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> Home care providers' management of mentally ill member during the pandemic Buthaina Al Asfoor, Nehad Al Rashed, Yaser Adel, Najeeba S.Khalil, Khadija Saeed

Abstract:

The widespread of COVID 19 in the kingdom of Bahrain was associated with adverse effects on mentally ill patients and their families. Controlling mentally ill patients during the quarantine is extremely difficult task and keeps home care providers at high rang of continuous stress. This paper aims to study factors affecting caregivers' anxiety during the pandemic and best used coping strategies. The study is significant to formulate an integral care plan for families and mentally ill member during global outbreaks. A quantitative survey was used, data was collected during psychiatric community nursing visits. Subjects included 182 adult direct care providers. Hamilton Anxiety Scale and a formulated questioner were used. Results showed that care providers suffer different levels of anxiety. Almost half of the caregivers were parents. The majority controlled mentally sick individuals during the pandemic at home by strictly following universal precautions. Yet few depended on seclusion, medications, and close observation and very few used divertive in-door activities. Most care providers managed their own anxiety by praying, few practiced in-door activities, and very few depended on news, and talking to others to relieve their anxiety. **Implications** involve guidance of health care policy towards a better health care planning for mentally ill patients and family carers during pandemics and disasters and directing formal healthcare system to empower home caregiving by providing psychosocial interventions, enhancing coping strategies and redirecting community resources to help caregivers.

Introduction:

Continuity of mental health care in the community is critical to prevent relapses that accelerate hospital admissions and result in further strain on the health care system. As a major health crisis affecting several nations, COVID-19 pandemic caused paralysis of many community services including health services. Such widespread associated with adverse effects on people with mental disorders in the community and their families because compliance to treatment and homewards quarantine was a big challenge for the families during the pandemic. Furthermore, failure or delay in initial treatment has been recognized as an important public health problem that increases relapses and hospitalization. Therefore, patients with severe mental illness were among most vulnerable populations affected by the COVID-19 pandemic (Kahl K.G. et al 2020)1.

As each mentally sick member manifest alteration in behavior in a different way depending on the type of psychological illness, their response, cooperation, and obedience differ. For instance,

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people suffer from depression and anxiety may manifest social withdrawal and refuse to be examined by health care personals, they may not cooperate during swabbing and testing, and they may need to be sedated for testing purposes or for any other procedures. Whereas people with schizophrenia manifest delusions, hallucination, bizarre behaviors, somatic symptoms and therefore suffer low insight to adequate infection control and protective measures. They may not listen to family care providers, obey precautionary and/or take decisions to prevent self-harms such as going out, roaming in the street, and putting themselves and others at risk.

Such situations put family care providers at a high range of continuous stress. It was found that 90% of carers are adversely affected by the caring role in different aspects of their life such as leisure activities, career progress, financial circumstances, and family relationships (Jones K. 2010)2. Therefore, COVID 19 outbreak associated with adverse psychological effects on families care givers of people with psychosis disorders. Studies showed that supporting carers not only helps to decrease patients' relapse rates and hospital admissions, but also reduces caregivers psychological stress (Jones K. 2010)2.

This paper aims to assess anxiety level of home caregivers of mentally ill patients during Covid 19 outbreak in the kingdom of Bahrain. Researchers intended to study some variables to further elaborate factors that contribute to care providers stress level. The study assumed to add in the formulation of integral family care plan and guide to reduce the severity of caregiving anxiety. Furthermore, the study explores most effective ways to manage mentally ill patients during global infections outbreaks. To the author knowledge, the study is the first in Bahrain.

Methodology:

A quantitative design was used as the most relevant paradigm. A randomized process was used to collect information to exclude bias and to make duplication of the study possible. The authors intend to have the higher possible participants to ease an accurate generalized conclusion.

The study subjects are all families who receive community psychiatric service from psychiatric hospital including 340 families from different regions all around kingdom of Bahrain. Inclusion criteria involve adult (18 years and above) family members who are main care providers for mentally ill patients at home. Disregard was considered to gender, age, and socio-economic level. Final sampla size reached 182 participants (95% confidence rate according to the targeted sample size).

The researchers followed strict ethical approval guidelines from the Secondary Health Care Research Sub Committee (SHCRC) and a written approval was obtained. Verbal consent was obtained from each participant and adequate research information was provided prior to data collection. Information includes purpose of the research, procedure, potential benefit, anonymity, and confidentiality, right to refuse or withdraw from the study without penalty, offer to answer all questions, and right to obtain results upon request. It is believed that standards related to validity credibility and reliability were met in this research.

Data was collected during the regular community home visits by researchers who are community psychiatric nurses by utilizing anxiety scale and a structured questioner. Hamilton Anxiety Rating Scale (HAM-A) was used to explore anxiety of caregivers. It is one of the first developed

rating scales to measure the severity of anxiety symptoms, and widely used in both clinical and research settings (Thompson E. 2015)3. The scale contains 14 items, to define series of symptoms, and measures both psychic anxiety (mental agitation and psychological distress) and somatic anxiety (physical complaints related to anxiety) (Hamilton M. 1959) 4. The scale was translated to Arabic to ease the data collection process. The structured questionnaire was designed to explore factors that contribute to stress level and methods to adjust stressful situations at home. These factors included care giver kinship to the patient, number of family members, housing conditions, and anxiety management strategies. Time consumed for interviews was 10-15 min/participant. SPSS statistical package was used to obtain statistical data and figures.

Analysis:

The Hamilton Anxiety Rating Scale reveals more than half participants present mild anxiety level (57.1%), some present moderate anxiety level (8.2%), few present sever anxiety level (4.9%) and a considerable rate present very sever anxiety level (9.3%). Surprisingly 20.3% of participants didn't suffer anxiety at all (Figure 1).

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not present	37	20.3	20.3	20.3
	Mild less than 17	104	57.1	57.1	77.5
	Moderate 18-24	15	8.2	8.2	85.7
	severe 25-30	9	4.9	4.9	90.7
	very severe more than 30	17	9.3	9.3	100.0
	Total	182	100.0	100.0	

Hamilton Score

Figure (1)

Factors that influence anxiety level were explored through the structured questionnaire. Following was revealed:

1) <u>Care givers' kinship nature</u>

Data analysis revealed almost half of participants were parents (45.6%), followed by siblings (32.4), children (6%), and lastly "significant others" such as grandchildren, grandparents, cousins, and housemaids (5.5%). A small percentage found to be independent patients (3.3%) (Figure 2).

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	spouse	13	7.1	7.1	7.1
	parents	83	45.6	45.6	52.7
	siblings	59	32.4	32.4	85.2
	others (cousin, grandparent, housemaid)	10	5.5	5.5	90.7
	patient himself	6	3.3	3.3	94.0
	children	11	6.0	6.0	100.0
	Total	182	100.0	100.0	
		\mathbf{E}_{i} (2)			

Care provider's Kinship

Figure (2)

2) <u>Housing condition</u>

The majority consider housing condition has not been related to their anxiety level (86.8%). Few expressed concerns about small spacing (4.9%), number of occupants and crowdedness (3.3%), poor housing condition (.5%) and relate it to their anxiety level (Figure 3).

	Housing condition				
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No Impact	158	86.8	86.8	86.8
	convenient	8	4.4	4.4	91.2
	space problem	9	4.9	4.9	96.2
	extended family/crowded	6	3.3	3.3	99.5
	poor condition	1	.5	.5	100.0
	Total	182	100.0	100.0	

Housing condition

Figure (3)

4) Majority depend on following "universal precautions" during pandemic to prevent cross infection (81.3%). Few depend on restraining methods like seclusion, medications, and close observation (12.6%) to control the patient. Only 2.7% used diversional methods "home activities" to prevent cross infection (Figure 4).

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	universal precaution	148	81.3	81.3	81.3
	patients' education	4	2.2	2.2	83.5
	using seclusion, restraints, and observation	21	11.5	11.5	95.1
	medication	2	1.1	1.1	96.2
	activities	5	2.7	2.7	98.9
	don't have	2	1.1	1.1	100.0
	Total	182	100.0	100.0	

(Figure 4) Managing mentally sick people at home during Covid 19 pandemic

Figure (4)

5) Health care providers expressed different ways to manage their anxiety. Majority (71.4%) used to pray, some (10%) practiced in-door activities to divert themselves, and very few (8.8%) used other methods like following "universal precautions" (3.3%), following "health news" consult and ventilate to others to relieve their anxiety (5.5%). Surprisingly, a considerable percentage didn't do anything (9.3%) (Figure 5).

Health providers' anxiety management strategy during Covid 19 pandemic

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	universal precaution	6	3.3	3.3	3.3
	praying	130	71.4	71.4	74.7
	activities	19	10.4	10.4	85.2
	consultation /talk to others	10	5.5	5.5	90.7
	don't have	17	9.3	9.3	100.0
	Total	182	100.0	100.0	

Figure (5)

Discussion

Health Care Providers Anxiety level:

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Vigilant caregivers at home find themselves on duty even when they are doing nothing (Mahoney D.F. 2021)5. They are considered a high-risk group for developing emotional symptoms such as nervousness, exhaustion, decreased appetite and sleeping difficulty (Clipp E.C. 1990)6. Because of the difficult caregiving role, care givers are prone to a high degree of emotional exhaustion, depersonalization and low personal accomplishment (Takai M. et al 2009; McDaniel et al 2012)7&8. Particularly younger caregivers, often experience disruptions to their education, putting school on hold or dropping out entirely, which can impact their future career and earnings (Hunt G. G. et al 2015; American Psychological Association 2015)9&10.

Family caregivers of mental care recipients in specific, are more likely to encounter verbal and physical abuse from the recipient and therefore more psychological strains (Erosa et al 2010)11. The potential negative effects of mentally ill caregiving extend beyond mental and physical health effects due to nature of care recipient. People with psychiatric disorders might be more susceptible to transmission of COVID-19 and other types of infections, due to several factors such as patient cognitive impairment, lower awareness of risk, and adequate infection control (Yao H et al., 2020)12. Many researchers found evidence that people with psychosis are less motivated to comply with infection control measures such as hand washing, social distancing, or isolation (Maguire PA et al 2019; Iancu et al 2005)13&14, especially with schizophrenic people who are characterized by impairments in insight and decision-making capacities (Larkin A, 2017)15.

The situation becomes harder in times patients did not comply with the required infection control practices and caregiver has no choice but placing them in an enforced quarantine (Pang, 2004)16. The quarantine by itself is stressful to anyone and more for those who are somehow locked with mentally ill members. Quarantine was associated with a range of adverse psychological effects, including fear and anxiety (Brooks et al., 2020)17. In addition to physical effects of decreased motor activity, changes in diet, and exposure to sunlight (Lippi et al., 2020)18. Brooks S.K. et al (2020) explained that negative psychological impact of forced quarantine can be wide-ranging and long lasting, whereas voluntary quarantine associate with less distress and fewer long-term complications. Unfortunately, this is not the case with mentally ill people. Although it is recommended to quarantine them as short as possible (Brooks S.K. et al2020)17, maintaining it is very difficult because of lack of "insight" regarding cross- infection precautions.

It was not surprising that half participants of this study (57%) suffered mild anxiety that manifested in different forms of mental and somatic symptoms. The researchers find it worth mentioning the lower categories of participants who constitute 8.2% for "moderate anxiety" and 14.2% for "sever and very sever anxiety", as a valuable indicator of the pandemic impact on care providers in the community. Some existing research described the psychological impact of other infectious diseases on survivors and their families. For instance, James P.B. et al (2019)19 conducted research about the psychological distress experienced by "Ebola" pandemic on families. The study revealed various forms of psychological distress, depression was one of the most common outcomes. On a similar study conducted by Bohlken J. et al (2020)20, care provider experienced depressive and anxiety symptoms higher than other people in the community during the outbreak. Berger W. et al (2012)21 studied the prevalence of

posttraumatic stress disorder PTSD on health care providers during infection breakout. A higher prevalence (10%) of PTSD was found among family care providers, compared to the general population.

There are, however, participants who didn't experience anxiety (20.3%) in the current study The anthers implied it due to the level of readiness and successful management strategies used by carers to handle their mentally ill patients during the pandemic.

Family care providers experienced further stress due to the alteration in "Psychiatric Community Service" delivered during the pandemic which made them bear extra responsibilities. Doctors' visits for many cases were substituted by phone consultation. Community psychiatric Nursing visits though continued but with some alteration in the frequency of visits which may cause families to feel less supported by the health care system during the pandemic and therefore add to their anxiety level. The nursing team delivered medication and injectable antipsychotics given to the health plan to reduce relapses and hospitalizations (Correll C.U. et al, 2016)22.

Factors influence care providers' anxiety:

Caregiving strain is often worsened by certain kinds of demands and circumstances of caregiving role such as lack of resources (knowledge, skills, social support, respite, and community services) (American Psychological Association, 2015). Following are factors contributed to care providers' anxiety level:

1. Caregiver kinship to the patient:

Because of the increasing number of people with psychiatric illness, the majority are cared for at home. The responsibility of caregiving expectedly falls on parents, spouses, children, saplings or adult offspring (Riley E. M. et al. 2000; Gutiérrez-Maldonado et al. 2005 cited in McAuliffe R. 2013)23&24. In the current study, most carers are parents (45.6%), followed by siblings (32.4%), spouse (7.1%), significant others (5.5%) and least were independent patients (3.3%). Nyström & Svensson's (2004) cited in McAuliffe R. (2013)24 reported that parents being richer for the experience of living with an adult child with schizophrenia had become more understanding and sympathetic in dealing with disability and facing the hardships of life. Consequently, parents amassed a wealth of personal learning about managing their adult child's illness as well as their own lives. Regardless, Jones K. (WHO Mental Health report 2010)2 explained that parents experience high levels of family stress and heavy responsibilities. The typical age of first psychosis episode onset in adolescence or young adult, where their parents average age is between 40 and 60 years, stage of life parents already attempt to cope with their child onset of mental illness, burdened by other children attending school or college, retired or elderly grandparents, as well as career and financial worries. Therefore, carers parents have a reduced social life, their family relationships are seriously affected, and many have significantly or moderately reduced mental and physical health. Researchers of this study inferred that as most participants were parents, this might affect the percentage of participants suffered mild anxiety level.

Interesting controversial studies were found regarding spouse careers. One study conducted by Schulz & Beach, 2009 (cited in American Psychological Association, 2015)2 concluded that spouse caregivers who reported strain were at risk for premature mortality. However, five more recent population-based studies of caregiving and mortality, all with larger sample sizes than

Schulz & Beach (2009), have reported the opposite effect, revealing that caregiver living longer than non-caregivers (American Psychological Association 2015)2.

2. Housing conditions:

To investigate the carers' anxiety, it was beneficial to set the scene by examining the environment in which care being delivered to mental ill patients, regarding the importance of the environment in term of infection transmission during the pandemic.

In a study conducted by Hammer C.C. et al (2018)25 aimed to identify risk factors for communicable disease outbreaks, a group of factors that interact with each other forming a complex risk cascade were concluded. Those included poor water, sanitation, and hygiene, overcrowding, poor nutrition, poor living conditions, exposure to indoor air pollution, insecurity, lack inadequacy, vector habitats and increased animal contact. In the current study, researchers referred to these factors as "Housing condition".

The proper housing spacing in specific was estimated to affect social distancing, which is called to be the most effective way of preventing the spread of the virus (Rothstein M.A. et al 2003)26. Shannon H et al. (2018)27 searched the association between household crowding and the risks of respiratory infectious diseases such as flu-related illnesses, pneumonia, and acute respiratory illness. The number of occupants and dwelling space found to increase the transmission of respiratory infectious diseases. Additionally, household crowding was found to have an adverse effect on individuals' mental health (Shannon H et al. 2018)27.

Majority of Bahrain population came from middle socio-economic class, however there are some from poor socio-economic class who suffer poorer housing conditions. The crowded housing was investigated as an expected hinder to a proper quarantine, especially with uncontrolled psychotic patients, but unexpectedly the result revealed (86.8%) considered housing condition has no relation to their anxiety or their ability to manage mental ill patient at home. A very small percentage (5%) considered their housing "poor condition" and related it to their anxiety and 9.3% only has "space problems" and relate it to their anxiety level. The researcher concluded a positive relationship between "poor housing" condition and the carer's anxiety level shown in the segment of the study sample.

Managing mentally sick people at home during the pandemic of Covid 19:

The caregiving needs of mentally sick people increase over time resulting in intensifying and accumulating financial, social, psychological, and physiological effects on family caregivers (Gaugler J.E. et al 2008)28. As a result, care providers may suffer burnout especially when lack the medical and social support to enhance their coping with difficulties encountered.

Therefore, partnerships between informal (Family care providers) and formal (Health care professionals) must complement each other (Choi N.G. 1996)29. The latest role can make an important contribution by providing direct and indirect forms of emotional and instrumental support to carers (McCann T.V. et al 2015)30. Furthermore, the reciprocal interactions between the families with the formal support bodies enhance family's adaptability, access to information, and motivation to seek help from others (Edvardsson J.D. et al 2005)31. In Bahrain, members of community psychiatric team are the health care planners, who take the role of conducting regular visits to psychiatric patients at home and deliver appropriate assistance to relieve caregivers and

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improve the quality of caregiving to mentally ill people in the community. Researcher of this study imply that families follow instructions of formal health system (Hand washing, cleaning with disinfectants, distancing, and using facial mask) showed as most participants (81%) depend on precautionary measures to manage mentally ill patient at home.

Nevertheless, carers have always adopted different coping strategies to strengthen their own resilience. Some participants (11.5%) find that secluding mentally sick members is the best way to prevent cross-infection. Whilst few participants (2.7%) adopted indoor activities as an effective strategy in managing psychiatric patients at home. Many studies emphasize the effectiveness of various physical training interventions in alleviating severe mental diseases, and relieving symptoms of depression and psychosis (Knöchel C. et al 2012; Scarmeas N. et al 2001; Harvey S. B. et al 2018)32 33 34. Nevertheless, leisure activities in general are important components of quality of life and tools for rehabilitation of patients with chronic psychosis (Pondé M.P. et al, 2009)35. The least strategy used by families (1.1%) is hypnotizing or sedating mentally sick patients with medications. Researchers concluded that most families successfully used non-medicated methods to control them during the pandemic.

Management of Care Providers' Anxiety level during the pandemic of Covid 19:

Prayer was shown to be the most used strategy by participants (71.4%) to control their anxiety. Participants of this study were all Muslims who used to pray five times a day and read Quran (Muslim's holly book). It is also worth to mention that Muslim's prayer involves certain level of physical activity which includes standing, bowing prostration and sitting consecutively which is considered as a simple type of physical exercise. Furthermore, there is increasing evidences that prayer can reduce stress, alleviate pain, ease the symptoms of some chronic health conditions, enhance flexibility and enhance the immune system (Ranch C. 2020; Ferguson J. K. et al 2010; Kamran G. 2018) 36 37 38. Listening to Holy Quran, nevertheless, was found to provide a positive effect in reducing anxiety in various settings (Ghiasi A. & Keramat A. 2018)39. Controversially, some researchers suggested that prayer has the power of placebo effect in stimulating healing (Ranch C. 2020)36.

The second used strategy by participants to manage their own anxiety was performing varieties of activities such as reading books, watching T.V, cooking, gardening, and practicing different hobbies. Numerous studies have shown that leisure activities can prevent diseases, improve physical health and mental wellbeing by reducing anxiety and stress (Weng P. 2014; Sandmire D. et al 2012) 40 41. D.Callow D. et al (2020) 42 added that performing even light physical activity during the COVID-19 pandemic may help alleviate some of the negative mental health impacts.

One interesting way of managing your own anxiety was seeking others for news, information, and advice. This method was found to enhance the adherence to quarantine procedure by percieving the benefits of the quarantine and the risk of the disease (Koh Y. et al 2011; Teasdale E. et al 2014) 43 44. Care providers in this study gathered information (5.5%) from watching and/or reading news from trustable and reliable sources such as health care individuals. The authors imply that this percentage indicate a collaborative approach between the multidisciplinary health team (Community psychiatric nursing) and service user (Care providers at home) resulted in sustained improvement in understanding of the pandemic and best ways of controlling self-anxiety and patients at home. This type of collaboration was approved to

enhance confidence, reduce anxiety, and motivate continuation of home caregiving (Richmond C. et al 2005) 45. Nevertheless, D.Callow D. et al (2020) 42 reported that seeking information about the current situation of the viral pandemic is advised just to the alerting level but not too alarming to avoid further and unnecessary anxiety.

The least strategy used by care providers to control their anxiety was adherence to universal precautions (3.3%). The researchers assumed that participants considered other discussed strategies more effective in reducing their anxiety regardless of the last strategy importance in preventing the cross infection.

Implication for practice:

- 1. For Health policy makers:
- Health system to develop a disaster management plan and a health-related policy for mentally ill people and their families during pandemics focusing on the followings:
 - **a.** Highlight the psychological impact of infectious diseases on family care providers, raise public awareness regarding contributing factors to carers' psychological stress and guide to ways of seeking psychological support and healthy coping strategies.
 - b. Develop and strengthen a partnership approach (informal and formal systems) in providing home care, considering the carers as an integral part in the planning and delivery of mental health services. Such support provides kin caregivers the necessary guidance, resources, and training to facilitate a successful fulfilment of caregiving role during the pandemic.
- 2. For Mental Health Nurses:
- Community mental health nurses should address the needs of each family and enhance caregiving role by providing emotional and instrumental support, and by enhancing carers' coping strategies.
- *3. For population:*
- Families to actively attend educational programs to learn basic facts about mental illness and its treatment, behavior management skills, recognizing the early indications of a relapse and alert the mental health system accordingly to better cope with their relatives' illnesses during pandemics.
- Families seek organizational help for care coordination, especially when experiencing high levels of strain or burden and to maintain resilience in caring role.

Conclusion:

Families are the primary care-giving resource for adults with mental illness in the community. Yet they may expose to lots of psychological pressure especially with the prolonged Covid outbreak in the kingdom of Bahrain. Because continuity of home care is critical for these patients to prevent psychological relapses, this study was conducted aiming to explore factors affecting caregivers' anxiety during the pandemic and best ways used for stress management and coping strategies. The rationale for addressing the needs of families/carers is two-fold. Firstly, carers play a key role in supporting patients towards recovery and adjustment. Secondly, since the families themselves are subjected to distress, they should receive support and assistance.

The study results showed that care providers suffer different levels of anxiety and therefore affected their tolerance level and caring behavior towards psychotic patients. Almost half of the carers were parents burdened by other familial obligations which accelerated their anxiety. Most participants explained that housing conditions are not related to their anxiety level. Regardless some expressed concerns about small spacing problem, crowdedness and poor condition and related it to their anxiety.

Regarding controlling mentally sickness at home during the pandemic, the majority depend on universal precautions to prevent cross infection, and few depend on other methods like seclusion, medications, and close observation to prevent cross-infection. Very few used to divert mentally ill members by using home activities.

Regarding anxiety self-management majority used prayer as the most effective way, few practiced in-door activities to divert themselves, and very few depend on other methods such as following news through media and ventilate to others to relieve their anxiety.

The findings of this study are assumed to guide health care policy makers and professionals to set a better health care planning for mentally ill patients and their care providers at home during pandemics and disasters. The study is also assumed to empower the family carers of persons suffering from mental illness by providing psychosocial interventions, enhancing coping strategies and redirecting community resources to help them.

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