitive topics with me in the researcher-participant relationship even though I am an outsider and male.

Based on literature I had read (e.g., Rashad, Phipps, and Haith-Cooper 2004; Killawi et al. 2014), I expected that some women may be hesitant to consent to research participation without their husband’s permission. Killawi et al. (2014) dealt with this issue by including a family member in the consent process if this was requested by the potential participant. I included a plan to deal with this in my research protocol, which was inclusive of the family member. However, none of the female participants voiced this concern. In fact, it was quite the opposite for several
participants who saw the interview as an opportunity to confidentially voice their experiences even while acknowledging that their families would not approve of them doing so.

2.5.2 Confidentiality and data protection

Confidentiality and data protection are governed by well-established legislation in developed countries. In Qatar, privacy is widely acknowledged to be important, but a coherent, consistent policy does not exist and there is no specific legislation addressing privacy issues (Salt and Earley 2011). According to Fadel (2010), confidentiality is a ‘basic tenet’ of Islamic law. This principle is evident in everyday life: high walls surround all private residences to protect families’ privacy, most GCC Arabs consider the posting of personal photos and information on social media sites to be unacceptable, and family matters are rarely discussed in public. The position of the Islamic Organization for Medical Science is that confidentiality of research subjects must be maintained, within limits (Council for International Organizations of Medical Sciences and Islamic Organization for Medical Sciences 2004). These limits include cases where maintaining confidentiality poses a risk to the research subject, or when sharing confidential information has the potential to benefit the wider society (Fadel 2010). However, it is unclear what type of social benefit would overrule the principle of confidentiality.

This study was designed to comply with the UK Data Protection Act (“Data Protection Act 1998” 1998) and The University of Manchester’s Data Management Policy (“University of Manchester Research Data Management Policy” 2013). A data management plan was created in order to help ensure compliance. In summary, all interviews were conducted in a private location, interview and demographic data
were transported in a locked box and stored securely. Electronic files were encrypted and stored securely on the University of Manchester research server and on a secure backup. All identifiers were removed during transcription. Names and contact details for participants were recorded in order to arrange follow up interviews or if future contact becomes necessary. This information was (and continues to be) stored securely and only available to me. Access to other data was limited to study personnel only for the length of time it is necessary for them to access (e.g., for transcription and analysis). Data will be securely destroyed five years after the end of the study.

2.5.3 Safety

The safety of participants and researchers is an important ethical consideration in all research (Royal College of Nurses 2009). Several potential risks to safety were identified while planning the study. For participants, mental illness can be a sensitive topic due in part to the associated stigma. Additionally, several interviews led to discussions of alcohol/drug use (both of which are illegal for Muslims in Qatar), attempted suicide (which is also illegal in Qatar) and sexuality (another taboo issue). From my clinical experience however, it is clear these topics are within the boundaries of what is acceptable for a patient to discuss with a nurse or other health care professional. While the research interviews were not conducted within the context of a therapeutic relationship, my position as a university instructor seemed to make discussing these health-related topics less distressing for the participant.

Additionally, a predetermined distress policy was used to safeguard participants. This policy outlined the protocol to follow if a participant became
upset during an interview. Key steps included terminating the interview, providing verbal support and reassurance, remaining with the participant until a family member or caregiver was present, assessing need for referral to psychiatric services, and providing contact information for support services. The policy also required follow up after 24 hours. It was implemented only once during the study. In this case the distress was resolved by terminating the interview and providing support and reassurance.

As mentioned in the methods section, the RAs felt that their safety was threatened on a few occasions. In these cases, they were able to communicate their discomfort to me, and I was able to terminate the interview. We were not prepared for this risk prior to beginning the study but I was able to recognize the RA’s discomfort and subtly inquire about their wellbeing. After the initial occurrence, I conducted a debrief with all the RAs and we agreed on a code phrase (“I need a pencil”) if similar situation arose in the future.

Professional counselling services for the research team were freely available throughout the project. To my knowledge, no one needed to make use of these. Weekly meetings were held with the RAs to debrief potentially stressful situations and discuss other issues.

2.6 Rigour

In *The Discovery of Grounded Theory*, Glaser and Strauss (1967) proposed a unique set of criteria for evaluating rigour in grounded theory studies. Glaser (1998) has since revised these criteria:

1. **Fit** – does the theory fit the substantive area in which it will be used?
2. Workability – do the concepts, and the ways in which they are related, account for how participants resolve their main concern(s)?

3. Relevance – is the theory relevant to a wider audience than academics (e.g., participants, healthcare professionals)?

4. Modifiability – theories should have enough flexibility to allow changes when new data is obtained.

Glaser (2015) stresses the importance of asking questions 1-3 throughout the research process. This ensures that rigour is maintained throughout the research process and not viewed as having a post-hoc evaluative function (Morse et al. 2002). I believe that question 4 should also be assessed throughout analysis. For Glaser (1998), modifiability refers to changing or updating a grounded theory after publication. However, emerging concepts and theory should be consistently modified and updated throughout development of the pre-published theory. It seems likely that ‘forcing’, in particular, may be an issue if a researcher is unable or unwilling to modify a developing theory based on their data.

Several other characteristics of the project helped to ensure rigour.

Continuing theoretical interviewing until theoretical saturation (described in section 2.4.7, p.57) ensures that data collection is based on emerging concepts and that sample size is determined by theoretical saturation (Baker, Wuest, and Stern 1992). Reflexivity was used to help ensure that my own effect on the data is monitored and acknowledged and helped to prevent forcing. Finally, I avoided inappropriate mixing (i.e., ‘slurring’) of methodological approaches (Baker, Wuest, and Stern 1992) and increased precision (Cutcliffe 2000) by adhering to the methods of classic grounded theory. These methods were developed and underwent ongoing
assessments by studying the key texts on classic grounded theory (Glaser 1978, 1998; Glaser and Strauss 1967), by discussing my approach in person with Barney Glaser and other members of the Grounded Theory Institute at a seminar in California (May, 2015), and through regular discussions with my supervisory team.

2.7 Summary

The methodology for this project was selected and customized in order to address the following aims:

1. Explore service users’ experience of mental illness Arabic context.
2. Identify service users’ main concern(s), related to mental illness self-management.
3. Identify and describe the actions service users take to address their illness self-management concerns.
4. Develop a substantive theory of mental illness self-management.

Classic grounded theory was chosen as the most suitable methodology because of its focus on social processes and its prioritization of participants’ main concerns. Adult mental health service users with an ongoing potential need for services were identified as the most appropriate population group for the development of a substantive theory because of mental health care planning priorities at the time. Inpatient psychiatric units were chosen as the main recruitment location but word-of-mouth recruitment was also included in order to access participants who were not currently engaged with services. Unstructured, face-to-face interviews were selected as the method for collecting data. In keeping with grounded theory methods, constant comparative analysis was chosen as the primary method of analysis. Memoing, sorting, and writing were planned as integral
aspects of the analysis. Access to the participant population and development of culturally appropriate protocols was facilitated by stakeholder consultation and ongoing rapport building with gatekeepers. Rigour was approached as an ongoing, rather than post hoc, process based on established criteria for grounded theory research.

The next chapter present results from the empirical study that was conducted. The grounded theory of reciprocity membership is discussed in detail. This study was based on the aims that were developed through the two literature reviews presented in chapter 1 (p.15 and 16) and according to the methodology that has just been discussed in chapter 2. The results are presented in the form of a journal article. As such is the case, some of the information from chapters 1 and 2 are necessarily repeated.
Chapter 3 Contents

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3.3 Summary ............................................................................................................... 105
3.1 Introduction

Chapter 1 presented the background and literature reviews that provide much of the foundation for the empirical study. Chapter 2 described the methodology and methods that were developed to address the research objectives. This chapter provides the results from the grounded theory study that was completed and is presented in the form of a journal article. Much of the introduction and methodology sections in the article repeat content that has already been discussed in Chapters 1 and 2 of this thesis. The results and discussion sections provide novel content. The article was submitted to Qualitative Health Research in November 2017 and is currently under review. Note that tables and figures in the article are numbered according to their position in the thesis rather than their position with the article.
3.2 Study 3 – Reciprocity membership. A grounded theory of recovery among adults with mental illness in an Arabic context
Abstract

Classic grounded theory was utilized to explore the illness self-management concerns and strategies of mental health service users in an Arabic context. The theory of *reciprocity membership*, a process involving ongoing mutual exchange with a group or community, was developed. *Reciprocity membership* becomes balanced when an individual is satisfied with their *contribution to* the group, the *acknowledgement from* other group members, the *expectations of* the group, and their *alignment with* the values of the group. Balance among these conditions is appraised by a sub-process called *valuing*, and developed or maintained by two further sub-processes called *positioning* and *managing relationships*. *Reciprocity membership* seems to be associated with recovery and positive mental health.

Findings provide the first theoretical framework for recovery in an Arabic context.
Personal recovery in mental illness refers to a person’s ability to live a meaningful life regardless of limitations imposed by illness. This concept has origins in a service user movement that started in the 1980s and began as somewhat of a protest against the predominant biomedical focus of symptom resolution through medication. Since then, it has been taken up by mental health professionals and policy makers as a popular approach to mental health care. However, this widespread professionalization has been criticized by some service users (#UnRecovered 2017). These service users argue that generalized theories of recovery have created unreasonable expectations within the mental health care system. Thus, in some cases, recovery has become a policy-directed goal rather than a service user-experience.

In recent decades, theoretical models of recovery have been incorporated into mental health policy and practice across the globe (Pincus et al. 2016). Common concepts, developed through numerous qualitative studies and service user accounts, include hope, social connectedness, control/empowerment, personal responsibility, finding meaning, and identity (Repper & Perkins 2003; Slade et al. 2012; Whitley & Drake 2010). However, the application of these concepts has had mixed results. For example, Slade et al. (2015) found no difference in the main recovery outcome measure between control and experimental groups in a community-based RCT. The authors suggested that the lack of positive outcome may have been related to limited implementation of the intervention by front-line multidisciplinary teams. If true, this may be because concepts such as hope and
self-determination are subjective and difficult to operationalize. Criticism from service users, described earlier, also suggests that those with mental illness may not share the same recovery goals as professionals. Thus, recovery models need to fit with service users’ priorities.

Other trials have shown more positive results. For example, Segal, Silverman and Tempkin (2010) demonstrated the effectiveness of a ‘self-help agency’ intervention. They attributed success to the empowering nature of the program, which gave participants decision-making ability in the ‘agency’. Although not stressed by the authors, this program offered the additional benefit of creating a valuable social role that was not previously available to the service user. Thus, the new social role that was created, along with the empowerment offered by the program may have contributed to recovery.

Another criticism of personal recovery models is that they been developed largely from monocultural data (i.e., Anglo-Caucasian service users) and may not be transferrable to other population groups (Slade et al. 2012). For example, Hickey, Pryjmachuk and Waterman (2017) discuss how common recovery concepts may not be a good fit in an Arabic context. The collectivist culture, doctor-patient relationship, and supernatural beliefs (e.g. jinn, black magic) seem to be in contrast to several common recovery features. Similarly, Bayetti, Jadhav, and Jain (2017) caution against the uncritical adoption of a Western recovery model in India. Authors of both these articles argue that applying current models of recovery to non-Western populations has the potential to impose values that are detrimental to health care outcomes. This suggests that recovery models grounded in the local context may be more effective that a one-size-fits all model.
The current study was conducted in Qatar, a rapidly developing Arabic country. A major influx of immigrants since the 1980s, based mainly on labour migration, has created a diverse population with complex needs. However, public mental health services are limited and consist primarily of a 63-bed inpatient hospital with an outpatient department and a residential care centre offering day programs, long term care, a child/adolescent outpatient clinic and outreach services. These serve a population of approximately 2.7 million people, around 90% of whom are non-Nationals (Ministry of Development Planning and Statistics 2017). Recently though, considerable resources have been directed towards development and expansion of existing mental health services, and in 2013, the first National Mental Health Strategy was published (Supreme Council of Health 2013). This report incorporated a focus on the concept of personal recovery and called for better contextual understanding about people’s experience of mental illness.

The aim of the current study was to develop a theoretical understanding of mental illness self-management in an Arab context. Self-management, defined as “the actions taken by people to recognise, treat and manage their own health” (NHS n.d.), was chosen over recovery so as not to force potentially inappropriate concepts of recovery into the study. Additionally, self-management may encompass components of recovery, but does not imply or require that recovery is taking place. Our objectives were to:

1. Explore service users’ experience of mental illness in an Arabic context.
2. Identify service users’ main concern(s), related to mental illness self-management.
3. Identify and describe the actions service users take to address their illness self-management concerns.

4. Develop a substantive theory of mental illness self-management.

**Methodology**

In the context of the current study, service users have had limited input into the development of service and policy, and the National Mental Health Strategy acknowledges a need for additional service user perspective (Supreme Council of Health 2013). The professional experiences of the primary author have shown that opinion and advice from international experts is often valued above that of local experts, including experts-by-experience and front-line staff, and that service users’ voices in particular often go unheard.

We chose a Classic Grounded Theory (CGT) approach (Glaser 1978; Glaser & Strauss 1967) to address our research objectives because of its exclusive focus on the concerns of participants. Several other popular approaches to grounded theory are available (e.g., Charmaz 2014; Corbin & Strauss 2007). However, these distribute the focus of the research. For example, Corbin and Strauss (2007) place importance on the researchers’ own perspective and what has already been written in the literature and use these as data to be explored with participants. Charmaz (2006) directs attention towards “…larger and, often, hidden positions, networks, situations, and relationships” (p.130). These other approaches would offer unique insight into the mental illness management process in this context but may also shift the focus of the research from the participants’ concerns to other perspectives. Thus, we consider classic grounded theory as best suited to address the lack of service user voice in the current context.
The core principles of CGT are 1) generation of theory through induction based on emergence rather than deduction or verification, 2) theoretical sampling of participants, 3) constant comparative analysis, 4) and conceptualization rather than description (Christiansen 2007). Grounded theory enables the development of a substantive theory, essentially an interrelated set of concepts and their properties, which is relevant and useful to lay practitioners (Glaser 1998). CGT also requires that the researcher remain open to the main concerns of participants (Glaser 1978). Thus, we entered the study with an interest in self-management of mental illness but we were open to the topic of the study potentially changing depending on the concerns of the participants.

This study received ethical approval from the University of Manchester University Research Ethics Committee, University of Calgary Conjoint Health Ethics Research Board, and the Hamad Medical Corporation Medical Research Council. All participants provided audio-recorded verbal informed consent. This consent was obtained after the study had been explained and understanding had been verified through a brief set of questions about the main aspects of the study (e.g., purpose, voluntariness, etc.).

Participants

We used purposive sampling to recruit service users with a range of psychiatric diagnoses with the intention of developing a mid-range theory that would be useful to front-line staff working with diverse patients. We also attempted to recruit similar numbers of male and female participants because previous literature in the region favoured males by a ratio of 2:1 (Hickey, Pryjmachuk, & Waterman 2016) and we felt this would lead to a more equitable
grounded theory. After concepts began to emerge, we used theoretical sampling (Glaser 1978; Glaser & Strauss 1967) to recruit participants who were likely to be able to offer additional perspective on these concepts.

Inclusion criteria for participants included, 1) aged 18 or older, 2) able to converse in Arabic or English, 3) not repatriating after discharge (in the case of non-nationals), 4) diagnosis of any mental illness, 5) capable of providing informed consent, and 6) willing and physically able to participate in an interview. Participant characteristics are presented in Table 6.
Table 7. Participant characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Religion</strong></td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>19 (90.5)</td>
</tr>
<tr>
<td>Christian</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (57.1)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (42.9)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>11 (52.4)</td>
</tr>
<tr>
<td>Married</td>
<td>10 (47.6)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>11 (52.4)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>10 (47.6)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>21-29</td>
<td>11 (52.4)</td>
</tr>
<tr>
<td>30-39</td>
<td>7 (33.3)</td>
</tr>
<tr>
<td>40-47</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td><strong>Nationality</strong></td>
<td></td>
</tr>
<tr>
<td>Qatari</td>
<td>8 (38.1)</td>
</tr>
<tr>
<td>Egyptian</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>British or Canadian or</td>
<td></td>
</tr>
<tr>
<td>Indonesian or Iranian or</td>
<td></td>
</tr>
<tr>
<td>Lebanese or Omani or</td>
<td>10 (48)</td>
</tr>
<tr>
<td>Pakistani or Pilipino or Saudi Arabian or Tunisian</td>
<td></td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
<td></td>
</tr>
<tr>
<td>Qatar</td>
<td>14 (66.7)</td>
</tr>
<tr>
<td>Outside of Qatar</td>
<td>7 (33.3)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>9 (47.6)</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>6 (28.6)</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>Anxiety disorder</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Post-partum depression</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>ADHD</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>Eating disorder</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>Post-traumatic stress disorder</td>
<td>1 (4.8)</td>
</tr>
</tbody>
</table>

*Being born in Qatar does not result in citizenship
**n/% add to more than 21/100% because some participants had multiple diagnoses; Diagnosis based on self-report
Recruitment and Data Collection

Recruitment and data collection were led by the primary author of this article, a male nursing instructor at a local university and a PhD candidate at the time of the study. Six undergraduate nursing students, fluent in English and Arabic, were engaged as co-researchers in the study and contributed to data collection under direct supervision of the primary author. These students had all completed two mental health nursing courses prior to joining the project and were familiar with mental disorders and communicating with mental health service users. All received additional training in research methods (e.g., ethics, data collection, transcription, translation, dissemination) as part of their participation in this project.

The primary method of recruitment was to approach inpatients at the public psychiatric hospital. This was done by the primary author and a student co-researcher after an initial discussion with the charge nurse to identify potential participants. Once a potential participant was identified, an introduction was made by a member of the nursing staff. The study team was introduced as a nursing instructor and student at the local university who were conducting a study about people’s experience of mental illness. We also used word-of-mouth as a secondary method of recruitment in order to access potential participants who were not currently engaged with mental health services.

Open-ended interviews were conducted in either Arabic or English, depending on the preference of the participant. These interviews were audio recorded. We chose several open-ended questions to begin the interviews, “please tell me about yourself”, and “please tell me about your illness”. We then used
prompts to encourage elaboration. In keeping with grounded theory methods, data collection and analysis were conducted concurrently.

When concepts began to emerge during analysis, we began to follow ‘grand tour’ questions with focused questions about those concepts. In that way, we were able to elicit a broad range of information and gain a deeper knowledge of certain topics. Near the end of data collection, no new concepts were emerging so we began to focus more on saturating our knowledge of the main concepts. Follow-up interviews with key informants were particularly useful in this regard.

Twenty-eight interviews were conducted with 21 participants. Interviews ranged from 6-60 minutes with an average length of 31.3 minutes and were conducted either in a private location in the hospital or in the private office of the lead author. The combined length of all interviews was approximately 878 minutes.

Data Analysis

English audio-recordings were transcribed by the primary author or a student co-researcher. Arabic audio-recordings were translated and transcribed by the student co-researchers. Arabic translation and transcription were done simultaneously (i.e., Arabic audio was transcribed as English text). English transcriptions were double-checked by the primary author for accuracy. Arabic transcriptions were checked by another student co-researcher. Inconsistencies were discussed and resolved by consensus. All identifiers were removed during this process. A total of 248 pages of transcripts was produced.

Data analysis began with open coding, aimed at ‘fracturing’ (Holton 2010) the data. This was done line-by-line and focused on the question of ‘what is going on in the data’ (Christiansen 2007). Gerunds, action words ending in ‘ing’ (e.g.,
improving, connecting), were used for the majority of codes. This focused the
analysis on processes in the data. Selective coding began after the main concern of
participants became clear and several sub-core processes emerged. At this point,
only data related to the main concern was coded. Finally, theoretical coding was
undertaken to identify relationships between the theoretical concepts. Coding was
done by the primary author using NVivo10 (QSR International Pty Ltd 2013).

Constant comparison (Glaser 1978) was used throughout the analytical
process. Initially, incidents were compared to other incidents. This led to the
development of concepts. Then, subsequent incidents were compared to concepts
in order to develop, modify and saturate these concepts. Finally, concepts were
compared to concepts to develop understanding of the relationships between them
and to develop theoretical codes (Glaser 1998).

Memoing (Glaser 2014) was an important technique used throughout the
data analysis. All analytical thoughts, musings, and ideas about emerging concepts
and theory were recorded. Throughout analysis, memos functioned as analytical
memory and facilitated constant comparison. When theoretical saturation (Glaser
1978) had been reached, all memos were reviewed and sorted (Glaser 1998) into
groupings representing the concepts in the grounded theory. These memos then
provided the majority of content for the written theory.

Rigour

In The Discovery of Grounded Theory, Glaser and Strauss (1967) proposed a
has since revised these criteria:

1. Fit. Does the theory fit the substantive area in which it will be used?
2. Workability. Do the concepts, and the ways in which they are related, account for how participants resolve their main concern(s)?

3. Relevance. Is the theory relevant to a wider audience than academics (e.g., participants, healthcare professionals)?

4. Modifiability. Theories should have enough flexibility to allow future changes.

Questions 1-4 were reflected on throughout the research process as suggested in the literature (Glaser 2015). Doing this ensures that rigour is maintained throughout the research process as opposed to being based on a post-hoc evaluative function (Morse, Barrett, Mayan, Olson, & Spiers 2002). Rigour was also maintained by adhering to the systematic methods aligned with classic grounded theory. This helps to ensure precision (Cutcliffe 2000) and prevent inappropriate mixing (i.e., ‘slurring’) of methodological approaches (Baker, Wuest, & Stern 1992).

**Results**

The majority of participants directly stated, or alluded to, their desire to make a meaningful contribution to others. They valued the support they received from others, but equally, if not more, important was the contribution they made to those others. What participants wanted was 1) to feel a sense of belonging to group of ‘others’, for example, family, co-workers, friends, etc. and, 2) for there to be reciprocity in those relationships. Thus, *reciprocity membership*, emerged during analysis as the main concern of participants in this study.

Reciprocity is traditionally understood to be a process of exchange for mutual benefit (Oxford Dictionaries 2017). However, reciprocity has a more complex meaning for participants in this study due to its association with an active
group association. Thus, reciprocity membership builds upon the concept of reciprocity.

Four conditions need to be met in order to achieve reciprocity membership. These are contribution to, acknowledgement from, expectations of, and alignment with. Contribution to refers to what someone provides to the group. Emotional support, parenting, volunteer work, money for rent, and sharing knowledge are all examples of contributions made by participants in this study. Acknowledgement from refers to what someone receives in return for their role as a member. These rewards can be tangible, such as clothing, housing, and money, or intangible, such as praise, acceptance, or a sense of esteem. Expectations of refer to the demands placed upon individuals by their community members. Having a reasonable amount of responsibility can encourage individuals to maintain their contribution. Having too much or too little can cause distress. Alignment with refers to the similarity between an individual’s values, interests and beliefs, and those of the group.

Balance between these conditions is appraised through a secondary process, valuing. Two other secondary processes, positioning and managing relationships, are employed as strategies to achieve balance, or to respond when intrinsic and extrinsic pressure leads to unbalance. These secondary processes are explained in more detail later.

Reciprocity Membership, Mental Health and Mental Illness

This study began as an exploration of how people self-manage mental illness outside of the hospital setting. However, during initial analysis, most of the concerns that arose seemed to have very little to do with mental illness. Participants wanted to see themselves as productive, and while their mental illness
sometimes made this easier or more difficult, it was often set aside for the more concerning work of achieving or maintaining reciprocity membership.

Eventually though, mental health and mental illness found their way back into the analysis. For example, mental illness can be seen as a threat to reciprocity membership. One female had been hospitalized in the past with postpartum depression, and expressed a concern during the interview that she would relapse. Her fear was not directly related to becoming ill again or being hospitalized, but to her not being able to work (i.e., contribute to).

*I will be admitted again in the hospital, and, it will change my life, you know? Because I have children, and I have to take care of the children. I have my future to work, you know? It will affect my work, how can I go to work...that’s why I’m taking my medication and going to my appointments because I don’t want to relapse (Arab female).*

Other participants hide their illness from friends and colleagues at work because they fear that exposure will prevent them from being promoted or maintaining their position in the group.

*I don’t mind telling people, but there are certain people I don’t like telling just for career [reasons]. I know people have a stigma so I won’t share that information with people in the career field (Arab male).*

When reciprocity membership is absent or breaks down, it seems to be associated with distress. This distress is a burden on one’s mental health and can lead to deterioration and relapse. One participant is not able to support his family financially due to current but temporary circumstances. He says, “How am I supposed to support my family [under these circumstances]? ...even if I am happy with my new wife, I feel depressed.” His circumstances and resultant inability to contribute to his family in the way he feels he should cause his mental health to
deteriorate. He begins hearing voices and sleeping in his car at night to avoid his family.

Some participants have tenuous connections with others, but no real sense of membership or belonging. These people seem to have poor mental health, low resilience and frequent relapse. One such participant described her disconnection with her family,

_Why my ex-husband doesn't ask about me or take care of me (stated with distress)? Why doesn't he put me in a house with the children? Why didn't he take me back? He should do that. He is supposed to ask about me in this long absence (Arab female; translated from Arabic)._ 

However, it is also possible that mental illness is the cause for not having reciprocity membership rather than the other way around. Another participant talks about how her illness harmed her membership status.

_I was suspecting that my husband was cheating on me and having relationships with other women, but he wasn’t. Being suspicious harmed and destroyed me and not only me but also people who are around me (Arab female; translated from Arabic)._ 

Prioritizing reciprocity membership over one’s individual needs or problems may be protective for an individual’s mental health. One participant provides an example of how his responsibilities to his family prevent him from acting on suicidal impulses,

_I say to myself, what will happen if I just do like this – makes a motion of suddenly turning the steering wheel of a car – at high speeds? I will finish my life and I’ll be happy. [My wife and daughter] is what just prevents me now (Arab male)._ 

Throughout the study it seemed that individuals with balanced reciprocity membership were more hopeful and optimistic about the future, had multiple strong and resilient connections, and were empowered to make choices and
undertake challenges. In other words, these people seemed to have a more positive recovery experience.

In summary, it seems that *reciprocity membership*, mental health and mental illness are potentially related in several ways: 1) Mental illness can be a barrier to achieving or maintaining *reciprocity membership*; 2) When *reciprocity membership* breaks down, it may lead to a decrease in mental health; and, 3) When *reciprocity membership* is balanced, it seems to contribute to resilience, positive mental health, and recovery.

**Grounded Theory of Reciprocity Membership**

As mentioned previously, *valuing*, *positioning*, and *managing relationships* (described later) are secondary processes that support *reciprocity membership*. These processes form the grounded theory that emerged during data analysis. This theory is illustrated in Figure 5.

*Reciprocity membership* is situated just to the right of centre in the illustration. It is the main concern of people in the study and is determined by four conditions. *Valuing*, to the left of centre, is the process by which people appraise the four conditions of *reciprocity membership* (*contribution to*, *acknowledgement from*, *expectations of*, *alignment with*). These can be judged as balanced/unbalanced or satisfied/unsatisfied. If *reciprocity membership* is perceived as being unbalanced/unsatisfied, the *valuing* process prompts action in one or both of the other sub-core processes, *positioning* and *managing relationships*. The strategies associated with these processes function to create or restore balanced *reciprocity membership*. On the right of the diagram, mental
health has been included as an implication or point of relevance related to the overall process.

Figure 5. Illustrated grounded theory of reciprocity membership

One participant provides an interesting example of the processes illustrated in Figure 5 when she describes her recent experience as an inpatient. She has had many admissions in her life in several countries and sees herself as an expert-by-experience. The community she is currently a member of is the treatment team, and as the quote below illustrates, she feels that the expectations of her psychiatrist are unreasonable.

...this guy, he just, makes me feel like I’m, I’m, stupid for, for feeling the way I do. I’m stupid for having depression, I’m stupid for having anxiety, I’m stupid for the fact that I haven’t fixed it (Western female).

Her valuing process appraised reciprocity membership as being unbalanced because she felt she was being expected to fix her problems on her own. This prompted action through managing relationships and positioning. These processes were activated with an emotional outburst that might seem unproductive. However, through the outburst, she was able to situate herself as an expert-by-experience (positioning) and establish that she wanted to negotiate roles and responsibilities (managing relationships) in the treatment team.
...it was like a red flag to a bull. You can imagine the profanity he might’ve heard, which I don’t really think he appreciated. I told him he was a disgrace to the healthcare profession and told his residents who were there to learn from him how NOT to be a doctor and asked him if he got his degree off the back of a cereal packet (Western female).

In effect, she was advocating for the treatment team community to adjust their expectations of her and increase their acknowledgement of her efforts and experience. She was also making it clear that there is poor alignment with her and her psychiatrist’s idea of adequate care.

Valuing

Valuing is an appraisal of reciprocity membership. It is an invisible process whereby a person continually assesses their contribution to the community and their place within it. The valuing process entails asking questions that relate to one’s reciprocity membership. Two main questions are asked:

1. Does this reciprocity membership equate to positive mental health and satisfaction?

2. Is this reciprocity membership reciprocal/balanced?

In this study, contribution to was most often the focus of the valuing process. Participants judge themselves in relation to the contribution they are able to make in the community(ies) in which they hold membership. Self-worth seems closely linked to the perceived value of these contributions. For example,

Interviewer: Do you see yourself as having any productive roles?

Arab male: Not yet. I’m aiming for one. I think being useful to other people is what makes a person useful, ultimately. I’m trying, but I don’t feel I am doing any good at the moment. I feel I am only causing harm. To my family, to my job, to this hospital...I’m just trying to get out of here, get my life back, and start new. And be productive, of course, that’s part of it.

Valuing also appraises whether or not the contribution is balanced by what one receives in return. For example, when someone is satisfied with the
acknowledgement from others, it can boost self-esteem and motivate them to contribute even more.

Even if it’s a small thing, when somebody appreciates, like “oh you did well, you can do all this”. You feel like, it’s huge. For the people who have mental illness it’s really, really, huge. “Oh wow, I can do this,” and it’s pushing those people to do more productive things (Arab female).

Conversely, one participant recounts the disappointment he felt when the acknowledgement from his supervisor was perceived to be lacking. The result was discontinuation of membership in the group.

I was happy doing it. Since my volunteers were happy, I was happy. But it was the last day and what [my supervisor] did, that was it for me. I’m giving everything...And in return I get disrespect...That breaks me. I stopped volunteering for one and a half years (Arab male).

Similarly, expectations of can be perceived as both positive and negative depending on how they are valued. Expectations that are reasonable and achievable can be helpful and motivating while unreasonable expectations can cause distress. One participant who was hospitalized after a suicide attempt discusses how his family want him to succeed but that sometimes they push too hard.

[My family is] the source of stress for me. Well, it’s a good thing, they’re trying to push me to...do better and better and better. But it just doesn’t stop, you know. It’s good, and not good at the same time. I should be calling my own shots (Arab male).

Alignment with is the fourth condition of reciprocity membership, and is also subjected to valuing. Participants questioned their satisfaction with the fit between their own values, beliefs and interests, and those of the group. During data analysis, an idea emerged that if mental health services could intervene to connect people with groups where they have the opportunity to make a meaningful contribution, then this may bolster the person’s mental health. Shortly after the idea emerged a
participant was recruited who described himself as being “not very social”. The interviewer assumed the intervention would not work for a person like this, but was quickly corrected.

*Interviewer: In your case, you probably wouldn’t want to be connected with a bunch of people that you don’t know, right?*

*Asian male: Well, I don’t know. Maybe...I just go with people who can benefit me as an individual...For example, help me in business. We are going to plan for business because [living here] is not permanent. So, if you introduce me to people who are interested only to be going out with the girls and drinking, I wouldn’t like that. But with people whose goals are similar to mine, okay.*

This excerpt provides evidence that participants would be open to having health care services help to connect them to others. This may facilitate service users’ ability to develop *reciprocity membership*. However, these others must share similar goals.

*Valuing* is based on what the individual, rather than the group, deems ‘good enough’. It is based on one’s own expectations, cues from the group, and perceived or actual rewards. In some cases, it is possible for health care practitioners to work with people to develop a more realistic *valuing* process. One participant felt he was paying too much rent to his mother, became severely distressed about what he saw as an unfair *expectation of* and overdosed as a “*cry for help*”. He felt he got the help he needed when he was in the hospital.

*I [got a] lesson...that I should discuss. Listen more than talking. And [discuss] with the family. Even when I [don’t] get everything. Not everything I can expect to take [from] my mom (Arab male).*

*Valuing* is an ongoing, invisible and highly subjective appraisal of *reciprocity membership*. It entails two main questions relating to whether a person is satisfied with their contribution and whether reciprocity is balanced. When a person judges *reciprocity membership* as being unsatisfactory or unbalanced, *valuing* activates
other strategies. These strategies, *positioning* and *managing relationships* are discussed in the following sections.

**Positioning**

*Positioning* occurs in response to an unsatisfactory or unbalanced appraisal of *reciprocity membership* and is used to improve one or more of the conditions for *reciprocity membership*. It does this by enabling people to bring new skills, knowledge, education, experience, ideas, or credentials to the group. *Positioning* is achieved through several sub-processes: *envisioning*, *leveraging*, *improving*, and *repositioning*.

*Envisioning* enables participants to imagine a stronger contributory role for themselves. It relates to hopes, dreams, and goals. People ask themselves, ‘How can I do more in the future?’ ‘What steps do I need to take?’ Imagining a different future is a precondition for taking action to achieve that future. One participant describes what she is *envisioning* for herself.

*I have aspirations you know, [my family] canceled education for me, for the time being, so I will [start a business] in the meantime. When I have kids, at least I can tell my children I have done something (Arab female)*

This person is *envisioning* multiple paths for growth and contribution. She primarily desires postsecondary education, but her family will not permit this. Instead she plans to run a small business with her friend, so that once she has children, she can be a role model to them.

Although participants’ mental illness was not usually a primary concern, it was sometimes leveraged to achieve a goal. In this study, *leveraging* refers to using one’s mental illness to help maintain or achieve *reciprocity membership*. For example, one participant was so committed to his relationship, to keeping his
marriage together that he let his mental health deteriorate in an attempt to
maintain that relationship.

_I saw her support for me at the beginning. And this helps me too much to
improve. But after that [she didn’t] care about me. So, I didn’t want to take
medications... because I want my case to become worse to see her care about
me again (Arab male)._ 

This person used _leveraging_ in a seemingly counter-productive, or harmful,
way in order to keep his family-community intact. His mental health suffered as a
result of his desire to maintain balanced _reciprocity membership_. However,
_leveraging_ can also be used in a more productive manner.

One participant became a spokesman. He felt his illness gave him something
special to share with others. In fact, his illness increases his ability to _contribute to_
in certain communities. For example, by _giving_ lectures to university students and
_providing_ a service user perspective on healthcare workers’ _continuing_ professional
development. Unfortunately, though, very few others leverage their illness in this
way due to the stigma associated with their condition.

_Improving_ is another form of _positioning_. Education is the most common
way that people undertake this action. This allows people to gain new knowledge,
skills and credentials, which in turn, improves their potential _contribution to_. It also
potentially facilitates entry into new communities through _employment_
opportunities. _Improving_ seems to be a bigger concern for the younger participants
in the study.

_Repositioning_ also occurs. This happens when community members react to
changes in membership structure or roles by adapting to new circumstances. For
example, one participant began a new job. This job allowed her to contribute to her
family in a different way, financially. This contribution was highly valued by the
participant and allowed her to renegotiate certain undesirable expectations of. This repositioning led to a higher sense of self-esteem and eliminated thoughts of suicide, which had been frequent over the preceding several years.

In summary, positioning is a group of strategies used by participants to initiate or rebalance reciprocity membership. Envisioning is generally the first step and involves imagining new possibilities. Leveraging refers to using existing strengths, skills, and resources to achieve a goal. Improving was mostly related to post-secondary education in this study and seemed to be used more so by younger participants. Repositioning occurs in response to changes in the structure or function of one’s community.

**Managing Relationships**

Managing relationships allows participants to initiate, maintain, improve and terminate connections to communities. As mentioned previously, this process is used when someone is unsatisfied with current reciprocity membership. It allows people to overcome challenges and extend their range of influence and contribution. It is enacted through a number of sub-processes.

One of these sub-processes, enlisting, refers to joining a community. This usually happens by making new connections with people who facilitate access to a community, or by reconnecting with previous acquaintances. These new communities can be temporary, such as a peer support group on an inpatient unit, or longer lasting, such as a new job. One person provided an example of how enlisting can occur through social media.

> Online, I feel more free and I can talk to people. I met a lot of cool people and there are a couple of communities that I’m part of (Arab female).
Enlisting can entail an adjustment period where a person finds a balance point for *reciprocity membership*. During this period, expectations are managed, challenges addressed, and roles are negotiated. After *enlisting* in a job in a new country, one participant faced an unexpected challenge related to obtaining medication.

*I really didn’t know it was going to be hard to, I guess, navigate the system...I think if I had known that...I would have found a way ahead of time to know how to handle this* (Western female).

*Limiting* is another sub-process of *managing relationships*. This process was enacted in two ways by participants in this study. One was by *limiting* engagement and the other by *limiting* disclosure. In regards to engagement, participants may have to distance themselves from some memberships in order to maintain their balance or position in others. One participant describes how she was not able to fully engage in a group due to her more important responsibilities to her family. This trade off was a personal sacrifice undertaken for the benefit of maintaining *reciprocity membership* in her family.

*I tried to contribute [to the other group] as much as I could because I want give the most I could, without disturbing my family’s time. But there are times that I was really disappointed, when I wasn’t able to participate in a certain activity that was a dream of mine. But because of my family, I couldn’t do it, and I stepped back again* (Asian female).

*Limiting* disclosure occurs in response to the perception that sharing information related to one’s mental illness might prevent *reciprocity membership*. One form of *limiting* disclosure involved people distancing themselves from community members when they were unable to hide their mental illness. For example, during periods of relapse. People who used this strategy usually
associated it with stigma. For example, one participant chose to tell his wife he was in jail rather than in the psychiatric hospital in order to protect his marriage.

One final sub-process involved in managing relationships is substitution. If reciprocity membership fails in one community, the community can be replaced. Substitution can be temporary or permanent. One interesting example of temporary substitution is provided by an Arab male, who became unsatisfied with his family’s expectations of him. He took an overdose of medication, not with the intention of committing suicide (“I did not mean to kill myself. I don’t want to die”) but with the intention to substitute his family community with his treatment team community. The steps he took seem extreme and illogical, but in fact, this is probably the only way he could guarantee re-entry into the treatment community. This type of behaviour is commonly referred to as ‘secondary gain’, which carries a negative connotation. However, the example above demonstrates how it can be an adaptive response to worsening mental health.

Managing relationships is used by participants to achieve reciprocity membership or to rebalance it. As with positioning, it includes several sub-processes: enlisting, limiting, and substitution. Enlisting refers to developing new roles in new or previous communities and involves an adjustment period. Limiting can refer to either engagement with certain communities or disclosure of information about oneself. It serves a protective function. Substitution involves changing communities, either temporarily or permanently. These processes are potential targets for healthcare interventions. Fostering people’s efforts at managing relationships could potentially help them achieve reciprocity membership, and subsequently, better mental health.
Summary

Simply put, people want to make a meaningful contribution to others whom they are associated with in some way. In order for this relationship to be satisfying, group members should have reasonable expectations of each other and give reasonable acknowledgement for the contributions people make. It is important that there is alignment between values, interests and beliefs of individuals in the group. Individuals constantly appraise whether these conditions are balanced. If not, several actions can be undertaken to try to create or restore balance. When balance is achieved, it seems to promote positive mental health.

Discussion

The aim of this study was to develop a theoretical understanding of illness self-management in mental illness in an Arabic context. This was done through an exploration of the main concerns of service users and the strategies used to resolve these concerns. The grounded theory that emerged from our data suggests that participants were most concerned with seeking reciprocity through relationships with others. When reciprocity membership is balanced, it seems to be associated with the process of recovery and positive mental health. In the following section, we will situate the theory of reciprocity membership within the limited literature on recovery in an Arabic context, discuss practical implications of our findings, address study limitations, and propose directions for future research.

Recovery in an Arabic Context

Little has been published on recovery in an Arabic context. One review article found that extended family is important for supporting mental health service users (Hickey et al. 2016). However, extended family can be both detrimental and
beneficial to recovery. In some cases, extended families provide practical, emotional and spiritual support (Bilal, Kristof, Shaltout, & El-Islam 1987; El-Islam 1982). In others, they are a source of stress and a trigger for substance use and suicide (Al-Nahedh 1999; Suleiman, Nashef, Moussa, & El-Islam 1986).

Religion has also been identified as important to Arabic mental health service users (Hickey et al. 2016). Like extended family support however, religion has also been reported as having a dual role. Prayer is a source of strength and resilience (Daradkeh & Moselhy 2011), and many people seek treatment from traditional (i.e. faith) healers prior to seeking psychiatric services (Salem, Saleh, Yousef, & Sabri 2009). However, religion can be a source of distress, particularly when one is not able to meet their perceived religious obligations (Al-Solaim & Loewenthal 2011).

These discrepancies challenge the commonly held view that social support and spirituality are beneficial for mental health (Corrigan, McCorkle, Schell, & Kidder 2003; Ozbay et al. 2007). Reciprocity membership theory provides a potential explanation for these discrepancies. As explained earlier, when reciprocity membership is unbalanced, it can be detrimental for mental health. Thus, if a person feels that their family is having a negative impact, it may be possible that one of the four conditions for reciprocity membership is out of balance. For example, that person may not have the opportunity or ability to make a meaningful contribution to their family, or their family’s expectations may be too high.

Similarly, the process of reciprocity membership can be applied to religion. Islam places all Muslims within the ‘Umma’ or nation (Abudabbeh 2005). The Umma can be viewed as a community with potential for reciprocity. The
contribution people offer is prayer, devotion and service. The expectations relate to the type of life people are expected to lead. Acknowledgements are generally the good things that happen in life. For example, feeling that God has blessed a relative with a new baby. Finally, there must be alignment between individual and religious values. When these conditions become unbalanced, for example when people are not able to complete daily prayers as they would like, then reciprocity membership becomes unbalanced and religion may become a source of distress.

Practical Implications

Participants’ main concern in the study was achieving reciprocity membership. Nurses and other front-line staff are well positioned to work with service users to resolve this concern. Potential interventions include assessing reciprocity in groups in which the service user is already involved and providing counselling and support to maintain or achieve reciprocity in these communities. Members of the mental health team could also assist service users to identify and connect with new communities with potential for reciprocity membership. Close collaboration between mental health services and community organizations would facilitate this work. Providing training and education to service users that would allow them to make new or improved contributions to various communities would also be of potential benefit. Educational and vocational training are common aspects of many mental health services, but it is possible that incorporating an awareness of reciprocity might improve outcomes for these programs. Finally, practitioners are well positioned to advocate for the creation of new communities or organizations (e.g., self-help groups, user-led advocacy groups, etc.) that could also facilitate service users’ desire for reciprocity membership.
Study Strengths and Limitations and Directions for Future Research

While this study adds to the literature on recovery in mental illness, we recognize its limitations. Classic grounded theory has the advantage of prioritizing participants concerns. However, it largely ignores social and institutional factors (e.g., discrimination, power imbalances) that may affect reciprocity membership but are invisible to participants. Future studies using different methodological approaches may be useful in shedding light upon some of the invisible contextual influences on reciprocity membership.

This is the first study of mental illness self-management or recovery conducted in an Arabic context. Thus, it offers new insight into the experiences of service users in the GCC. However, the study is limited to mental health service users and does not include others (e.g., family members, co-workers, classmates, etc.) who may contribute to reciprocity membership. Future research that is inclusive of the extended groups or communities in which reciprocity membership occurs would help to improve understanding of the social dynamics of this process.

This study was designed to sample a broad range of participants. We were successful in recruiting people with many nationalities and diagnoses with potential need of mental health services in Qatar. However, because the sample was so broad, we do not know how well the theory of reciprocity membership applies to any one specific sub-group of mental health service users in Qatar. It is possible that the theory may have limited applicability to some of these sub-groups.

We also attempted to recruit equal numbers of men and women. Our gender balance was close to being equal (11 men, 9 women), which suggests this theory is applicable to both genders. However, our data also suggests that women
may not be able to initiate strategies to balance reciprocity membership as easily as men. This seemed to result from the lack of autonomy and decision making power some female participants had in relation to male family members.

Finally, operationalizing any of the potential implications above would need to be guided by additional research. In particular, the link between reciprocity membership, mental health and recovery would require further investigation. Examining the fit of the theory outside of an Arabic context would also support implementation over a broader context. Additionally, changes to mental health practice based on the theory presented in this article would require an evaluative component to ensure it matches the needs of the service user population.

Conclusion

Personal recovery has become an increasingly popular focus for mental health services around the world. Recent evidence suggests that research among more diverse populations is important to provide a more inclusive view of recovery. We investigated the concerns of mental health service users in an Arabic context as well as the strategies they use to address this concern. We found that reciprocity membership was the main concern. Specifically, participants wanted opportunities to make a valuable contribution to some form of community where expectations of them were reasonable, acknowledgement was adequate, and interests and values align. Balanced reciprocity membership seems to foster positive mental health. Our research offers the first exploration of mental health service users’ illness self-management concerns in an Arabic context and offers potential directions for service development and future research.
References


3.3 Summary

The literature reviews presented in Chapter 1 revealed a gap in current understanding of the recovery process in an Arabic context. As discussed in Chapter 2, grounded theory was chosen to explore the processes that mental health service users employ to resolve their concerns. This approach led to the development of a mid-range grounded theory called *reciprocity membership*, which was presented in this chapter. The theory has potential implications for mental health service administrators, front-line staff, and service users themselves.

In the discussion section of the article, *reciprocity membership* was compared to current knowledge of recovery in the region and proposed as an explanatory framework for certain ambiguous components (e.g., role of extended family and religion). In Chapter 4, this discussion will be extended to include a more detailed examination of these components. Chapter 4 will then return to the Western recovery literature and discuss how *reciprocity membership* offers a potential reinterpretation of several common components of popular recovery models. We will also extend our discussion of study limitations that were touched upon in study 3 (p.100-101).
Chapter 4. Discussion

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4.1 Introduction

This chapter presents a discussion of the work that was undertaken for this thesis. Section 4.2 summarizes how this thesis offers a unique contribution to the body of knowledge on service users’ experience of mental illness in the Gulf Cooperation Council (GCC), with an emphasis on recovery. Section 4.3 reviews the key findings and implications of the two literature reviews and the grounded theory study that were conducted for this thesis. Section 4.4 presents the general discussion, which begins with a focus on recovery, collectivism, and the Arab extended family (4.4.1) and then shifts to consider modernization, shifting roles and recovery beyond the extended family (4.4.2). Sub-section 4.4.3 places religion within the context of reciprocity and recovery. The discussion then goes on to compare reciprocity membership and descriptions of recovery in a Western context (4.4.4). Section 4.5 explores the strengths and limitations of the thesis as a whole, including the personal benefits I have experienced through doing this research. Section 4.6 summarizes the discussion.

4.2 The nature of recovery in an Arabic context

In the introductory chapter of this thesis I argued that little was known about recovery in an Arabic context and that models prevalent in the predominantly Western literature may not be appropriate in such a context. I also pointed out that input from service users on service development in Qatar is potentially important but also lacking.

This thesis has addressed some of these gaps. The scoping review was the first to synthesize research on mental illness from the GCC. It offers a better understanding of service users’ experience of mental illness and highlights three
regional factors that are not commonly integrated into mainstream conceptualizations of recovery: extended family, traditional healing, and religion. However, the body of literature that was reviewed was limited in its scope (e.g., mostly cross sectional design, only one qualitative study) and did not address the concept of recovery specifically or in detail. Thus, the review offers a glimpse of what concepts may be important to recovery in an Arabic context rather than a clear understanding.

The second review article contrasts Arabic sociocultural factors with common conceptualizations of recovery. It is the first to do so. The article provides an evidence-based argument against uncritical adoption of Western recovery models into non-Western contexts, providing some direction for mental health service development in the GCC region.

Finally, the empirical grounded theory study illuminates the main concern of the mental health service user study sample in Qatar and the strategies they use to resolve this concern. The substantive theory that was developed describes a potential pathway to recovery in an Arabic context. The study has implications for service development in Qatar and the GCC and also adds to the international body of knowledge on recovery.

4.3 Key findings

The two literature reviews included in the introduction chapter were undertaken to inform the empirical study. These articles contribute to a new perspective on mental illness in the region, particularly in combination with the empirical study. Because of this, all three studies will be summarized in this section.
4.3.1 Study 1 (p.15) - Mental illness in the Gulf Cooperation Council: A scoping review (Hickey, Pryjmachuk, and Waterman 2016).

The aim of this study was to review and synthesize mental illness research from the GCC. Articles reporting mental health service users’ subjective experiences of mental illness were examined. The review included 55 articles reporting research that was conducted in the GCC.

Three main themes were identified: service preferences, illness and recovery. Service preferences seemed to vary with gender. Illness was further subdivided into symptomology, perceived cause, and impact. Symptomology seemed to be influenced by context (religion and language) in several studies (Hamdi, Amin, and Abou-Saleh 1997; Kent and Wahass 1996; Zarrouk 1975). Perceived cause was often linked to the supernatural (e.g., *jinn* [evil spirits], black magic and the evil eye). This finding is similar to studies of other traditional cultures (Arthur et al. 2010; Lapsley, Nikora, and Black 2002). Illness impact was often highest in relation to family and social relationships. The third main theme of recovery was also divided, into sub-themes of extended family, religion, and traditional healing. These aspects of recovery are uncommon in mainstream literature on this topic and seemed to be contextually dependent.

Findings from this scoping review demonstrate that service users’ experience of mental illness and recovery are influenced by their sociocultural context. However, the overall low quality and limited extent of the literature reviewed suggests that service users’ experience of mental illness in the GCC is poorly understood. This is particularly true regarding the potential relevance of
mainstream recovery concepts in an Arabic context, which is the topic for the second review.

4.3.2 Study 2 (p.16) - Exploring personal recovery in mental illness through an Arabic sociocultural lens (Hickey, Pryjmachuk, and Waterman 2017).

The aim of this review was to “debate the potential fit of recovery-oriented services in a traditional Arabic context” (Hickey, Pryjmachuk, and Waterman 2017, 163). Common Western models and recent non-Western models of recovery were examined. The key concepts in these models were then compared to components of Arabic society and culture, such as collectivism, the doctor-patient relationship, and belief in the supernatural.

The review presents an argument that “one size does not fit all” (Hickey, Pryjmachuk, and Waterman 2017, 167) in regards to recovery models. In other words, incorporating recovery models into new contexts with different cultural values and beliefs may be inappropriate, ineffective, and potentially harmful to the intended service user population. If recovery oriented services are to be developed, they must be based on the recovery experiences of the intended service user population. These experiences are explored in the third (empirical) study.

4.3.3 Study 3 (p.73) - Reciprocity membership. A grounded theory of recovery among adults with mental illness in an Arabic context (Hickey, Pryjmachuk, Waterman, submitted November 2017)

The aim of this study was to develop a theoretical understanding of mental illness self-management in Qatar. As mentioned in Chapter 1 (p.23) illness self-management was chosen over recovery in order to expand the potential scope of the study and not limit it to mainstream conceptualizations of recovery. The main
objectives were 1) to explore service users’ experience of mental illness in an Arabic context; 2) to identify service users’ main concerns(s), related to illness self-management the strategies they use to resolve these concerns; 3) to identify and describe the actions service users take to address their illness self-management concerns; and, 4) to develop a substantive theory of mental illness self-management. Twenty-one service users with a range of diagnoses were interviewed, some multiple times.

The findings of the study reveal that participants are highly concerned with finding opportunities to be a productive member of their community(ies). Within these memberships participants seek reciprocity, where an opportunity to make a valuable contribution to is balanced by the acknowledgement from the group, the expectations of the group, and participants’ alignment with the values and interests of the group. It is not enough for a person to receive social support from the community, they must also have the opportunity to make a valued contribution. Balanced reciprocity membership seems to be one potential path towards recovery in the study population.

The following section begins with a discussion of reciprocity membership in relation to the wider theoretical literature on reciprocity. It then goes on to highlight sociocultural factors that are relevant in the GCC context, including collectivism, extended families, religion, and modernization. All have potential influence on service users’ desire for, and ability to achieve, reciprocity membership. The discussion also considers whether reciprocity membership may be transferrable outside of the current sociocultural milieu by comparing elements of the theory to mainstream recovery concepts. Later sections include a discussion
of the strengths and limitations of this project. This part of the discussion focuses mainly on the grounded theory study, as these issues have already been discussed for the two literature reviews, within the published articles. Chapter 4 will conclude with a discussion of the personal benefit I gained from undertaking this work and a brief summary of the discussion.

4.4 General discussion

Trivers (1971) was one of the first to explain why cooperative behaviour often develops between individuals with no genetic ties when he proposed the theory of reciprocal altruism. This theory was based on animal studies and suggested complex mediators of reciprocity, such as, calculation of costs and benefits, detecting non-reciprocators, and others. Importantly, cooperative behaviour was proposed to develop alongside an expectation for some future reward.

Falk & Fischbacher (2006) contrast modern understanding of reciprocity with reciprocal altruism based on subsequent human studies. Their conceptualization of reciprocity refers to prosocial behaviours “that cannot be justified in terms of selfish and purely outcome-oriented preferences” (Falk & Fischbacher, 2006, p. 294). Instead, they propose that reciprocity occurs as a response to others’ kind behaviour.

Reciprocity among participants in the grounded theory study described in this thesis aligns somewhat with Falk and Fischbacher’s (2006) explanation. Participants did not want to be a burden on their communities. They wanted to contribute in response to the support (i.e., kindness) they received. Thus, many engaged in prosocial behaviour after being treated kindly by other community
members. However, reciprocity as a response to kindness occurs between individuals and does not fully account for the desire to be a contributing member of a community that was observed in this study, or observations that some participants had a desire to contribute even in the absence of kindness from others.

Simpson et al. (2018) discuss the concept of generalized exchange systems, where reciprocity, seen as the flow of good and resources, occurs in the context of a group or community. Receiving gratitude or gaining reputation are seen as the mechanisms within generalized exchange systems that ensure individuals contribute to the community. Gratitude can be seen as synonymous with one of the conditions for reciprocity membership in the current study, namely acknowledgement from. Reputation was also observed to be a motivating factor for some participants, particularly mothers who wanted to be role models for their children.

The theories of reciprocity described above all indicate a requirement for some kind of benefit (e.g., future reward, gratitude) or external stimulus (e.g., kindness) coming from others. However, some participants in the current study indicated a desire to be productive and feel useful, even in the absence of these external motivations. Klein (2017) examined the relationship between prosocial behaviour and individuals’ perception of meaning in their lives. The author found that prosocial behaviour can also be motivated by intrinsic psychological benefits. This suggests that balanced reciprocity membership may depend on both external and internal stimuli and rewards.

Klein’s (2017) work also strengthens the connection proposed in the current study between reciprocity membership and recovery. Specifically, the author found
that contributing meaningfully to others increased self-worth and self-esteem. Given that prosocial behaviour may also result in reciprocal kindness from others (Falk & Fischbacher, 2006) and access to goods and resources within generalized exchange systems (Simpson et al., 2018), a relationship between reciprocity and recovery seems likely, as these factors would seem to support recovery for many. Accordingly, the following subsections explore aspects of this relationship, with a focus on the sociocultural context in which the research for this thesis was undertaken.

4.4.1 Recovery, collectivism and extended family

Collectivism is seen as one of the defining aspects of GCC culture (Hofstede 2001). Collectivism places an emphasis on the group over the individual (Oyserman, Coon, and Kemmelmeier 2002). This means that decisions are made based on what is best for the group rather than the individual. Group membership is highly valued, and in return for their loyalty, individuals expect care and protection from the group (Hofstede 2001). This suggests that recovery may be a group endeavour, rather than an individual one, as it is often promoted in the West.

Perhaps the most important group to consider is the extended family, which is common and highly important in the GCC. Within this structure, parents, siblings, aunts, uncles, and cousins and grand-parents form the basic societal unit (Long 2003). The extended family is socially and economically interdependent (El Haddad 2003) and authority is traditionally placed with the elder male members of the family who have decision making responsibilities over most aspects of family life (Abudabbeh 2005).
All three articles included in this thesis identified family as an important part of recovery. This is not surprising considering that the Arab extended family is acknowledged as the main source of support for individuals (Abudabbeh 2005). However, the scoping review demonstrated that extended family can also be a burden, and detrimental to mental health (Hickey, Pryjmachuk, and Waterman 2016). For example, substance abuse and attempted suicide were sometimes precipitated by stressful family interactions (Al-Nahedh 1999; Suleiman et al. 1986).

Some recovery literature from non-Arab countries similarly identifies family as a potential impediment to recovery. Alderey and Whitley (2015) conducted a qualitative inquiry of family influence on recovery and found that stress, stigma/lack of understanding, and forced hospitalization were negative issues faced by service users in the family environment. Similarly, Englandkennedy and Horton (2011) interviewed service users who experienced a loss of trust, problematic communication, inappropriate boundaries and stigmatization from family members. Negative experiences were associated with lack of family knowledge about mental illness and recovery. These studies highlight the need for mental health services to work with families to provide education and support, and to help prevent the potential negative influences of family.

Family psychoeducation is one example of an approach that might address these issues. This intervention generally aims to educate family members about an illness and its management with a frequent emphasis on stress and coping (Sin, Norman, and Norman 2013). One review of family psychoeducation found that it increased medication adherence, decreased relapse and improved hospitalization rates (Lyman et al. 2014). Perhaps more relevant to the issues mentioned in the
previous paragraph are the results of a meta-analysis of family interventions that found lower caregiver burden, distress, and better patient-family relationships in families receiving psychoeducation (Cuijpers 1999). Counselling an Arabic family would likely be most effective if it addressed elements of religion and cultural beliefs (Ahmed and Amer 2011; Rassool 2015). However, in Qatar, this approach can be difficult because of family reluctance to become involved in care.

There is a dearth literature in Arab countries on families’ reluctance to support members with mental illness. However, my clinical experience and anecdotal evidence from health professionals, students and service users I have worked with in Qatar, suggests that stigma and lack of understanding are the main reasons families are reluctant to be involved. Specifically, many families feel shame that a loved one has a mental illness and go to great lengths (e.g., inventing cover stories to explain absence during inpatient admittance; travelling outside of the country for care) to avoid having others find out. In regard to lack of understanding, families sometimes think there is no way someone can recover, or conversely, that the psychiatrist can completely eradicate the illness during a short inpatient admission. In the Western literature, families sometimes do not want to intrude on the relationship between the doctor and patient (Peters et al. 2011). This may also be an issue in GCC countries where the psychiatric system is less collaboratively-oriented and the psychiatrist is viewed as the authority figure (El-Islam 2008; Rashad, Phipps, and Haith-Cooper 2004). In these cases, family members may have low expectations about their potential contribution (Petrakis, Bloom, and Oxley 2014). Working with families to help them understand and accept their potential role may be a necessary precursor to having them participate in care. However,
caution must be taken as service users may not want to encourage family involvement due to factors such as privacy concerns, potential stress, or becoming a burden (Landeweer et al. 2017).

The burden of caring for a family member with mental illness seems to be another reason why families are reluctant to become involved in care in Qatar, based on my professional experience in the country. Caregiver burden refers to the physical and psychological impact that family members may experience as a result of providing care for a family member with a chronic illness (Zahid and Ohaeri 2010). In Qatar, families often report frustration, repeated failures, and also inappropriate coping strategies such as locking their sick family member in a bedroom for days.

A recent study that examined caregiver burden in Saudi Arabia found that types of caregiver burden varied with context (Alzahrani et al. 2017). For example, ‘tension’ was common for caregivers under the age of 30, while ‘worrying’ was higher in caregivers who lived with their spouse and children or in smaller households (i.e., fewer people). Burden was highest in people caring for a close relative (e.g., parent or spouse). In another regional study, Zahid and Ohaeri (2010) examined levels of caregiver burden and factors associated with high levels of burden in Kuwait. They found that “disruptive or difficult behaviour” (p.9) was the strongest determinant of burden. Several other factors (e.g., age, education) were also identified. These studies highlight the need to understand caregiver burden in context and suggest that mental health professionals should be aware of factors within families that may increase caregiver burden.
Working with families to address caregiver burden is important not just to make caregiving easier, but to facilitate the family’s ability to provide an environment that is supportive of recovery. Caregiver burden is sometimes the cause of interpersonal conflict among families and in family relationships (Meijer et al. 2004). As discussed in the preceding paragraphs, this conflict can be detrimental for mental health. Thus, caregiver burden, along with stigma and lack of mental health education, are important topics to address if mental health services hope to engage family members.

Stigma, caregiver burden and family education are all current topics of attention in Qatar. Stigma is being investigated through a mixed methods study of service users, their families, and healthcare professionals (Kehyayan, V., Ghuloum, S., Al-Amin, H., Mahfoud, Z., Stirling, B., Hickey, J., Omar, H., ongoing); data collection for a cross sectional study on caregiver burden among families of service users with schizophrenia is nearly complete (Ghuloum, S., Al-Amin, H., Graham, J.M., Hickey, J., Mahfoud, Z., ongoing); and, mental health nurse educators have recently started a staff development initiative aimed at increasing nurse engagement with family education. These initiatives may increase families’ capacity to support recovery. However, it is important to better understand why, and under what circumstances, the family environment is helpful or harmful.

The grounded theory that was developed as part of this thesis provides a potential explanation for these opposing family roles. It proposes that reciprocity is needed in order for the family environment to be supportive of mental health. When reciprocity is balanced, family membership strengthens or sustains mental health. If the conditions for reciprocity membership are not met, then relationships
with the family can be stressful and anxiety-provoking. Although I have discussed balanced vs. unbalanced reciprocity membership throughout the thesis, a more accurate description would include a continuum of balance, where absolute balance or unbalance may never actually be realized. Thus, there may always be some supportive and detrimental elements. However, working towards reciprocity membership should aim to maximize support while minimizing detriment.

Reciprocity membership also provides a potential explanation for caregiver burden. When families lack understanding of mental illness, have limited knowledge of caregiving strategies, or are otherwise ill-equipped to provide care for a family member, they are likely to appraise their contribution to as lacking. In other words, perceiving the care they are providing as being inadequate is synonymous with being unsatisfied with their contribution to. Additionally, family members may feel the expectations of them are too high. In other words, caregiving can be an unwanted or overwhelming responsibility. Both these situations, not being able to adequately contribute and experiencing unwanted or unreasonable expectations, can negatively influence mental health according to reciprocity membership theory.

However, reciprocity membership theory provides several potential strategies to balance reciprocity in caregiving situations. For example, increasing acknowledgement from. One author of a recent study on recovery and caregiving in India states that being “adequately acknowledged and recognized…[can] act as motivating for them to continue to care [for] their mentally ill family members” (Janardhana et al. 2015, 192). Accordingly, the authors suggest that this can be achieved if health care providers acknowledge the important support caregivers
provide, and value caregivers’ expertise, opinions and experience as a resource for service and policy development.

Family intervention also has the potential to strengthen family members’ contribution to. Providing knowledge and skills training (e.g., coping, stress management) is important for families to be able to contribute to the recovery process (Macleod, Elliott, and Brown 2011). In the context of reciprocity membership, family members’ mental health could potentially be improved by working towards balance in the family unit.

These potential actions highlight how reciprocity membership theory has the potential to inform and improve mental health practitioners’ work with families. More specific actions for working with families towards balanced reciprocity membership are described in chapter 5 (p.155-157).

4.4.2 Modernisation, shifting roles and recovery beyond extended families

As mentioned in the previous section extended families are an essential component of life in GCC. However, modernization has had an impact on the structure and function of the family. For example, economic prosperity has led to the widespread use of foreign nannies and maids; one government survey conducted in Dubai found that 94% of 28,000 Emirati (National) families surveyed employed a maid (Bennet 2009). These domestic workers take on many of the previous roles of mothers and grandmothers in the household, such as raising children and preparing meals. Perhaps as a result of having domestic help, women in most GCC countries have begun to enter the workplace. For example, from 1993-2013 in Qatar and the United Arab Emirates the number of employed women has increased by 19% and 63%, respectively (Willen et al. 2016). This is generally seen
to be a positive change. However, it has created a shift in women’s roles, responsibilities, and decision making within the home (Alsharekh 2012).

Additionally, urbanization and digital connectedness have led to social interactions outside of the extended family or tribe, which is another departure from traditional extended family life (El Haddad 2003). Social customs remain in place that limit the extent of inter-group mixing, particularly between males and females. However, new contexts exist that remove these social barriers. One example is Western educational institutions, which are common in some GCC countries. On Western campuses in the GCC, students from many cultures learn and socialize in a co-educational environment. This limits the traditional control that parents, aunts, uncles and grandparents have over who their sons and daughters interact with and frequently causes conflict in more traditional families. Additionally, many students in Western educational institutions are taught to question social norms and authority, and engage in critical thinking. These aspects of Western education are in direct opposition to expectations of children in the Arab extended family. This exposure to Western ideas and values can lead to Arab youth questioning roles within the extended family (El Haddad 2003).

The changing nature of people’s roles and responsibilities in the GCC suggests that extra-familial memberships or associations have become important, and may continue to increase in importance as modernization continues. As mentioned in section 4.4.1 the family seems to be the most important membership for many participants, but it is not the only important membership. Thus, the concept of reciprocity membership goes beyond the regional literature, which somewhat blindly acknowledges family as the key support for mental health, to
include other potentially important communities. Work, volunteerism, friends, and educational institutions all provided opportunities for *reciprocity membership* for participants in this study. Yet, they remain relatively unacknowledged in the regional mental health literature.

*Reciprocity membership* suggests that the shifting in roles, responsibilities, and expectations in families is likely to be detrimental to people’s mental health because it should theoretically cause imbalance in *reciprocity membership*. This may be true in some cases, but there is little if any evidence in the current data to support the claim. Conversely, it is equally likely that new opportunities for *reciprocity membership* that have been created by modernization are having a positive effect on mental health in the region. In fact, participants provided numerous examples of this during interviews. Thus, extra-familial communities have the potential to provide opportunities for *reciprocity membership* that can be beneficial for mental health.

This assertion raises a question about what can be done to support reciprocity in these communities. Ideally, health care professionals could meet with members of these groups and the service user, as they do with families, to provide counselling and support. However, many of the participants in this study refused to disclose their diagnosis outside of a very close circle of understanding confidents. Stigma seems to be the main cause of this reluctance. While very little, if any, research on stigma has been conducted in the region, participants in this study often blame a lack of community-level understanding. This suggests that community education about mental illness and stigma prevention activities may be
a necessary first step for promoting reciprocity membership in extra-familial communities.

Another potential approach mental health professionals could use to encourage reciprocity membership outside of the family is developing opportunities for engagement with communities that have higher understanding of mental illness (and potentially lowered levels of stigma). For example, peer support groups, and other groups that give service users an opportunity to contribute as an expert-by-expertise (e.g., consulting on service development or research). In Western countries, communities such as these are more common, and mental health services in some cases have been able to provide training for service users to undertake these activities (Tew 2012, Simpson 2013). Additionally, policies put in place by some funding agencies have made service user involvement in research a requirement (Green 2016). Policies such as these provide acknowledgement of the valuable contributions service users can make as experts by experience. In the GCC however, service user contributory opportunities are limited. Reciprocity membership theory highlights the potential benefits to placing value on, and creating policies and practices that support, the development of contributory opportunities and communities for mental health service users.

4.4.3 Reciprocity, recovery and religion

Religion is another important aspect of Arabic culture to consider in relation to recovery. Like extended family, religion can be both a source of strength and a source of stress (Hickey, Pryjmachuk, and Waterman 2016). One limitation to existing models of recovery is that most were developed based on the experiences
of non-Islamic participants. This means that they have the potential to impose values that are incongruent in an Islamic context.

The grounded theory of reciprocity membership provides a prospective framework for incorporating religion into recovery efforts in an Arabic context. Islamic culture emphasizes individuals’ place within the much broader community of all Muslims, or the *Umma* (translation: nation) (Abudabbeh 2005). Therefore religion can be viewed as a membership within the *Umma* with potential for reciprocity.

A person’s *contribution to* can be the prayers and religious ceremonies they undertake, or the charity they are involved with. *Acknowledgement from* can be the good things in life, often seen as blessings and attributed to God (e.g., a new baby in the family). *Expectations of* may relate to the religious observances and modest lifestyle that are expected of GCC Arabs. When reciprocity is balanced, religion is a source of mental strength. Unbalanced reciprocity (e.g., not being able to complete daily prayers or undertaking forbidden activities) causes guilt and anxiety. This is an oversimplification of the complex role of religion in the daily lives of GCC Arabs. However, it provides a frame of reference that could be used to incorporate religion into recovery efforts or to guide future research.

Linked to religion is the use of traditional (i.e., religious) healers. In both reviews undertaken for this thesis we concluded that traditional healing is potentially important for recovery in an Arabic context. This is because research on mental illness in the GCC demonstrates that people often seek treatment from traditional healers prior to accessing psychiatric services (Hickey, Pryjmachuk, and Waterman 2016). A commonly held belief in the supernatural is one potential
reason that traditional healers are the first point of contact. Individuals who eventually access psychiatric services report little symptom relief using traditional healing methods (Salem et al. 2009) but may receive other benefits (Al-Subaie 1994).

References to the supernatural were unexpectedly absent during interviews with participants in the grounded theory study. Only three participants made reference to these factors. This may be due to a number of reasons. First, because I was present at all interviews and because I am a cultural outsider, it may be possible that participants were uncomfortable discussing this topic with me or might have thought I was not interested or that I would not understand. However, participants did discuss other sensitive issues with me, including ones that were culture-based (e.g., sexuality, drug use) so this explanation is unlikely.

A more likely reason might be that the participants I interviewed had moved beyond the point of supernatural attribution and traditional healing to the point where they acknowledged the need for psychiatric help. This explanation is supported by Sorsdahl et al. (2009) who found that a lower percentage of participants sought traditional healing after receiving a psychiatric diagnosis. The lack of focus on traditional treatment from participants in our grounded theory study suggests that this becomes less important after seeking psychiatric intervention.

In the scoping review, I recommended that psychiatric services should work more closely with traditional healers. This recommendation still has validity, but it is likely that collaboration would be more important at the beginning of a person’s illness experience. Early access to psychiatric services results in better long-term
outcomes but many people delay seeking psychiatric treatment (Kohn et al. 2004). Traditional healers are well positioned in GCC society to facilitate early access because they are many people’s initial point of contact. However, integrating traditional healers into a modern health care framework comes with challenges. These are mainly related to regulation and ensuring safe, consistent practice (World Health Organization 2013). Future research and policy development would be necessary in order to facilitate successful partnerships between traditional healers and the mental health care system.

4.4.4 Reciprocity membership and recovery in a Western context

The theory of reciprocity membership emerged from interviews with mental health service users in an Arabic context. While it is sometimes possible to transfer results to other populations, the success of doing so relies partially on similarities in context between the populations (Polit and Beck 2010). One contextual factor in the current study in particular suggests caution should be taken in attempting to transfer results outside of the GCC context. Specifically, participants’ concern for developing reciprocal group memberships may be a direct result of a culture of collectivism. As discussed earlier (p.114), group membership and loyalty are paramount in collectivist culture. However, broad cultural theories do not necessarily account for individual and group behaviour, particularly in a region that is as rapidly changing as the GCC (At-Twaijri and Al-Muhaiza 1996). Additionally, some findings from the current grounded theory study, such as participants’ transfer between groups and the negative impact of some family relationships, suggest that the process of reciprocity membership is not determined exclusively by collectivism.
With the caveat of potential contextual influence in mind, this section of the discussion proposes that \textit{reciprocity membership} is applicable in a Western context, despite sociocultural differences. In fact, a re-examination of recovery literature in Western populations suggests that \textit{reciprocity membership} offers an explanatory reinterpretation of several common concepts. Drake and Whitley (2014) highlight the “numerous competing definitions and models” (p.237) of recovery that have been published during the past three decades. To address this lack of clarity, the authors provide a synthesis of recovery concepts from service user narratives and qualitative research. Some of these include ‘recovery as a process’, ‘importance of everyday activities’, ‘social connectedness’ and ‘empowerment’. These will be reinterpreted through the lens of \textit{reciprocity membership} in the following paragraphs.

\textit{4.4.4.1 Process rather than an outcome}

Recovery refers to a process where people strive to lead a meaningful life in spite of the limitation caused by their illness (Anthony 1993) within a social context (Topor et al. 2011). \textit{Reciprocity membership} can be viewed as a parallel process through which people find meaning, where meaning is synonymous with the concepts of value and satisfaction. This meaning is based primarily on the contributions participants made to others. These contributions helped people feel “useful” and “productive” and give meaning to their lives.

Deegan (1988) explains that recovery happens through a series of small steps and achievements with frequent ups and downs. Similarly, people work towards \textit{reciprocity membership} by becoming better positioned and strengthening or maintaining relationships. This happens through a series of adjustments and
readjustments, often in small steps. Additionally, *reciprocity membership* is unstable. External and internal pressures can cause it to become unbalanced (‘downs’). When it does, people take action to restore balance (‘ups’).

For participants in the current empirical study, *reciprocity membership* and recovery seemed to be parallel and inseparable processes. Balanced reciprocity seems related to positive recovery. When it becomes unbalanced, recovery suffers and relapse can occur. In fact, participants were more cognizant of, and more concerned with, reciprocity than recovery. Based on the similarities between *reciprocity membership* and the process of recovery as described in the Western literature, it is possible reciprocity is also linked with recovery in the West.

4.4.4.2 Importance of everyday activities, specifically education and employment

Education and employment have long been recognized as health determinants. However, people with mental illness often have limited access to both. Additionally, leisure activities have been identified as being associated with recovery (Shank et al. 2015). Education, employment, and leisure are seen to have a range of benefits for recovery, such as symptom reduction, improved quality of life and increased social integration (Canadian Mental Health Association Ontario 2010; Shank et al. 2015). However, these activities are not always effective in promoting recovery and in fact can sometimes be detrimental to one’s mental health (Benach et al. 2014; Zimmerman and Woolf 2014). This can be better understood in the context of *reciprocity membership*.

Education, employment and leisure can all be viewed as providing opportunities for *reciprocity membership*. Someone who is employed makes a *contribution to* their employer through their role as an employee and in many
cases, to their team of co-workers. The money they earn allows them to improve contributions to other memberships (e.g., paying rent for a family apartment or sending a child to university). Students contribute to their classmates by sharing knowledge and have opportunities to contribute to student groups or societies. Education also fits into reciprocity membership theory by facilitating *positioning*. This may allow a person to obtain a preferable job where they will be able to make what they envision to be a more substantial contribution. Individual leisure activities do not fit within the theory, but group activities do. For example, joining a jogging club provides the opportunity to motivate members to run, a form of peer support. Reciprocity membership theory suggests that when reciprocity is balanced these activities are supportive of mental health. If reciprocity is unbalanced, these activities may become detrimental.

### 4.4.4.3 Social connectedness

Social connectedness as a recovery concept is most closely aligned with *reciprocity membership*. However, it is often vaguely or inconsistently defined in the literature. Some refer to ongoing or long term interpersonal ‘closeness’ with accompanying social support (Fraser and Pakenham 2009). Others describe connectedness as trusting relationships that promote feelings of belongingness and identity (Galloway and Henry 2014). In these definitions, connectedness is often seen as one-sided with the service user occupying the role of ‘consumer’ or recipient of support.

Reciprocity membership theory suggests that social connectedness occurs in the context of reciprocity. Taking this view, I suggest that recovery is supported by social connectedness primarily when the conditions for *reciprocity membership* are
present in the connection. In other words, simply being connected with others is inadequate. There has to be opportunities to contribute, expectations need to be reasonable, acknowledgement may be tangible or intangible, and interests or values have to align.

Ware et al. (2007) provide a definition of social connectedness from an American study that aligns very closely with reciprocity membership theory. The authors interviewed 56 individuals with psychiatric disabilities and conducted 8 site visits with organizations working to connect service users with the community. The authors define connectedness, based on study data, as, “…the construction and successful maintenance of reciprocal interpersonal relationships...[that extend] well beyond receipt of social support” (Ware et al. 2007, 471). This definition highlights the importance of balancing contributions to the community with support received. The authors also write that service users must identify with the larger group and have things in common. This is analogous to the condition of alignment with in reciprocity membership theory. Ware’s study provides a clear example of the importance of at least some aspects of reciprocity membership theory in a Western population. It also raises questions about whether the conditions for reciprocity membership differ in a Western context and whether reciprocity membership is a main concern for service users in a Western context.

4.4.4.4 Empowerment that fosters choice, autonomy, and personal responsibility

Within the mental health care system, recovery can be supported when service users are given the opportunity to make their own treatment decisions (Mead and Copeland 2000). This autonomy or agency is seen by some service users to be empowering and supportive of self-esteem and self-worth (Deegan 1996).
Indeed, there has been a movement away from paternalistic care towards inclusion of the service user as an active member of the treatment team (Igel and Lerner 2016).

Reciprocity membership theory suggests that the treatment team can be viewed as a membership where the service user has a role to play. When the role is passive, it can be a hindrance to recovery. However, when the service user has the opportunity to contribute to the treatment team, when the expectations of the service user are acceptable, etc., then reciprocity membership may contribute to positive mental health outcomes. In other words, the process of reciprocity membership may provide some explanation of why and how empowerment within the mental health care system facilitates recovery.

This proposition aligns well with a recent report commissioned by MIND on the co-production of services (Slay and Stephens 2013). The report defines co-production as “A relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities” (p.3). One of the key principles of co-production is ‘reciprocity and mutuality’, where professionals and service users have shared responsibilities in the context of treatment. This report mirrors findings from the current study that suggest treatment outcomes can be improved through empowerment of the service user as an active participant in his or her own care.

Empowerment outside of the mental health care system is also a common concept in the recovery literature (Drake and Whitley 2014). It aids recovery when people have the ability to make choices about things like housing, education,
employment, etc. The ability to make choices and decisions can be seen as synonymous with the ability to respond to unbalanced *reciprocity membership*. A person may leave a job because they feel expectations are too high, or join another where they will be able to make a more meaningful contribution. In other words, exercising autonomy and choice can be used as strategies to develop, maintain or improve *reciprocity membership*.

Hope is another recovery concept, which is linked to empowerment (McGeer 2008). For example, it would be difficult to be hopeful about getting a job if one was not empowered to take the necessary actions needed to obtain that job. In terms of *reciprocity membership*, hope relates to *envisioning*, part of the *positioning* process. Participants often envisioned themselves making a more valuable *contribution* to a group. This initial hope was a key step in the process of taking action to actualize what was envisioned. Thus, reciprocity membership theory acknowledges hope as important in the recovery process, but places it as strategy used to resolve the main concern of *reciprocity membership*.

Autonomy is also linked to empowerment. In our review of recovery through an Arabic sociocultural lens, we concluded that autonomy is one recovery concept that may not be an appropriate goal in an Arabic context (Hickey, Pryjmachuk, and Waterman 2017). We argued that community was placed above the self in order of importance, meaning that personal choice (i.e., autonomy) is less important that the greater good of the community. This may still hold true; however, participants in the empirical study expressed that a certain degree of autonomy and self-determination is desirable. Participants were not able to achieve *reciprocity membership* if they were restricted from making choices and
taking action that furthered their personal ambitions (receiving an education, getting a job, etc.). However, *reciprocity membership* sets these individual ambitions within the context of a community membership. Autonomy was valued because it allowed people to achieve personal goals, but personal goals were mainly aimed towards being a better community member.

**4.4.4.5 Summary of reciprocity and recovery in a Western context**

In summary, both *reciprocity membership* and recovery are unstable processes that occur over time and involve ups and downs. Reciprocity membership theory provides a potential explanation for situations that are important for recovery but can also negatively affect mental health. For example, social support, education, employment, and leisure. All can be potential sources of stress and dissatisfaction despite being recognized as health-promoting (Association and Centre for Addiction and Mental Health 2010; Benach et al. 2014; Shank et al. 2015). In cases where they are stressful, the underlying reason may be unbalanced *reciprocity membership*. When mental health service users are able to use strategies to rebalance *reciprocity membership* and make valuable contributions as a member of a group they feel a sense of empowerment and autonomy that benefits recovery. Based on the similarities between *reciprocity membership* and common recovery concepts it seems reasonable to suggest that *reciprocity membership* is transferrable to a Western context. However, an extension of this research (e.g., further data collection with Western participants) is necessary to ensure an adequate fit.
4.5 Strengths, limitations and personal benefit

As with all research, work undertaken for this thesis has strengths and weaknesses. The two published literature reviews included in this thesis include discussions of strengths and limitations of those reviews (p.15/12 & p.16/166-167), which will not be repeated here. This section will focus on the strengths and weakness of the grounded theory study. These include, the methodology, my ‘position’ in relation to participants, the study sample, and personal benefit.

4.5.1 Methodology

Using grounded theory to explore people’s experiences of mental illness in Qatar was a strength of this study. It enabled me to speak directly with mental health service users about their experiences with mental illness and the social processes involved in managing their illness. This methodology also led to the development of a substantive theory that is grounded in the concerns of service users in Qatar. This theory has implications for the ongoing development of health and social services in the country. The theory has also led to several hypotheses that provide grounds for future research in the area. Before now, anecdotal evidence was the main source of service user data available for planning services and research. This study is the first to provide in-depth, systematically collected evidence on people’s experiences of mental illness in Qatar.

Using classic grounded theory (CGT), as opposed to other types of grounded theory, was also a strength. As argued in the methodology chapter (p.33), it gives primacy to the voice of participants above other potential sources of data. This was important because mental health service users do not have a strong voice in Qatar. There are no charities or community organizations to advocate for them, mental
service administration is very top-down, and stigma prevents many from speaking publicly. This study allowed service users to share their voices anonymously. Many were grateful for the opportunity to do so. Furthermore, CGT allowed me to address the primary research objectives (p.23) and make an original contribution to the literature.

Following the methods of CGT as closely as possible was another strength. Glaser and Strauss (1967) and Glaser (1978) call for interpretation and adaptation of the methodology, despite being prescriptive about the actions the researcher needs to take. As a novice grounded theorist, I did not feel comfortable reinterpreting what I had no experience with. Adhering to CGT guidelines allowed me to avoid methodological ‘slurring’ (Baker, Wuest, and Stern 1992) and the associated loss of rigour. Sampling a wide range of participants allowed me to develop a theory that should be applicable to a range of service users in Qatar. I was not able to undertake theoretical sampling but the use of theoretical interviewing (as discussed on p.47) allowed me to broaden my understanding of emerging concepts. Constant comparison helped to ensure that the concepts and associated theory were grounded in the data. Additionally, approaching rigor as an ongoing, rather than post-hoc, assessment (see p.66) enabled the development of a high quality grounded theory. Although not a part of the dictum of CGT methods, close contact with my supervisors helped to keep me on track, overcome challenges and maintain confidence that I was adhering to the research plan.

The use of CGT was also a weakness because it ignores some potentially important factors. Concepts are incorporated into the theory only if they are relevant to participants. However, cultural, social, and institutional factors, stigma,
and power imbalances can be invisible to participants while still having an impact on their day-to-day lives. As a result, this study does not account for these factors. In fact, some of the strategies that participants used to achieve *reciprocity membership*, such as changing group membership or undertaking further education (i.e., *improving*), are not an option for many because of these factors. For example, females may need their father’s or brother’s permission to attend school. Approaching this topic using constructivist grounded theory (Charmaz 2014) may have elicited some of the structural factors that organize people’s behaviour. Using a more critical approach, such as feminism, would have allowed an exploration of power imbalances, diversity, and wider social issues (Reay 1996; Wuest 1995). However, academic freedom to undertake research that is critical of Qatar or its institutions is restricted (Romanowski and Nasser 2010). Taking such an approach and disseminating the results would have jeopardized my job security and may also have had negative consequences for my employer.

4.5.2 My ‘position’ in relation to participants

Another factor that was both a strength and a weakness was my position as a cultural outsider. Having a limited knowledge of a culture can help the researcher to identify differences and social patterns that would not normally be apparent to someone who is native to the culture (Hammersley and Atkinson 2007). It also allowed me to be open to participants’ concerns because I entered the field really having no idea about what to expect. If I had conducted this study in Canada, where I am more familiar with service users’ concerns, I might have entered the field with more preconceptions. Being a cultural outsider may have also been a weakness. Service users may not have felt comfortable sharing personal information with a
foreigner, and I may have misunderstood or misinterpreted culturally-nuanced information. However, I believe I addressed these potential weaknesses by employing a group of local RAs.

My position as a nursing instructor at a local university was also both a strength and a weakness. Foremost, it enabled access to the participant population that would not have been possible without an official designation. This position also meant that potential participants were familiar with my position and that of my RAs (nursing students), even if they were not familiar with us personally. This seemed to put service users at ease with our presence on the units and may have facilitated recruitment. However, my position is viewed as one of authority, and this may have been a coercive factor in people’s decision to participate and affected the type of data that was collected (Grimm 2010; Nuffield Council on Bioethics 2002). To overcome these issues, we made sure to take adequate time during the consent process to explain that people’s decision to participate had no bearing on their treatment. I believe these explanations were successful, as one service user declined as soon as he learned that participating would not help him get discharged. Another potentially limiting factor of collecting data from a position of authority is the possibility for social desirability bias (Grimm 2010). In other words, participants sometimes tell the researcher what they think they are expected to say. In regard to the data that was collected, participants were often critical of the health care system, their families, and the treatment they were receiving. This leads me to believe that participants were not just telling me what they thought I wanted to hear.
4.5.3 Study sample

The study sample has several potential weaknesses. Some might view the sample size as a weakness. However, other theses using grounded theory have samples that range from 4-87 with an average of 32 (Mason 2010), making the current sample typical. Additionally, sample size in qualitative research is more about quality than quantity (Sandelowski 1995). I interviewed 21 participants and continued to collect data until I felt I had achieved adequate saturation (Glaser 1998). Several key informants were interviewed multiple times over a year and a half to gain in-depth perspective on theoretical concepts. Because of these factors, I believe my sample size was adequate to address the objectives for the study (i.e., not a weakness).

One potential limitation of the study sample, however, is the relatively young age of participants. The oldest participant was 47 and the average age was 30. This reflects the composition of the inpatient population; older participants were infrequent in this setting. I may have been able to access older participants through the outpatient service and a small older adult outreach service. However, this limitation did not become apparent until about mid-way through data collection. By that point, it would not have been feasible to change the recruitment protocol because of the time it would have taken to gain local approval to access these new areas. This may limit the applicability of results (i.e., transferability) to the older service user population.

Also, in regard to limitations of transferability, is the potential relevance of this research to populations outside of Qatar. Grounded theory aims to develop a mid-range theory that is relevant for people in a substantive area (Glaser and
Strauss 1967). In the case of this study, these people are mental health service users in Qatar. Making assumptions about the applicability of reciprocity membership theory outside of this population would be inappropriate. However, the participant pool was broad, including service users from many countries in and outside of the region (see Table 7, p.79). Additionally, earlier in the discussion section (p.133) I drew parallels between reciprocity membership theory and Western recovery concepts. The diverse sample and the alignment with international literature suggest that reciprocity membership theory may be transferrable to other areas. However, it would be important to investigate this claim and most likely modify the theory in new contexts.

4.5.4 Personal benefit

This project has had a range of benefits. Those that have been discussed up to now concern mainly the scientific and potential social benefits. For example, the study has added to the body knowledge about recovery and mental illness management in an Arabic context (section 1.7) and also provided new directions for research and practice (these will be discussed in more detail later in chapter 5). The study has also given a group of mental health service users in Qatar the opportunity to share their experiences, many for the first time, in a way that may enable future service development. In addition to these scientific and social benefits, this project has also provided me with a substantial amount of personal growth and experience.

One of the primary goals of PhD studies is to help the student develop as an independent researcher. I have had the opportunity to conduct two literature reviews, undertake in-depth learning about a methodology that was previously unknown to me and implement a research plan based on it, learn about constant
comparative analysis and apply it to the data collected, and write several papers for publication. Prior to my PhD I had had some experience with these activities, but not to the same degree. The supervision I received helped me to develop a more rigorous and critical approach to all these activities and also helped me develop confidence as a researcher. Perhaps as a result, I have been able to increasingly set my own agenda and progress with less and less feedback from my supervisors. I feel I have now reached a point where I could plan and implement a study of equal quality independently, albeit with feedback from my colleagues, peers and the public. The progress I have in my studies combined with my work experience in Qatar recently allowed me to secure a tenure-track Assistant Professor position at a Canadian university.

4.6 Summary

This chapter has presented a discussion of the knowledge gained throughout the thesis and synthesized work undertaken. It has situated service users’ experience of mental illness within the GCC sociocultural context in which the research was undertaken and explored these experiences through the perspective of recovery. The discussion also presented reflections on the strengths, limitations, and personal benefit of the project and established the foundation for recommendations on future research, service and policy work. These implications along with a final summary will be presented in the following chapter with the goal of supporting care and treatment for mental health service users in the GCC and beyond.
Chapter 5. Conclusions

Chapter 5 Contents

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5.1 Introduction

This chapter presents the conclusions of the thesis based on the work described in the previous four chapters. Section 5.2 begins with a review of the work undertaken and the links between each stage (e.g., literature reviews, methodology development, empirical study, etc.). It also includes a table that summarizes theoretical concepts of the substantive grounded theory that was developed. Section 5.3 presents a concise summary of the contributions to the body of knowledge that this thesis has made. Sections 5.4 and 5.5 present detailed recommendations for research and mental health services, respectively. Section 5.6 contains a final summary.

5.2 Review of work undertaken

Work undertaken for this thesis began with a scoping review (Arksey and O’Malley 2005) of research on mental illness conducted in the Gulf Cooperation Council (GCC). The review included 55 studies and identified several themes and gaps in the regional research. One of the themes was recovery, which included elements of traditional healing, family and religion. These elements are uncommon in the recovery literature and suggested that recovery in an Arabic context may differ from current, common, understandings. One of the gaps was service users’ experience of mental illness outside of the hospital setting. This gap and the suspected differences in recovery pointed towards a study on service users’ experiences of managing their illness outside of the hospital setting.

However, an additional review was conducted prior to developing an empirical study. This second review examined common concepts of recovery in the literature, contrasted these with limited literature on recovery in non-Western
countries, and critiqued several concepts using an Arabic sociocultural lens. The review led to the conclusion that some common recovery concepts may not be appropriate in an Arabic context and that research into the recovery of Arabic mental health service users is needed.

These reviews led to the development of a classic grounded theory study on the illness self-management strategies of mental health service users in Qatar. As discussed in Chapter 1 (p.23), my original interest was in recovery, but the chosen methodology (CGT) requires the researcher to enter the field being open to the main concerns of participants. Thus, illness self-management was chosen over recovery to facilitate a broader approach that would be more inclusive of participants’ concerns than a narrower focus on recovery would allow. The aim of the CGT study was to develop a theoretical understanding of mental illness self-management in Qatar. The specific objectives were to:

1. Explore service users’ experience of mental illness in an Arabic context.

2. Identify service users’ main concern(s), related to mental illness self-management.

3. Identify and describe the actions service users take to address their illness self-management concerns.

4. Develop a substantive theory of mental illness self-management.

These four objectives were achieved through a series of interviews with 21 participants over a year and a half, and concurrent analysis. Outcomes have been incorporated into a grounded theory entitled reciprocity membership. The main
concepts of this theory are summarized in the following table and were previously illustrated in Chapter 3 (p.88).
Table 8. Summary of theoretical concepts

<table>
<thead>
<tr>
<th>Concept</th>
<th>Relevance of concept</th>
<th>Summary of concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Reciprocity</td>
<td>Main concern</td>
<td>Participants were most concerned with having membership in a group with the potential for reciprocity. <em>Reciprocity membership</em> is achieved through balancing the four conditions below.</td>
</tr>
<tr>
<td>membership</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1a. Contribution to</td>
<td>Condition of <em>reciprocity</em></td>
<td>Participants wanted to make a valuable or productive <em>contribution</em> to the group.</td>
</tr>
<tr>
<td>membership</td>
<td>membership</td>
<td></td>
</tr>
<tr>
<td>1b. Expectations of</td>
<td>Condition of <em>reciprocity</em></td>
<td>Participants wanted reasonable and achievable expectations from groups members related to their own contribution.</td>
</tr>
<tr>
<td>membership</td>
<td>membership</td>
<td></td>
</tr>
<tr>
<td>1c. Acknowledgement</td>
<td>Condition of <em>reciprocity</em></td>
<td>Participants wanted <em>acknowledgement from</em> group members for the contribution they make.</td>
</tr>
<tr>
<td>from</td>
<td>membership</td>
<td></td>
</tr>
<tr>
<td>1d. Alignment with</td>
<td>Condition of <em>reciprocity</em></td>
<td>Participants wanted to be part of groups where members have similar interests and values.</td>
</tr>
<tr>
<td>membership</td>
<td>membership</td>
<td></td>
</tr>
<tr>
<td>2. Valuing</td>
<td>Strategy to maintain/achieve</td>
<td>Ongoing appraisal of the balance of, or satisfaction towards, the conditions for <em>reciprocity membership</em></td>
</tr>
<tr>
<td><em>reciprocity</em></td>
<td><em>reciprocity</em></td>
<td></td>
</tr>
<tr>
<td>membership</td>
<td>membership</td>
<td></td>
</tr>
<tr>
<td>3. Positioning</td>
<td>Strategy to maintain/achieve</td>
<td>Strategy aimed at gaining and applying new skills, knowledge, or experience</td>
</tr>
<tr>
<td><em>reciprocity</em></td>
<td><em>reciprocity</em></td>
<td>membership</td>
</tr>
<tr>
<td>3a. Envisioning</td>
<td><strong>Sub-strategy of positioning</strong></td>
<td>The first step in positioning is imagining new and better ways to contribute</td>
</tr>
<tr>
<td>3b. Leveraging</td>
<td><strong>Sub-strategy of positioning</strong></td>
<td>Using personal strengths and resources to access new contributory opportunities</td>
</tr>
<tr>
<td>3c. Improving</td>
<td><strong>Sub-strategy of positioning</strong></td>
<td>Gaining new knowledge, skills and experience can enable increased contributions</td>
</tr>
<tr>
<td>3d. Repositioning</td>
<td><strong>Sub-strategy of positioning</strong></td>
<td>External factors can cause unexpected changes to group structure. Roles and responsibilities may change in these situations</td>
</tr>
<tr>
<td>4. Managing relationships</td>
<td><strong>Strategy to maintain/achieve reciprocity membership</strong></td>
<td>Strategy aimed at initiating, maintaining, improving or terminating connections to communities</td>
</tr>
<tr>
<td>4a. Enlisting</td>
<td><strong>Sub-strategy of managing relationships</strong></td>
<td>Joining new groups offers new contributory opportunities that can also have secondary benefits for reciprocity membership in existing groups</td>
</tr>
<tr>
<td>4b. Limiting</td>
<td><strong>Sub-strategy of managing relationships</strong></td>
<td>Demands in multiple groups may create the need to limit contributions to one in order to maintain reciprocity membership in another</td>
</tr>
<tr>
<td>4c. Substitution</td>
<td><strong>Sub-strategy of managing relationships</strong></td>
<td>If one membership is presently detrimental, it can be helpful to substitute that membership temporarily or permanently with another</td>
</tr>
</tbody>
</table>
5.3 Summary of contributions to the body of knowledge

Recovery in the GCC context is a social or community endeavour. Participants’ main concern was directly related to their associations with others. Recovery seemed to be strengthened when these associations were productive and satisfactory. When associations or memberships were perceived as satisfactory, participants seemed to experience positive mental health outcomes, such as feeling a sense of esteem, confidence, belonging and/or pride.

The most important community was the family. It was frequently referred to as the group where participants most valued their relationships. Participants demonstrated that family took priority over other communities. However, when family relationships were strained (i.e., when reciprocity membership was unbalanced), it caused significant distress for participants. This distress seemed to lead to low feelings of self-worth and even attempted suicide.

Family are viewed throughout the GCC literature as the most important source of support for individuals. However, as noted in the discussion (p. 116), they are often reluctant to become involved in the care of family members with a diagnosis of mental illness. Some of the reasons for this may be shame/stigma, lack of knowledge or caregiving skills, perceptions of the psychiatrist as an authority figure, and caregiver burden. Reciprocity membership theory provides a framework for working with families that may increase families’ capacity to provide care for members with a diagnosis of mental illness.

Modernization in the GCC region has created a situation where traditional family roles are shifting. For example, more women are entering the workplace, mothers and grandmothers are taking less responsibility for raising children, and
youth are able to interact with people outside of their extended family using social media or by attending university. These shifting roles have created a context where people have new opportunities to contribute to previously inaccessible communities. Reciprocity membership theory may provide a framework for understanding whether these connections are supportive of, or detrimental to, mental health. However, community education and a reduction in stigma is needed before health professionals will be able to adequately support service users to achieve reciprocity membership in these communities.

One type of extra-familial community that is rare in Qatar, compared to many Western countries, is where service users contribute as expert-by-experience. Examples include, peer support groups, research and service development consultation, and service user-led advocacy groups. There is an opportunity in Qatar to develop these communities. Doing so may have a positive impact on the mental health of service users who choose to be involved.

Religion can also be viewed as a type of community for the Muslim participants in this study. Placing religion within a framework of reciprocity membership provides a potential explanation why it can be both a source of strength and a source of stress. Religion provides opportunities for people to experience reciprocity as a member of a larger community. When reciprocity membership is balanced it can potentially strengthen an individual’s mental health and vice versa. Viewing religion through the lens of reciprocity membership theory provides some guidance on how mental health professionals and caregivers can leverage religion to support mental health (i.e., by promoting reciprocity membership).
The theory of reciprocity membership emerged from the main concerns of participants in Qatar, the majority of whom were Muslim Arabs. However, the theory also has alignment with some of the common recovery concepts in the Western literature. Both recovery and reciprocity membership are processes that highlight the importance of everyday activities and social relationships where hope and empowerment allow people to act to resolve their concerns. This suggests that reciprocity membership theory may also be applicable for a range of service user populations. It also seems that reciprocity membership theory provides an explanatory reinterpretation of why some common recovery concepts are important and how they promote recovery. Thus, reciprocity membership theory provides potentially useful guidance for new interventions and programs aimed at supporting recovery internationally.

5.4 Implications for research

Work undertaken for this thesis has led to multiple implications for research in the areas of mental health and recovery in an Arabic context, in particular. The supportive/detrimental role of the extended family, the influence of Islam on mental health, interplay between modern and traditional mental health treatment, and stigma are all areas where additional knowledge would be helpful. Additionally, gaining broader and more in-depth perspective from service users in the region would strengthen mental health service and policy development. Future studies on reciprocity membership theory and its utility in promoting positive mental health outcomes are a logical next step for the current research. Investigating the potential importance of reciprocity membership theory outside of an Arabic
context also has potential value. These research implications are discussed in more detail in the following paragraphs.

5.4.1 Role of the family in supporting recovery

A better understanding of the role played by the Arab extended family in supporting mental health is needed. As I have documented throughout the thesis, family has been shown to have both positive and negative influences on people’s mental health and family members are often reluctant to participate in care. Examining the types of positive and negative support that occurs, and the conditions under which they occur, would provide direction for further development of family-oriented services. Additionally, looking beyond the traditional view of the Arab extended family to develop a better understanding of the modern Arab family, and whether the changes in family roles and structures that have been occurring along with modernization affect the types of support for, and the mental health of, family members.

5.4.2 Role of religion in supporting recovery

Objective research on the role of religion is needed. Much of the regional research comments on the supportive role of religion without having empirical evidence to support these claims, and religion is often assumed to be an essential positive aspect of people’s experiences of mental illness. However, it can also be a negative factor. Systematic research is needed in order to better understand the role of religion in recovery for mental health service users, to identify specific aspects of religion that may be leveraged by mental health services to support recovery, and also to identify potential negative consequences of religion or assumptions about the role of religion.
Linked to religion is a need for research on the interplay between traditional and modern treatment of mental illness and how these can be combined to best effect. The presence and widespread use of traditional healers in the GCC region presents a potential opportunity for mental health services to improve access to services, promote early referral, and engage in a broader (i.e., inclusive of the supernatural) conversation about mental illness with service users. Research on outcomes of traditional-modern treatment collaboration would be particularly useful in providing guidance.

5.4.3 Stigma

Stigma is surprisingly understudied in the region. As discussed in the scoping review (p.15/11) not one of the 55 studies that were included addressed this topic, even though its presence is widely acknowledged and effects are commonly presumed (Hickey, Pryjmachuk, and Waterman 2016). This disparity between empirical research on the topic and presumed impact highlights the need for future research. When I was planning the grounded theory study, several stakeholders told me I was wasting my time. Their reasoning was that service users would not talk to me about their illness-related experiences because of “stigma”. As I learned, this was not at all the case. However, attitudes such as these are counterproductive to the development of new knowledge and evidence-based services. Developing a better understanding of stigma in the GCC and its impact on service users, healthcare professionals, researchers, educators, and the general community is important for the recovery of service users and all involved in their treatment and support.
5.4.4 Further examining reciprocity membership theory

Perhaps most relevant to the current study would be future research aimed at confirming, refuting or clarifying the role of *reciprocity membership* within the family and other group environments (e.g., work, volunteer organisations, etc.).

Examining the fit of reciprocity membership theory in other GCC countries would help to confirm or refute the importance of the theory in the region. It may also help to identify additional concepts or add to current understanding of existing concepts in the theory. Exploring the fit of *reciprocity membership* outside of the GCC region would also be useful. As mentioned earlier in the discussion (p. 126-133), the theory aligns well with several common recovery concepts in the Western literature. Thus, reciprocity membership theory may have potential application in a range of contexts.

Future research aimed at exploring the applicability of the theory would also be useful. For example, reciprocity membership theory could be used as a framework to examine the positive and negative influences of family and religion on mental health. It could also be used to develop and test interventions aimed at promoting recovery. For example, assessing the impact of the suggested guidelines listed below in Table 9 (p.155-157) for family assessment of *reciprocity membership*. Additionally, services aimed at assisting service users to connect or maintain connections with extra-familial groups could be developed and assessed.

Developing a *reciprocity membership* questionnaire would be another logical next step for this research. This tool would aim to assess balance in the conditions for *reciprocity membership*. Validating such a questionnaire against measures of recovery (e.g., Mackeith and Burns 2008; Neil et al. 2009) and illness
severity (e.g., Kay, Fiszbein, and Opler 1987) would help to establish the presumed link between *reciprocity membership* and recovery. If the scale were to be validated, it could be used as an assessment for interventions aimed at improving *reciprocity membership*.

5.4.5 Further exploratory research in the GCC

Finally, the personal recovery movement in the West has grown over several decades. What began as a service user movement now provides direction for mental health service and policy development worldwide. Taking a top-down approach, as is mainly the case in Qatar, seems contrary to the underlying values of the movement. In other words, implementing recovery services and policies that are based on the opinions of academic experts rather than the experiences and expertise of the local service user population may be a backwards approach. This can be seen as a ‘colonisation of recovery’ that is at odds with the principles it is intended to promote (#UnRecovered 2017). Thus, further exploratory research is needed to better understand what recovery means for service users in the GCC if recovery is to be included as a component of mental health services. This research will help to improve mental health professionals’ and policy maker’s understanding about the day-to-day issues and treatment experiences of service users. It may also help to support a more bottom-up approach to service and policy development.

5.5 Implications for mental health services

Work undertaken for this thesis has potential implications for mental health services in Qatar and, most likely, throughout the GCC region. Perhaps most relevant in the GCC context is using reciprocity membership theory to guide work with families of mental health service users. Mental health professionals might also help service
users identify and access reciprocity membership opportunities in extrafamilial communities. Working to reduce stigma at the community level could support service users’ engagement with these communities. Religion is another area with potential service implications, namely providing religious counselling to Muslim service users and working with traditional healers to facilitate early access to services. It may also be important that mental health professionals engage in dialogue about perceived causes of illness that are outside of a biomedical framework (e.g., jinn, black magic). Development of community mental health organizations is another avenue that might facilitate service users’ interest in reciprocity membership. These implications are discussed in detail in the following paragraphs.

5.5.1 Using reciprocity membership theory to guide work with families

The importance of family to recovery has been stressed throughout the thesis (e.g., p.15/10, 16/167, 114-120). The grounded theory developed through this project provides a potential explanatory mechanism by which families can be helpful or harmful, or both. Mental health professionals could potentially use the theory to help promote recovery in the family environment. More specifically, reciprocity in the family could be assessed as part of routine care. This would enable mental health professionals to work with service users and their family members towards balanced reciprocity membership. The following table outlines a number of suggestions on how mental health professionals might undertake this work.
Table 9. Applying reciprocity membership theory to work with families

<table>
<thead>
<tr>
<th>Theoretical concept</th>
<th>Assessment</th>
<th>Potential actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Reciprocity membership</td>
<td>1a. Contribution to the person contribute?</td>
<td>Contribution lacking: - Help service user to strengthen current contribution(s) and identify additional ways to contribute - Work with family to negotiate additional roles for the service user Contribution excessive: - Work with family to negotiate reduced contribution - Work with family to increase acknowledgement from</td>
</tr>
<tr>
<td></td>
<td>1b. Acknowledgement from the family. What support or benefits does the person get?</td>
<td>- Work with service user to identify and positively value acknowledgement(s) they receive - Encourage family to increase acknowledgement or make it more explicit</td>
</tr>
<tr>
<td></td>
<td>1c. Expectations of the person’s family expect from them? Financial contribution? Help with chores?</td>
<td>- Help service user reframe expectations of as being appropriate if possible - Assist service user to negotiate more appropriate expectations of with family members</td>
</tr>
<tr>
<td>1d. Alignment with</td>
<td>- Ask if person’s beliefs and interests fit with beliefs and interests of family.</td>
<td>- Assist service user to see how their own interests do and do not fit within the broader interests and values of the family.</td>
</tr>
<tr>
<td>2. Valuing</td>
<td>- Ask if the person is satisfied with the conditions of reciprocity membership.</td>
<td>- Discuss reasonable expectations and assist service user to modify their expectations if necessary (e.g., setting more realistic goals for potential contributions; expecting reasonable acknowledgement from others).</td>
</tr>
<tr>
<td>3. Positioning</td>
<td>3a. Envisioning</td>
<td>- Assess personal hopes and goals.</td>
</tr>
<tr>
<td>3b. Leveraging</td>
<td>- Do the person’s resources present opportunities to contribute (E.g., as a peer support worker)?</td>
<td>- Help service user identify opportunities to leverage their strengths and resources in a contributory manner.</td>
</tr>
<tr>
<td>3c. Improving</td>
<td>- Explore if the person is involved in improving activities (e.g., education)</td>
<td>- Offer support and encouragement for improvement activities.</td>
</tr>
</tbody>
</table>
3d. Repositioning
- Explore potential changes in membership roles and responsibilities
- Assist service user to renegotiate (with self and others) conditions for *reciprocity membership* within new membership structures

4. Managing relationships

4a. Enlisting
- Discuss other groups that the person would like to become involved with or has been involved with in the past.
- Encourage engagement with other groups
- Assist service user to take the steps necessary to begin contributing to other groups

4b. Limiting
- Discuss groups that the person is involved with (e.g., time spent with each, conflicting expectations, etc.)
- Assist service user in achieving balance/satisfaction between the competing demands of different groups

4c. Substitution
- Assess degree to which the family is presently helpful or detrimental
- Explore which conditions of *reciprocity membership* person is most dissatisfied with
- Encourage service user to take a hiatus from the family environment if necessary (extreme cases only)
- Work with family to understand dissatisfaction with *reciprocity membership* and to achieve better balance
5.5.2 Promoting engagement with extra-familial communities

As discussed in chapter 4 (p.120-123), service users benefit from *reciprocity membership* outside of the family environment. Actual membership opportunities in this study included work, volunteering, social groups, and educational affiliation. Potential membership opportunities include those where the service user has the opportunity to contribute as an expert-by-experience. These potential communities are most likely underdeveloped in Qatar because of lack of policy support and stigma.

The actual and potential benefits from these extra-familial memberships highlight an opportunity for mental health professionals to help service users identify and access new extrafamilial memberships as well as helping them balance *reciprocity membership* in existing ones. Additionally, *reciprocity membership* might be further enhanced if mental health professionals were to advocate for policy and practice changes that acknowledge the potential contributions of service users in the support of peers, planning and implementation of research, and development of services. Mental health services are well situated to offer training to service users that enable them to make a valuable contribution in these roles (Simpson et al. 2013; Tew et al. 2012).

5.5.3 Addressing stigma

Stigma seems to be a limiting factor for service users wishing to engage in memberships outside of the family. As mentioned in the previous paragraph, stigma is one potential reason why service-user roles and communities are underdeveloped. Within other extra-familial memberships, it is unlikely that service users would accept support from mental health services to promote *reciprocity*
Because they may avoid disclosing their diagnosis. Allowing intervention or mediation from mental health professionals would likely necessitate this disclosure. It is generally accepted with the mental health care system in Qatar that stigma towards mental illness needs to be addressed at many levels (e.g., with the healthcare system, in the community, etc.). Doing so might help to improve conditions for reciprocity membership, and subsequently for mental health. Providing community education to raise awareness and understanding of mental illness may also help to increase the support of the community for people with mental illness and create new or more satisfactory opportunities for reciprocity membership.

5.5.4 Religious counsellors

Both the literature and interviews with participants highlight how religion impacts most aspects of life for Arabic people. Certainly, some are more devout than others, but religion is an organizing influence on the day-to-day to lives of all Muslims in Qatar. It can be both a source of great support and a source of stress. This implies that mental health services should be inclusive of formal religious support and counselling. This support is currently offered informally from Muslim staff members or, infrequently on an ad hoc basis. However, it would likely be helpful to have religious counsellors embedded into mental health services. Ideally, religious counsellors could help mental health service users find strength and comfort in religion, address potential feelings of guilt associated with not being able to fully adhere to religious practices, and work towards reciprocity in their religious community.
5.5.5 Collaboration with traditional healers

Some of the regional literature highlights the role of traditional healers in the illness experiences of mental health service users. However, as mentioned previously (p.124), few participants discussed this topic during interviews. One potential explanation for this is that traditional healers are seen as more important during the onset of illness and that once people enter the mental health care system, traditional healers become less important. From this, it seems of potential benefit that mental health service providers collaborate with traditional healers in at least two ways. First, to provide some support and oversight to help decrease the likelihood of negative outcomes (World Health Organization 2013). Second, and perhaps most importantly, to improve early access to mental health services. Traditional healers seem to be a first point of contact; working with them to encourage referral of certain cases to psychiatric care may lead to better long-term outcomes.

5.5.6 Acknowledging traditional beliefs about the cause of mental illness

Mental health care professionals should acknowledge and explore beliefs about supernatural causes of mental illness. Many service users in the GCC attribute their illness to jinn, black magic or the evil eye. Acknowledging and discussing these beliefs may lead to better therapeutic alliances between health care professionals and service users and may increase receptivity for treatment. For example, one participant felt it was important to take his medications because they helped to control the jinn better than traditional healing methods. However, one difficulty in having mental health care professionals undertake these discussions with service users is the difference in beliefs systems. Many of the Arabic staff have been trained
in the West and have been socialized to adhere to the biomedical model of mental illness (i.e., neurotransmitters, genetics, etc.). Many of the other staff are foreign workers from countries without supernatural explanatory models and do not fully understand or agree with these beliefs. Regardless of mental health professionals’ beliefs or training, traditional understandings of mental illness are inextricable from some service users’ experiences (Koenig 1998). Thus, a culturally appropriate mental health service would be one where staff acknowledge and respect “long-held sacred traditions and belief systems” (Koenig et al. 2014, 125).

5.5.7 Development of community mental health organizations

This section has outlined multiple implications for mental health services and people working in the field. However, I also acknowledge the restraints on services. At least in Qatar, a considerable amount of effort has been directed towards the ongoing development and scaling up of mental health services. It would be unreasonable to expect these same people, using the same limited budget, to undertake all of the recommendations outlined in the previous paragraphs. Therefore, a final recommendation, directed towards the Governments of the GCC countries and to community members is the funding and development of community mental health organizations (e.g., charities, NGOs) to undertake some of this work. These organizations are relatively common in Western countries but remain rare in the GCC. It is possible that stigma prevents service users from openly engaging in activities that identify them as having a mental illness and also likely that service users in Qatar have a lack of expertise establishing and operating such organizations. Development of these initiatives, however, could relieve some
of the pressure on overextended mental health services, provide support, and advocate for new reciprocity membership opportunities for service users.

5.6 Summary

Work undertaken for this thesis has provided an in-depth synthesis of service users’ experience of mental illness in the GCC, with an emphasis on Qatar. The knowledge that has been gained from the combination of literature reviews and empirical study has created a better understanding of mental illness and personal recovery in the GCC region. It also provides evidence-based and contextually-grounded direction for future research and suggestions for development of services and policy.

The following points outline potential future research priorities in the GCC and international contexts and suggestions for practice and policy in Qatar and throughout the GCC.

Potential future research priorities:

1. Develop a better understanding about the role played by the Arab extended family in supporting the recovery of family members with a diagnosis of mental illness

2. Undertake objective research about the role of religion on the recovery journey of Muslim mental health service users

3. Investigate outcomes of the recommended collaboration between traditional and modern mental health care systems

4. Explore levels of stigma in the GCC and its potential impact on service users, healthcare professionals, researchers, educators, and the community
5. Undertake investigations of *reciprocity membership* in other contexts in order to confirm, refute or modify the process within families and other community environments.

6. Examine the applicability of reciprocity membership theory in a range of contexts as a health promotion framework.

7. Create and validate a *reciprocity membership* assessment tool.

8. Continue to explore and disseminate the experiences of mental health service users in the GCC to create momentum for a bottom-up recovery movement in the region.

Suggestions for practice and policy:

1. Work with service users and their families towards achieving and maintaining balanced *reciprocity membership*; use reciprocity membership theory as a framework for working with families.

2. Help service users to identify and access new communities with potential for *reciprocity membership*; advocate for policy and practice changes that create opportunity for service users to contribute; offer training that enables service users to contribute as experts-by-experience.

3. Address stigma in the community.

4. Incorporate formal religious counsellors into mental health services.

5. Collaborate with traditional healers to promote better and earlier access to mental health services.

6. Acknowledge and explore beliefs about supernatural causes of mental illness with service users.

7. Fund and develop community mental health organizations.
Most significantly, the grounded theory study that was undertaken identified *reciprocity membership* as the main concern of participants. Belonging to, and receiving support from a group or community is inadequate to promote mental health. People also, and perhaps primarily, need the opportunity to *contribute to* that group. The act of making a valued contribution makes people feel useful and gives meaning to their lives. This quest for meaning may equate to the process of personal recovery in an Arabic context.

Thus, future research should aim to develop, and assess the impact of, *reciprocity membership*-supporting programs and clarify the relationship between *reciprocity membership* and mental health. Exploring the fit of *reciprocity membership* theory in other contexts has the potential to benefit the mental health of other populations. The ongoing personal recovery of mental health service users in the GCC, and perhaps beyond, may be improved by developing mental health services, policy, and community organizations that are supportive of service users’ desire for *reciprocity membership*. 
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Appendices

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Appendix 1. Interview Schedules

**Early Interview Schedule**

I am going to start by asking you some demographic questions. If you don’t feel comfortable answering something, just say you don’t want to answer.

- What is your date of birth?
- What is your nationality?
- Are you married?
- Are you employed?
- What is your religion?

Ok, now we will move on to the main part of the interview.

Instructions for interviewer:

- Let participant decide on priorities for discussion
- Use active listening and prompts to encourage elaboration

Questions for participant:

- Can you tell me about yourself?
- Can you tell me about your illness? (if not already discussed in previous answer)
- Can you tell me about how your illness impacts your life? (if not already discussed in previous answer)
- Is there anything else you would like to tell us?

**Late Interview Schedule**

- Demographic questions (same as early interview schedule)
- Can you tell me about yourself?
- Can you tell me about your life outside of the hospital?
- Can you tell me about your family and friends?
- How do you deal with your mental illness in the community?
- Some of the other people we have spoken to have talked about the importance of having some kind of productive role. Maybe within their work, or within their friends, etc. Do you see yourself as having any productive roles?
Appendix 2. Memo examples

This appendix provides examples of early and late memos demonstrating conceptual development of the sub-core category of *managing relationships* and the core category of *reciprocity membership*.

**Managing Relationships – Early Memos**

Memo title: Connection essential
Some people seems to have one or more ESSENTIAL CONNECTIONS, or PRIMARY CONNECTIONS. For participant C, this was his wife. He feels a strong responsibility to have a family and to be a good husband, as defined by social and religious expectations. When this essential connection failed, it caused him huge distress. The one thing that seems to have helped this distress is by replacing that failed connection with a similar connection, in his case, a new wife. Participants B1 talked about his father being the most important and supportive and participant A1 talks about his mother having that role. And a later participant talks about her sister. What would happen with A1 and B1 if they lost this connection? Would they try to replace it with a similar connection? This would be more difficult to do with a parent?

Memo title: Social synapsing
I have quite a few codes related to synapsing, but it it starting to seem like many of these can fit into membership. I will have to figure out the delineation between the two. I think new connections with an individual can be seen as synapsing. But then one the connection is made, a new or enlarged MEMBERSHIP is formed. Then, when that connection is later activated or utilized, it can be seen as a function of membership, rather than a SYNAPSING. Thus, SYNPSING is the process of becoming (or terminating?) a member of a community.

**Managing Relationships – Late Memo**

Memo title: Managing Relationships
This is the sub-core category that will subsume connections/synapsing.

MANAGING RELATIONSHIPS is the process of creating, limiting, or terminating relationships with other people or groups.

So, potentially, creating, limiting and terminating are the properties of MR. Other potential properties that have already been included in coding are enlisting, negotiating, distancing. But maybe these should/could be changed to fit into the creating, limiting, terminating?

People tend to engage in relationships with people who share their own values, qualities or characteristics. I1 complains that the staff in the hospital should be locals, instead of foreigners. This is likely because she thinks they would understand her better, be able to communicate with her better or both. Another participant (hanging case) talks specifically about only wanting to make relationships with people who share his interests. People who are interested in starting a business in the home country, and can therefore help him to achieve his own goals. He avoids relationships with people who doesn't share these interests and seeks to build relationships with people who do.
Substitution may be a property of this. N1 provides several examples. He drifts from group to group in search of reciprocity. One can leave a group and join another, maintain membership in both but change which is prioritized, and also come back to a group after previously leaving it. A1 or A2 also provides an example of this when he has tension with his family, takes an overdose, effectively exiting temporarily from his family group to re-join the treatment team.

**Reciprocity Membership – Early Memos**

Memo title: Growth in site of (main concern?)
Growth in spite of. Could this be the main concern? If so, the connections participants make could be the strategy used to resolve this concern. A related substantive theory would have implications for anyone with any issue who wants to develop. How does one overcome issues? By envisioning a new self/identity, but improving, and by developing the right connections/social synapsing.

Memo title: Core categories...
Main concern? Value adding membership. Participants judge themselves in relation to the contribution they are able to make in the community or communities in which they hold membership. Self-worth is closely linked to their own perception of the contribution they are able to make as a member. ADDING VALUE/IMPROVING enables a person to gain skills and knowledge that increase their ability to contribute...

Memo title: Social Synapsing
SOCIAL SYNAPSING is another main process that resolves the main concern. It is the process of making connections with people. These connections have several properties: They can function to enable a person to recognize and overcome limitations; they can also function as a network which enables achievement, opens doors, and creates new possibilities; or they can function as a node on a connection pathway to potentially useful future connection.

Memo title: Core categories...
VALUED CONTRIBUTORY MEMBERSHIP. Refers to the process of ensuring an ongoing contribution to the group or groups in which one holds membership. The two properties of this category are maintaining value and increasing value. Sub-core categories include SOCIAL SYNAPSING, where participants develop, renew, or restrict connections with others.

**Valued Contributory Membership** (is this the process or the main concern? is the main concern, then what is the process? could be an envisioning/appraisal/action cycle. conscious envisioning of how one can make the most valued member contribution, subconscious appraisal of how particular actions or events affect that contribution, planned or undertaken action to maintain or increase that contribution)

Today, I am wondering if ESTEEMED CONTRIBUTORY MEMBERSHIP is more appropriate. D1 made me think about this (see note on positioning). She wanted to do her masters so she could get a better position, professionally. The purpose behind this is so her sons will be proud of her. In other words, she strived to be an esteemed, contributing member of her nuclear family community.

Memo title: Maximizing membership
Maximizing? Value adding? Value added? membership is the core category? People do this
because they want to fulfill a social responsibility, because they want to set an example, and because they want to contribute to the group support system. Social synapsing is a sub-core category of maximizing membership because it allows people to overcome challenges and extend their range of influence/contribution. Improving is another sub-core category because it allows people to increase their member contribution by bringing new skills, knowledge, education, experience or credentials to the group.

Reciprocity Membership – Late Memo

Memo title: Reciprocity (note: this memo was developed over several weeks)
I had a recent discussion with a mentor about my prelim findings. She assumed that being part of a community provided a great deal of support and led to better health outcomes. I had to correct her by saying that it seems that with my participants at least, it is more than just being part of a group, that there has to be a contribution. When she finally understood she said, “oh so there has to be RECIPROCITY.”

This concept fit better with the emergent theory and led me to re-label the core category as RECIROCITY MEMBERSHIP.

When RECIPROCITY MEMBERSHIP goes out of balance, it can be a cue for the group or individual that something is wrong. The balance is a subjective marker, judged through the process of VALUEING, where the participant feels that he or she is making an adequate contribution based on his or her own expectations, cues from the group, and the perceived or actual rewards.

F1 provides an interesting example of RECIPROCITY MEMBERSHIP when she describes telling off her inpatient psychiatrist for providing care she felt was inadequate. Here, she is acting in the role of expert-by-experience. She is an experienced patient who has had many therapists over the years and is quite aware of what works for her and what doesn't. Her contribution is as a service user, a group that she is advocating for by advocating for herself, and another contribution is as a part of the treatment team. Through the process of VALUEING, she deems the contribution of the team lead to be inadequate, so she attempts to address the situation. During this process, she addresses the trainees in the room and tries to provide education on how to be better members. One of the biggest issues she had with the psychiatrist actually, was she felt he was placing all of the responsibility and work on her. Through the process of VALUEING, F1 determines this to be an unfair expectation for her contribution.

This is applicable to participant C as well. His parents lost their jobs, the reciprocity was destabilized and it had a negative impact throughout the group. This suggests two properties for VALUEING, stable and unstable. When RECIPROCITY Membership is stable, there is balance. When it is unstable, there is a lack of balance and there can be chaos and confusion as RECIPROCITY is readjusted through POSITIONING (e.g., improving) and/or MANAGING RELATIONSHIPS.
Appendix 3. Consent form

(see following pages)
# Research Consent Form for Primary Participants

**1. Title of research**

| Arabic | Exploring self-management of mental illness in Qatar |

**2. Principal Investigator**

| Arabic | السيد جيسيون هيكى من جامعة مانشستر وجامعة كالجاري في قطر |

**3. Why are we inviting you to join this research?**

| Arabic | نحن ندعوك للمشاركة في الدراسة التالية، الغرض من دراستنا هو تسليط الضوء على التحديات والنجاحات المرض النفسية التي قد تكون أثرت على رحلة الشفاء فقد قررنا الحديث الحكيم والسبب يعود إلى أنه قد تكون لدينا رؤية مختلفة، وتجاربك سوف تزودنا بمعلومات قيمة. |

**4. What should you know about the invitation?**

<table>
<thead>
<tr>
<th>Arabic</th>
</tr>
</thead>
<tbody>
<tr>
<td>نستقدم شرح البحث لك بشكل وافٍ، قرار الانضمام للمشاركة بهذا البحث أو عدمه يعود لك، يمكنك قبول أو رفض المشاركة، بغض النظر عن من يدعوك للمشاركة (يدعوك للمشاركة) هل مطلقت الخبرة، فإن تسأل أي سؤال قبل اتخاذ قرارك، أو بعد الدراسة، إذا وافق على المشاركة، بإمكانك أن تتغير رأيك لاحقًا لأننا نستخدم قرارك ضدك بأي حال من الأحوال</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>English</th>
</tr>
</thead>
<tbody>
<tr>
<td>We will explain the research to you.</td>
</tr>
<tr>
<td>Joining is an individual decision (you can accept or refuse regardless of who is inviting you to participate).</td>
</tr>
<tr>
<td>Please feel free to ask questions or mention concerns before deciding or during/after the research.</td>
</tr>
<tr>
<td>You can accept but change your mind later on.</td>
</tr>
<tr>
<td>We will not hold your decision against you.</td>
</tr>
</tbody>
</table>

**5. Who can you talk to?**

<table>
<thead>
<tr>
<th>Arabic</th>
</tr>
</thead>
<tbody>
<tr>
<td>إذا كان لديك أسئلة حول حقوقك كمشارك بالبحث، أو كنت ترغب في التحدث مع شخص من خارج فريق البحث، يرجى الاتصال بالسيد جيسيون هيكى، جامعات مانشستر - كلية التمريض والولادة والعمل الاجتماعي جامعة كالجاري في قطر - عضو هيئة تدريس في التمريض</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>English</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you have any questions, concerns, or thoughts you can contact the research team at:</td>
</tr>
</tbody>
</table>

| Jason Hickey |
| University of Manchester |
| School of Nursing Midwifery and Social Work |
| University of Calgary in Qatar |
| Faculty of Nursing |
| +974 4406 5205 |

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v.Nov22, 2015
6. Why are we doing the research?

There is a lot of work being done in Qatar to improve services for people with mental illness. One of the main goals of this work is to make it easier for people with mental illness to be healthy and have a satisfying life.

At the moment, we don’t know enough about the things that make it easier or harder for people with mental illness to have a healthy and satisfying life.

We are doing this research because your opinion on mental health services is important to us. We believe that we can learn from you about what makes it easier or harder for people to take care of themselves. We hope that this will help us to understand more about what kinds of mental health services and other supports are needed in Qatar.

7. How long will the research take?

We think that you will be in the research for as little as one hour. This is how long it will take to complete the interview. However, if you don’t mind, we may like to speak with you several times about the research. That would mean one to seven more interviews over the next two years. You can decide when to end your participation.

We expect the research to last for three years. This will include about two years of collecting and analyzing the data and another year to write about the results.

8. How many people will take part?

We expect that you will be one of many people participating in this research. We don’t yet know exactly how many people will take part, but we expect this number to be reasonable.
### Research Consent Form for Primary Participants

We plan to study about 30-50 people. The research will include about 20-30 people with mental illness and about 10-20 others who help those people to manage their illness.

<table>
<thead>
<tr>
<th>9. What happens if you take part?</th>
<th>9. ما الذي سيحدث إذا قررت الاشتراك بهذا البحث؟</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you agree to join, we will ask you to do the following:</td>
<td>إذا وافقت على المشاركة، سنطلب منك القيام بما يلي:</td>
</tr>
<tr>
<td>Talk to us about your interactions with the person who referred you to this study.</td>
<td>حديثنا تفاعلك الشخص المحمول للدراسة.</td>
</tr>
<tr>
<td>Talk to us about the things you believe make it easier or harder for the patients throughout their journey of recovery.</td>
<td>حديثنا عن الأشياء التي تعبد أنك تسهل أو تجعل على المريض خلال رحلة الشفاء.</td>
</tr>
<tr>
<td>Tell us about what you think it means for the patients to be healthy and what kinds of things make their life satisfying.</td>
<td>لماذا تعتقد أنها تسهل أو تجعل على حياة مرضية.</td>
</tr>
<tr>
<td>Tell us about what kind of changes you think would make it easier for the patients to be healthy and have a fulfilling life.</td>
<td>لماذا تعتقد أنها تسهل أو تجعل على حياة مرضية.</td>
</tr>
<tr>
<td>We would like to interview you for about an hour. In some cases we may decide that it would be helpful to interview participants more than once, however, this is only if you accept. This will help us go through our first interview with you and clarify information we may have missed or misunderstood. It will also help us gain a better understanding over time. The maximum number of interviews we will conduct with each participant is eight within a two-year span. We will contact you within a month if we would like to interview you again.</td>
<td>نحن نود أن نقابلك لمدة ساعة تقريبًا. في بعض الأحيان قد نطلب منك/Eحدياً/إجراكم لأي مقابلة أخرى في وقت لاحق، وذلك في حال مراعاة المعلومات وتقصي أي سوف قد حصل في المقابلة الأولى. وذلك سوف يساعدنا أيضاً على كسب فهم أفضل مع مرور الوقت. الحد الأقصى لعدد المقابلات التي سوف تجري هي ثماني مقابلات.</td>
</tr>
<tr>
<td>There will be two people from the research team at each interview. One researcher will lead the interview and the other researcher will either translate or take notes. If you participate in additional interviews it is possible that only one person from the research team will attend. We can interview you in the hospital or at the University of Calgary. Depending on your preference, we could also interview you somewhere else, as long as it is quiet and safe.</td>
<td>سيكون هناك شخصين من فريق البحث في كل مقابلة. أحد الباحثين سوف يقود الجلسة، والباحث الآخر سوف يقوم بتسجيل المعلومات أو سوف يقوم بالترجمة. إذا شاركت في مقابلة إضافية شخص واحد من فريق البحث سوف يقوم بإجراء المقابلة.</td>
</tr>
<tr>
<td>We are also interested in learning about the people who have helped you manage your illness. Therefore, we will ask you about those people as well. We may also ask to meet some of those people, but only if that is acceptable with you and also them.</td>
<td>نحن مهمون أيضاً في التعرف على من قد لقب/ي المساعدة في إدارة مرضك. وذلك، إذا سوف تقوم بمساعدتك عليهم، قد نطلب منك/Eحدياً/إعدادهم.</td>
</tr>
</tbody>
</table>

### 10. Could the research be bad for you?  

هو يمكن لهذا البحث أن يضرك؟

| 10. | 10. |
| Could the research be bad for you? | هل يمكن لهذا البحث أن يضرك؟ |

v.Nov22, 2015
There are no physical risks of being involved in this study. If you find the interview distressing, we will refer you to the appropriate services if necessary. For example, provide you with the number for the mental health crisis line and the outpatient department at the psychiatric hospital.

Lo tengkat mazhar mada'ah min munkara fi adhanna. Idha 'inda wadat-tasajār wa'allahu yahānu, tawajjad 'inda matnayati 'inda shahidātun dhiyā al-askarīna al-ghourī. Thariq al-tiza'ir munkara fi al-'iṣlahāt al-dhahabiyya, wa tawajja'īn al-'iṣlahāt al-dhahabiyya min lamh yahānu, sīf tawajjad bi-tawajjad bi-wadat-tasajār wa'allahu yahānu, yafadā ba'da lamh yahānu. Munkara fahāmu fi al-intilājī munkara wa'allahu yahānu. 11. Ḥa'il 'inda有些人ka biyīdīk?

We cannot promise any direct benefit to you or to others. One potential benefits includes contributing to the development of better healthcare services in Qatar. Your involvement may also help us reduce stigma towards mental illness and improve mental health training for future health care professionals.

12. What happens to information about you?

We have developed a system to protect your privacy. This includes using a code to identify you in our records instead of using your name. We will not identify you personally in any reports or publications about this research.

The information we collect during your interview will be stored safely on a computer. Only the research team will be able to access it. All of the information we collect will be destroyed five years after the study is completed.

We cannot guarantee complete secrecy, but we will limit access to information about you. Only people who have a need to review the information will have access. These individuals might include:

- Members of the research team and other HMC or University of Manchester representatives whose work is related to the research or to protecting your rights and safety.
- Representatives of the Qatar Supreme Council of Health who make sure the study is done properly and that your rights and safety are protected.

We plan to use data from this study in other projects in the future. This might include sharing the data with other researchers. Before we store the data for future use, we will destroy all links between your identity and the data about you.

13. What if you don’t want to join?

We have developed a system to protect your privacy. This includes using a code to identify you in our records instead of using your name. We will not identify you personally in any reports or publications about this research.

The information we collect during your interview will be stored safely on a computer. Only the research team will be able to access it. All of the information we collect will be destroyed five years after the study is completed.

We cannot guarantee complete secrecy, but we will limit access to information about you. Only people who have a need to review the information will have access. These individuals might include:

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We plan to use data from this study in other projects in the future. This might include sharing the data with other researchers. Before we store the data for future use, we will destroy all links between your identity and the data about you.
Participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and you will be asked to provide consent. If you do agree to take part in this study and decide at a later time that you would like to withdraw from the study, then you are free to do so at any time. Your decision will not influence your future care or treatment.

The University of Manchester, Review Board in Qatar and the Research Ethics Committee at the University of Manchester have approved this research.

This research has been approved by the Joint Institutional Review Board in Qatar and the Research Ethics Committee at The University of Manchester.

The participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and you will be asked to provide consent. If you do agree to take part in this study and decide at a later time that you would like to withdraw from the study, then you are free to do so at any time. Your decision will not influence your future care or treatment.

If you agree to be a part of the study we will audio record your agreement. We will also audio record the interview so that we do not forget any of the important information you tell us. We can stop the recorder at any time during the interview if there is something you do not want recorded.

We will tell you about any new information that might affect your health or welfare, or might affect your willingness to continue in the research.

If you need to take a taxi or driver to the interview, we can reimburse you up to 100QAR to pay for the taxi.

If you agree to be a part of the study we will audio record your agreement. We will also audio record the interview so that we do not forget any of the important information you tell us. We can stop the recorder at any time during the interview if there is something you do not want recorded.

We will plan to publish the results in a scientific journal and maybe a book or website. We will also present the results at conferences. We might use some of your words to help us explain our results but we won’t include any information that could be used to identify you.

This research has been approved by the Joint Institutional Review Board in Qatar and the Research Ethics Committee at The University of Manchester.

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We will plan to publish the results in a scientific journal and maybe a book or website. We will also present the results at conferences. We might use some of your words to help us explain our results but we won’t include any information that could be used to identify you.

This research has been approved by the Joint Institutional Review Board in Qatar and the Research Ethics Committee at The University of Manchester.

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**Research Consent Form for Primary Participants**

<table>
<thead>
<tr>
<th>Verbal consent for Capable Adult</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>If you would like to join the study I will just ask you a few questions to make sure you understand:</td>
<td></td>
</tr>
<tr>
<td>Correct answer:</td>
<td></td>
</tr>
<tr>
<td>What is the study about?</td>
<td></td>
</tr>
<tr>
<td>What are the main risks of the study?</td>
<td></td>
</tr>
<tr>
<td>What are the benefits of the study?</td>
<td></td>
</tr>
<tr>
<td>Do you have to participate?</td>
<td></td>
</tr>
<tr>
<td>If you participate, when can you withdraw?</td>
<td></td>
</tr>
<tr>
<td>Who will have access to the data?</td>
<td></td>
</tr>
<tr>
<td>How will we share the results?</td>
<td></td>
</tr>
<tr>
<td>Have all of your questions been answered?</td>
<td></td>
</tr>
</tbody>
</table>

**Volunteer**

**I voluntarily agree to join the research described in this form.**

Printed Name of Volunteer

**Future contact**

We would like your permission to contact you about participating in future studies. You may still join this study even if you do not permit future contact. You may also change your mind about this choice. Please tell us your choice:

_______ YES, you may contact me  
_______ NO, you may NOT contact me

**Person Obtaining Consent**

I document that:
- I (or another member of the research team) have fully explained this research to the volunteer.  
- I have personally evaluated the volunteer’s 

صفحة التوقيع للمشارك البالغ (العقل)  
إن كنت ترغب في المشاركة في هذا البحث، فضلاً أقرأ الأسئلة التالية للتأكد من صحة فهمك للبحث:  
الجواب الصحيح: 
 عن ماذا ينص هذا البحث؟  
ما هي المخاطر الأساسية لهذا البحث؟  
هل يقتضى هذا البحث منك فإنك ستحصل على البيانات الخاصة بك؟  
هل يمكنك تقويم نتائج البحث؟  
هل تم التأكد على جميع أسئلتك؟  

(شغل تسجيل الصوت)  
هل توافق على المشاركة في هذا البحث؟  
هل يمكننا تسجيل المقابلة؟  
هل يمكننا أن نستخدم مقولاتك (من غير استخدام اسمك)؟  
هل يمكننا استخدام البيانات مع الباحثين الآخرين (من غير استخدام اسمك)؟

**الاسم الكامل للمشارك بالبحث**

أوافق طوعاً على الاشتراك ببحث علمي للمشاركين  

**في حال التواصل مستقبلاً**

نود الحصول على إذنك للاتصال بك حول المشاركة في دراسات مستقبلية. بمثابة الاهتمام لهذه الدراسة حتى لو لم تسمح بأن تتصل بك مستقبلاً. كما ويمكنك أيضاً أن تغير آرائك حول هذا الاختيار. الرجاء التوقيع أدناه:

نعم، يمكنكم الاتصال بي  
لا، لا تتصلوا بي  

**الشخص الحاصل على الموافقة**

v.Nov22, 2015
**RESEARCH CONSENT FORM FOR PRIMARY PARTICIPANTS**

<table>
<thead>
<tr>
<th>understanding of the research and obtained their voluntary agreement.</th>
<th>على موافقته بالطوعية تم تسجيل موافقتنا الشفهية.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Verbal consent has been recorded</td>
<td></td>
</tr>
</tbody>
</table>

### Printed Name of Person Obtaining Consent

### Signature of Person Obtaining Consent

### Date

### Witness (if applicable)

I document that the information in this form (and any other written information) was accurately explained to the volunteer, who appears to have understood and freely given Consent to join the research.

### Printed Name of Witness

### Relationship to participant

v.Nov22, 2015
Appendix 4. Distress Policy

Participant number __________ Date __________ Interviewer __________

Cue: Interviewer suspects the participant may be distressed, or is becoming distressed.

Action: Interviewer confirms whether participant is feeling distressed/anxious/angry/etc

If yes, interviewer:

- terminates interview;
- provides empathy and verbal support/reassurance;
- remains with participant until a family member, friend, mental health worker, etc. is physically present to ensure distress participant is not left alone.
- assesses need/desire for referral to psychiatric services, provides contact information if appropriate;
- provides contact information for research team and mental health crisis line;
- reassures participant that interview can be resumed at a later time, or participant can choose to end participation;
- remains with participant until distress has subsided or can receive support from caregiver/support person
- records incident for discussion with supervisors and reporting
- follows up with participant after 24 hours
- reports incident to supervisors within 24 hours

If no, interviewer:

- Continues interview
- Monitors perceived level of distress
- re-addresses distress, if any change is noted