Administration and Policy in Mental Health and Mental Health Services Research (2019) 46:54–61
https://doi.org/10.1007/s10488-018-0893-7

ORIGINAL ARTICLE

Mastering the Art of Collaboration: Supporting Family Caregivers of Mental Health Patients by Service Providers in Iran

Mohammad Akbari[1] · Mousa Alavi[2] · Jahangir Maghsoudi[3] · Alireza Irajpour[4] · Violeta Lopez[5] · Michelle Cleary[6]

Published online: 31 August 2018

Abstract

Responsive support systems, designed and promoted by policy makers, are critical in supporting family caregivers. The purpose of this study was to explore viewpoints of service providers in supporting family caregivers of mental health patients in Iran. In this qualitative study, a purposive sample of 29 service providers and policy makers consented to participate in semi-structured interviews. Data were analyzed through qualitative content analysis and three main categories and seven sub-categories were identified. The main categories were: interpersonal collaboration, intra-organization collaboration and inter-sectorial collaboration. A common theme in this study was that service providers play a key role in coordinating responsive support services for Iranian family caregivers of mental health patients across all levels. The increasing complexity of the health care system and resource limitations have created complex problems, which require the use of participatory approaches by the various specialties, disciplines and departments to provide complementary services and mutual support. This approach is the best way of ensuring that service users receive the most relevant services from the right service providers in the right place as and when needed.

Keywords Responsive support system · Family caregivers · Mental health disorders · Qualitative · Iran

Introduction

Mental illness is a growing health concern, accounting for an increasing total burden of disease globally (Wildeman 2013). Mental disorders are highly prevalent across the globe, affecting people from all regions (Steel et al. 2014). Despite this prevalence, many people who live with mental health receive little or no effective treatment at all (Thornicroft et al. 2012). For those who receive in-patient care, readmission is not uncommon (Chang and Chou 2015; Sadock and Kaplan 2011).

Today, de-institutionalization of clients with mental illness has resulted in the increasing role of family caregivers who care for these clients in the community settings or in their homes (Awad and Voruganti 2012). Family caregivers of clients with mental illness provide not only management

✉ Mousa Alavi
m_alavi@nm.mui.ac.ir

Mohammad Akbari
mohammadakbari@nm.mui.ac.ir

Jahangir Maghsoudi
maghsoudi@nm.mui.ac.ir

Alireza Irajpour
Irajpour@nm.mui.ac.ir

Violeta Lopez
nurvl@nus.edu.sg

Michelle Cleary
michelle.cleary@utas.edu.au

1 Student Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

2 Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

3 Nursing & Midwifery Care Research Center, Mental Health Nursing Department, Faculty of Nursing & Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

4 Nursing & Midwifery Care Research Center, Critical Care Nursing Department, Faculty of Nursing & Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

5 Alice Lee Centre for Nursing Studies, Yong Loo Lin School of Medicine, National University of Singapore, Singapore, Singapore

6 School of Health Sciences, University of Tasmania, Sydney, NSW, Australia

of the condition but also play a crucial role in supporting other family members (Haresabadi et al. 2013). However, research shows that family caregivers also face tremendous physical, psychological and social challenges (Barker et al. 2012). These challenges include reduced functional levels of family members, negative impacts on emotional resilience and family relationships, financial hardship, reduced social interactions, and changes in reduced quality of life through changes to their role (Zendjidjian et al. 2012). Family tensions and pressures are common, reducing the capacity to provide care and support to the client (Awad and Voruganti 2012; Hudson et al. 2013; Möller-Leimkühler and Wiesheu 2012).

In Iran, university-affiliated hospitals offer treatment services for acute mental illness. The Ministry of Health and Medical Education supports these universities to administer these services (Forouzan et al. 2014). The Ministry of Cooperatives, Labor, and Social Welfare of Iran supports the supervision of those with mental health disorders as the main supplier of social administration in Iran and deals with engagement of patients and their families and improving psychological well-being (Damari et al. 2017). In Iran, the Foundation of Martyrs and Veterans Affairs also supports many war veterans with mental health disorders. These three organizations supply services to patients and families of clients with mental illness directly. There are other organizations in Iran providing these people with services directly or indirectly in emergency cases, such as the police, justice, municipal governments, social emergency services and non-government organizations (NGOs) (Damari et al. 2017). In Iran, as in other countries, most care is provided by their family caregivers, or relatives, neighbors, friends and even colleagues (Akbari et al. 2018).

According to the 29th principle of the constitutional law of the Islamic Republic of Iran, providing social security is a basic human right, a government responsibility to be afforded to all Iranian people. During the years after the Islamic Revolution in 1979, many organizations and insurance departments were established to provide social security services. The responsive support system (RSS), approved by law in 1975, provides insurance to people with a physical or mental disability and their families. Despite the many efforts of the government, family caregivers of clients with mental illness continue to report that they have limited social support or access to support services, with some reporting that they do not receive any support at all (Noghani et al. 2016; Shamsaei et al. 2013, 2015). Support systems need to be responsive in order to meet the needs of those they provide for, improve health care service quality (Mosadeghrad 2014; Valentine et al. 2003), strengthen the capacity of family caregivers, and ensure patients' rights are protected and promoted within the health care system (Gostin et al. 2003; Valentine et al. 2003). RSS aims to provide expedient, efficient and consistent responses to consumers and to establish a consistent quality of service by ensuring health services, health information and support accessible to people (Greenhalgh 2015).

Achieving adequate responsiveness remains a challenge in Iran's support system (Davari et al. 2005; Hooshmand et al. 2014). It is against this background that the present study was developed to explore the RSS in supporting family caregivers of clients with mental illness. This paper is derived from the first author's PhD and a companion paper reporting on the support needs of family caregivers of people living with a mental illness in Iran has been published (Akbari et al. 2018).

Methods

This nationwide project was conducted to gain a comprehensive understanding of the Iranian cultural and social context of RSS for family caregivers of clients with mental illness from the perspective of service providers.

Participants and Setting

A purposeful sample of 29 professional support providers, authorities, and policy makers from various organizations across Iran were recruited. Initially, the research team identified and listed the organizations involved in support service delivery using purposive sampling (Guest et al. 2006). Then the key stakeholders of these organizations were identified. These people had the largest roles in decision-making in regard to service provision to mental health patients or their families. In addition, people who provided services directly to patients or caregivers of mental health patients were chosen. Stakeholders were then formally invited to participate in the study, and they were provided with information about the research project, including the voluntary nature of the study and confidentiality. Some participants were asked to identify and nominate other relevant participants not previously identified, known as snowball sampling (Marshall and Rossman 2006). The first author then arranged interview sessions. All policy makers and professional support providers identified consented to be interviewed. The number of participants was not predetermined but rather defined by the achievement of data saturation (Holloway and Galvin 2016), which cannot be quantified by sample size but rather than achievement of evidence that has depth (Ziebland and McPherson 2006).

Data Collection

Data were collected from August 2016 to February 2017 after approval from the Medical Ethics Committee of the

Isfahan University of Medical Sciences (1395-3-250). All participants received written information about the study and written informed consent was obtained prior to interviews. Semi-structured interview questions were used. Interview questions covered the participants' understanding and experiences with RSS for family caregivers. The initial interview questions that were asked included: What support services do you usually provide for family caregivers of psychiatric patients and how do you do that? What are your experiences and perceptions of providing support for family caregivers of psychiatric patients? Please tell me your story about collaborating with other support providers (i.e. organizations, supportive groups or individuals) to cover support needs of family caregivers of psychiatric patients. These leading questions were then followed up with further questions to probe the participants' experiences and perceptions.

Interviews were conducted in a room where only the interviewer and interviewee were present. The duration of each interview was between 30 and 90 min. The first author, who is a mental health nurse with experience in conducting interviews with adult clients, conducted all interviews. Participants received US$15 as a token of appreciation.

Data Analysis

The audiotaped interviews were transcribed verbatim, and analysis undertaken using Braun and Clarke's (2006) method for thematic analysis The analyses used an inductive method starting with initial coding, classifying the codes under main categories, and forming sub-categories within these. First, the team leader (second author) introduced the codebooks and disseminated several segments from the transcripts to three team members. Then, they collaboratively coded transcripts. This collaborative activity facilitated the achievement of consensus around a reliable understanding of code definitions. After the collaborative phase, each of the team members separately applied a subset of codes to an entire transcript. This coding was then compared through team discussions to gain agreement. This exercise was repeated until the team members reached consensus and were comfortable to proceed to the coding process. Themes were then derived from codes and reviewed and cross-checked by the research team. Managing and analyzing data was undertaken using MAXQDA 10 qualitative and mixed methods analysis software.

Results

Demographic Characteristics of Participants

Of the 29 policy makers and professionals interviewed, 12 were male and 17 female. Their ages ranged from 26 to 64 and length of employment in the sector ranged from 1 to 29 years. Their roles within the health service were varied, including health education, psychology, psychiatry, occupational therapy, management, rehabilitation, social work, mental health, autism and justice. All but one were tertiary educated (the one exception did not state if they had a tertiary education), with 13 (45%) holding at least a Master's degrees, 4 (14%) with PhDs and 6 (21%) with medical qualifications.

Qualitative Findings

The main categories that emerged from the data included three types of collaboration that underpinned RSS in Iran: (1) interpersonal collaboration, (2) intra-organizational, and (3) inter-sectorial. Several sub- categories were also identified under each category (see Table 1).

Interpersonal Collaboration

Interpersonal collaboration was identified as those relationships that extended directly between individuals involved in service provision and care. This included interdisciplinary collaboration between health professionals and/or service providers and collaboration between service providers or health professionals and caregivers. Interpersonal collaboration was considered by participants to lead to more comprehensive services. Participants believed that collaboration amongst various professions was crucial to ensure optimal support services for family caregivers of clients with mental illness. There were three identified elements that underpinned good interpersonal collaboration, which were full transparency in regards to what each health profession or service actually did, a willingness to collaborate rather than duplicate or overlap on service delivery, and promoting strong interaction with the family caregivers.

Participants expressed the view that family caregivers needed to know about the roles of each profession involved in mental health care in order to help them find the right

Table 1 Categories and sub-categories

Categories	Sub-categories
Interpersonal collaboration	• Transparency of professional roles • Interpersonal interaction • Interaction between family caregivers and support provider
Inter-organizational collaboration	• Administrative rules • Organizational commitment
Inter-sectorial collaboration	• Referral systems • Family caregivers as mediators of collaboration

service. One consultant in the police department stated: "... We should clarify for them where to go for any problems and who they can ask for help. Our duties must be well defined for them ..." (IV22).

Most participants emphasized that one service alone could not meet all the needs of a caregiver and, there was an identified need for a willingness to engage in interdisciplinary interaction. However, participants had encountered challenges in this approach, as a representative of the Ministry of Cooperatives, Labor, and Social Welfare (a policy maker) stated: "We have difficulty in doing teamwork. We sometimes do not trust the professionals of other disciplines and we encroach into the scope of their roles unreasonably. We do not have a grasp of the full scope (of their role) and we should involve other professionals and even carers in decision-making" (IV25).

Participants viewed family caregivers as an important and complementary part of the team providing support and services to the person with a mental illness. Given the complex tasks involved in providing care and monitoring of the patients' conditions, participants believed that family caregivers needed to interact with a wide range of care providers within a variety of organizations. For example, family caregivers often attend medical appointments with the patient following discharge, and interact with home care service providers, providing multiple opportunities for interaction between caregiver and service provider. Those interviewed believed that both service providers and family caregivers should be provided with opportunities and skills to promote such purposeful interaction. A social scientist stated: "We must teach effective communication skills to caregivers" (IV20).

A psychiatric nurse also pointed out that: "We should not leave the caregiver on their own in society. We must follow them constantly. We need to give them enough motivation to continue caregiving. We should answer their questions and we should be available to them at any time" (IV1).

Intra-organizational Collaboration

Intra-organizational collaboration encompassed all elements of a service provider and its functioning, and included delivery of health services, social services, referrals, information, financial assistance and even administrative services. This form of collaboration further facilitated support for family caregivers. Participants perceived health care organizations, particularly service providers, as the initial and most important gateway of family caregivers into support networks and systems. Therefore, the effective processes and dynamics of such organizations were considered as initial predictors of service use and continued uptake of support networks and systems. Intra-organizational collaboration was impeded by two factors, being administrative rules or 'red tape' as well as lack of adherence to the core values and vision of service providers by health staff.

Participants perceived that bureaucratic rules and procedures acted as barriers to family caregivers entering the 'system' and receiving support services. A bureaucrat stated: "A number of caregivers are not supported because of hard administrative rules. The process of receiving support is so time consuming that some family caregivers even prefer to ignore it" (IV27).

Participants also emphasized that reducing the complex administrative rules may not guarantee the use of support services and that staff being committed to the core mission and vision of the service was of greater importance. A bureaucrat (service provider) stated, "The role of support staff in organizations is integral. They should accept and adhere to the goals of the organization and do their best to achieve them. They should understand the family caregivers and respect them." (IV27). The importance of providing non-judgmental support was emphasized. As a clergyman stated "Policymakers should enact laws that family caregivers receive support with respect and without obligation; they should not be judged" (IV17).

Inter-sectorial Collaboration

Inter-sectorial collaboration leads to accessibility and coordination of services. Participants suggested extending collaboration between sectors, such as health, social and educational departments, as an effective way to overcome the problems of accessibility. Participants expressed the view that there existed some duplication of support services and they believed that all sections could be unified and integrated through better coordination of care. Two factors were identified as the facilitators of more effective inter-sectorial collaboration: the formal referral systems, and family caregivers.

Those interviewed perceived inconsistencies and pitfalls in the existing formal referral systems as core barriers to service accessibility by family caregivers. They believed that an effective referral system not only helped caregivers to access support services, but also facilitated collaboration amongst those institutions involved. A psychiatrist highlighted this: "It should be clearly defined the location of the visit and the professional to whom the caregivers must refer. However, currently receiving support is a confusing process due to inconsistent referrals processes, which cause them (caregiver) to abandon the pursuit of patient care gradually." (IV13). A sociologist explained: "One of the challenges of our family caregivers of clients with mental illness in Iran is that there is no strong referral system. In other words, it is possible that some caregivers get full support, but some others drop out and never receive it." (IV18).

All participants agreed that health professionals perceived the family caregivers not only as consumers of services,

but as a common linkage, which helped them to engage in collaborative practice at both the interpersonal and intersectorial levels. As a Ministry of Health and Medical Education representative stated: "Sometimes family caregivers tell us what kind of support they need and whether they are satisfied with the method of support provided, they give us feedback on their situation. The three sides of a support-providing triangle are family caregivers, support providers and policy makers, among which, family caregivers are connecting the other two sides" (IV29).

Discussion

This study explored the service providers' responsiveness of the support system provided to family caregivers of mental illness patients. The findings showed three types of collaboration were required to provide effective and accessible support: interpersonal, intra-organizational and inter-sectorial collaboration for the family caregivers within the Iranian social context where they are becoming an important partners in patients' recovery within the community setting.

Our results indicated how interpersonal collaboration, through interdisciplinary collaboration and caregiver/service provider collaboration, could ensure that comprehensive services were accessible to service providers and that caregivers be accepted as an integral part of this collaboration. The participants of the study recognized that caregivers had special needs, which could be met through interpersonal collaboration, which concurs with other studies (Alavi et al. 2012; Reeves et al. 2017; Zwarenstein et al. 2009). Irajpour and Alavi (2015) showed how cultural differences could affect this level of collaboration, and how values and attitudes can impede or promote collaboration.

The results of our study highlight such barriers to interpersonal collaborations including the absence of clear professional roles and scope, limited interpersonal interactions and misunderstanding the dynamics between caregivers and service providers. In a study by Supper et al. (2015), clarity of the roles and the professionalism of team members were key to interpersonal collaboration. The participants in our study also reported that caregivers are often not fully aware of the role of the different service providers in organizations. Therefore, it was recommended that caregivers should be educated in the role and scope of each health service provider in order to better understand whom to contact for each problem.

Consistent with other research (Heller et al. 2015), our study found that the provision of appropriate services to caregivers needs the cooperation of various staff from related professions and disciplines. Participants stated that caregivers could experience discrete services and a lack of continuity. In likeness of this finding, the failure of service providers to advance the goals of coordination of care in line with client needs is reported elsewhere (Glasby and Lester 2004). In Iran, there are many professions and disciplines providing mental health care, including psychiatric nurses, psychologists, psychiatrists, counselors, volunteer workers, welfare specialists, sociologists, counselors for judicial affairs, and social workers. Studies have demonstrated that a system is responsive where these professions and disciplines can work together collaboratively (Reeves et al. 2017). The challenge existing in Iran and some countries is that interdisciplinary cooperation is inadequate and there are many inconsistencies in the provision of service (Hooshmand et al. 2014; Irajpour et al. 2012; Osaro and Charles 2014). Dynamic interactions between caregivers and the service provider team are one of the most important criteria for interpersonal collaborations (Rowe 2012).

The findings show that one of the weaknesses of supportive organizations in Iran is the inadequate follow-up of caregivers by service providers. In Iran, the Foundation of Martyrs and Veterans Affairs provides support services to caregivers of veterans with mental health issues, and considers itself obliged to follow the issues of these caregivers and provide support (Bagheri et al. 2015; Vagharseyyedin 2015). In Iran, these veterans and their mental health needs are valued more than the general population due to the culturally defined priority given to veterans, their sacredness, and their sacrifices during the war (Aflakseir and Coleman 2009). This example serves as an exception to the usual practice of follow-up by service providers in Iran, demonstrating the importance of active referral and communication to ensure other family caregivers in the general population can access support when and where required. This study demonstrated that 'red tape' compounded the issue of accessibility, making some caregivers reluctant to pursue the support services. Although not explicitly discussed in these findings, another of the most important factors of family caregivers not seeking support has been determined to be the social stigma associated with seeking such support (Lindsey et al. 2013; Thompson et al. 2013). Thus, the dynamic interaction of support providers with caregivers can compound this hurdle to receiving support.

The results showed that the quality of *intra-organizational* dynamics could impact the provision of services to family caregivers of mental health patients. The participants argued that administrative rules in such organizations should be based on the principles of impartiality and avoiding prejudice that may impede access of caregivers. These results were in line with the study by Mosadeghrad (2014), which showed that one of the factors in enhancing quality of service provision was facilitating more effective laws and processes. Service providers with a strong belief in the organization were seen as accepting the organizational goals and would try hard to reach them (Angle and Perry 1981),

thereby addressing the needs of service users. Rofcanin et al. considered corporate culture and organizational monitoring behaviors as an effective factor in performing and delivering services (Rofcanin et al. 2017).

Our results indicated how *inter-sectorial collaboration* could lead to better access and coordination of service delivery. The participants in the study stated that coordination and coherence of services are the responsibility of different sectors of the community—health services, educational services, social services, financial services—and the lack of coordination of these sectors could cause caregivers to be referred between services, without any one assuming the responsibility for support and coordination of services. Similar to other studies, an effective referral system is one of the important components of inter-sectorial cooperation in the support community (Amoah and Phillips 2017; Omotosho et al. 2016). Janati et al. (2017) recommended that transparent guidelines for all services, a structured referral format, continuity of the referral process, electronic registration, a central referral triage, and a referral tracking system as the characteristics of an effective referral system. They also stated that these features have been neglected in the referral system of services in Iran (Janati et al. 2017), something that is supported by the findings of this research.

A common theme presented by participants across the present study was that service providers play a key role in facilitating the coordination of services to support family caregivers of mental health patients whether it be at the multidisciplinary level, the organisational level or the sectorial level but at the same time accepting that family caregivers also need to understand the different roles and scope of work of health care providers to obtain their cooperation in supporting mental health patients in the community. Such cooperation can lead to greater access and acceptance of services and improve the accountability of services in the community (Whiston et al. 2017). Understanding the support requirements of family caregivers, as opposed to the patients themselves, provides a unique insight into service requirements and expectations, as these can be different for caregivers than they might be for patients. Considering the key role caregivers play in support and treatment of people with mental health disorders, knowing the perspective of this key stakeholder group allows support services to be better designed, targeted and utilized by those who require them.

Limitations

This qualitative study explored the service providers' viewpoints about RSS, and as such limited the results to their viewpoints. Incorporating the views of caregivers and patients could have further enhanced the findings. The study was also limited as to details regarding the cultural or social context in Iran and their impact on mental health care, thus further research is recommended. The sample size was also small however, we purposely recruited participants representing a broad range of services, government departments and professions to explore their views that would help policy makers in providing a more responsive service to patients with mental health in the community setting.

Conclusion

Caregivers of mental health clients need a RSS that is accessible and responsive aided by effective collaboration. The understanding of the RSS for family caregivers in this study was consistent with a number of studies. However, the difference in this study was the findings of the effect that engagement of support providers could have on caregivers, rather than patients, and the impact this can have on their capacity to provide care. Thus, all decision makers and service providers should be aware of their approaches and planning towards caregivers as their smallest positive decision can empower these caregivers and vice versa. Alternatively, the increasing complexity of the health care system and resource limitations have created complex problems, which require the use of participatory approaches with cooperation of various specialties, disciplines and departments to provide complementary services and mutual support. This is the best way of ensuring that service users receive the most relevant services from the right service providers in the right place as and when needed.

Acknowledgements This study is derived from a Ph.D. thesis of Nursing sponsored by the Isfahan University of Medical Sciences. The authors are thankful to the Vice Chancellor and participants. We also thank Dr. Sancia West for her review of this article.

Author Contributions All authors have agreed on the final version and meet at least one of the following criteria recommended by the ICMJE (http://www.icmje.org/recommendations/).

Funding This work was supported by the Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Iran.

Compliance with Ethical Standards

Conflict of interest The authors declare that there is no conflict of interest.

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