Original Article

Phenomenological explanation of women's lived experience with spouses with mental disorders

Reza Zeighami[1], Masumeh Ahmadi[2]

[1]Department of Psychiatric Nursing, Nursing and Midwifery College, Qazvin University of Medical Sciences,
[2]Department of Psychiatric Nursing, Qazvin University of Medical Sciences, Qazvin, Iran

ORCID
Reza Zeighami: https://orcid.org/0000-0001-8993-1300; Masumeh Ahmadi: https://orcid.org/0000-0003-0790-4152

Abstract

Context: The spouse has a very important role to play in increasing the emotional and supportive resources of the family as well as in increasing patient adjustment. Therefore, understanding their experiences can lead the health-care system to the improvement of effective care and support.

Aims: This study was conducted to the explanation of the lived experiences of women with spouses with mental illness.

Settings and Design: This qualitative study was carried out using the van Manen phenomenology method.

Materials and Methods: Ten women were participated by purposeful sampling. Data were gathered through semi-structured interviews, observation, and Memo.

Statistical Analysis Used: To analyze data, six-step method of "Van Manen" was used.

Results: The results of life with a mentally impaired spouse include the main theme of "frustration" that includes four subthemes of "gradual extinction", "disappointment", "forgotten", and "financial disconnection". The gradual extinction consists of three subcategories: "role relocation", "self-neglect", and "early aging". Disappointment consisting of four subcategories "misery", "obligate life", disturbance and distress" and "loneliness". Forgotten consists of three subcategories: "not being comprehensive of treatment system", "isolation and seclusion", and "lack of a support". Financial disconnection includes three sub-categories: "lack of governmental support", "economic disturbance of the family", and "working of woman and the children".

Conclusions: Participants in this research showed a lack of knowledge about dealing with the patient as well as the lack of attention to individual problems. Families expressed the need for effective support due to the status of women.

Keywords: Lived experiences, Mental disorders, Phenomenology, Qualitative research, Spouse, Van Menen

Address for correspondence: Mrs. Masumeh Ahmadi, Qazvin University of Medical Sciences, Qazvin, Iran.
E-mail: masoumehahmadi1393@yahoo.com
Received: 21 June 2020; **Accepted:** 29 July 2020; **Published:** 10 February 2021

Access this article online	
Quick Response Code:	Website: www.jnmsjournal.org
	DOI: 10.4103/JNMS.JNMS_79_20

How to cite this article: Zeighami R, Ahmadi M. Phenomenological explanation of women's lived experience with spouses with mental disorders. J Nurs Midwifery Sci 2021;8:34-41.

INTRODUCTION

Mental disorders are considered as most prevalent issues in current societies which are observed in all societies and cultures,[1] although, the novelty in mental health is being established, mental disorders are challenging concern in all countries.[2] Studies show mental diseases are becoming the major health priority in countries worldwide and hence that half of 10 major diseases that cause disability are related to mental disorders nowadays.[3] According to the estimation of the World Health Organization, >500 million individuals in the world are affected by one type of mental disorder.[4] The prevalence of mental disorders is about 11.9–30.2 in Iran and is reported as 21% on average.[5,6]

Despite the high prevalence of these disorders, it should be noted that the effects caused by them is not restricted to the individual but to the whole society. Regarding health economics, these patients need long-term hospitalization services rather than other patients, and this is a costly issue for countries. In recent years, institute relieving and progress in treatments lead to an increase of the number of individuals who, despite their mental disease, can live in society.[7,8] Therefore, patients are in the transition of hospital care to home care.[6]

In families with a patient with mental disorder, the patient is solely considered as an individual who needs support, and other family members are omitted from the treatment process.[9] It is while the presence of the patient makes a high load to the family.[10] In such cases, social communications of the family are changed,[11] and load induced to the family such as stress, deprivation, and fear is increased.[12] Concerns regarding the patient also affect the mental health of other members. While these families play supporter roles unofficially for the patient,[13] they usually have a feeling of sadness, shyness, and guilt.[14] Problems such as unemployment and poverty affect family status[15] produce economic problems for every member of the family.[16] Caring of the patient decreases the energy of the supporter member and causes disappointment and despair, helplessness, depression, erosion, and incidence or exacerbation of psychosomatic disorders in caregivers and other family members, especially the patient's spouse.[17]

The women as the most effective member of the family have the greatest role in the management of the family as well as an important role in the increase in supportive and emotional sources of family and also increase in the compatibility of the patient.[18] Women have greater sensitivity regarding the chronic diseases of the spouse,[19] and make more support for the patient, which this support and protection of the spouse play an effective role in the increase of health level and boosting dealing power against problems of the patient with mental disorders.[17] Thereby, the destructive effect of such diseases in a spouse is greatly observed.[19] When one of the spouses becomes ill, his/her illness makes great changes in bidirectional relations of them. In general, in health status, the couples try to make the balance between the support they received and the support they give, but when one of them becomes ill, his spouse is forced to allocate more time for caring of him/her, and besides, the patient is not able to perform marital his/her duties, and therefore, the balance is disrupted which this causes problems for him/her.[20] Women experience more stress than men.[21] Due to a lack of studies with a qualitative approach regarding the assessment of experiences of such women, this study aimed to explain phenomenological women's experience with spouses with mental disorders.

MATERIALS AND METHODS

This study is a qualitative study with Van Manen's phenomenological approach, which was to investigate and achieve the lived experiences of women who care for spouses with mental disorders. The phenomenological approach is for clarifying the nature of latent conception in experiences which its target is to understand the meaning of experience as so the individuals had experienced.[22] By the purposive sampling method, 10 individuals were participated as participants with spouses with mental disorders and were hospitalized in 22-Bahman Hospital in Qazvin. In addition to that 1 year should be passed from diagnosis mental disorder. The women should also have a history of marital life with the patient and are willing to participate in the study. Exclusion criteria are not cooperating and the tendency to exclude the study every time they want.

To gather data, deep and quasi-systematic interview was used which participants state their experiences on their life with the diseased patient freely. Interviews were conducted based on the agreement of the participants in the hospital and their proposed time. The interview was started by a wide and general question regarding individual's experience on living with diseased spouses, and then exploratory questions were proposed until achieving deeper information. The duration of the interview varies from 40 to 90 min. Gathering data were continued until data saturation was reached, and after receiving saturation, three other interviews were also done. During the interview, nonverbal messages of participants, such as voice tone, facial expressions, gestures, crying, and

appearance, were thoroughly and carefully observed and recorded. Interviews were recorded by the digital record, and immediately after the interview and transforming voice file using the computer, were written and typed word-by-word, to preserve data integrity and decrease bias of the researcher. Writing text of interviews maximally to 24 h after performing an interview was initiated and was written for each of the interviews.

To comply rights of participants, prior with the holding of the interview session, in a session held separately with each of participants; the aim of the study and the method was explained, and then the informed consent form was provided to participate in the study to be signed in case of willingness. In addition, they were assured regarding protecting their secrets, and they were told that they can quit study whenever they want without any explanation, or refuse to answer the questions they did not desire. All the manuscripts and also voice files were identified as code to preserve the anonymity of the participants. After obtaining consent form, background information of the participants was completed. This information was only used to generally describe the samples. Along with the interview, complying privacy of the participant was considered. This research was approved with the code of IR.QUMC.REC.1395.36 at the ethical committee of Qazvin University of Medical Sciences.

In order to analyze data, six-step method of "Van Manen" including facing to nature of experience, assessment of experience, thinking of native themes of the phenomenon, preserving directional strong association with the phenomenon, writing and interpretational rewriting and finally complying study texture by considering components and the entire of it.[23] Factors such as stability, validity, transforming, and assurance as criteria for evaluating qualitative researches were considered. Duration and integration increase the validity of data. The process of gathering and analyze of data lasts for 10 months.

Establishing communication based on trust with participants is the main principle to achieve high-quality data, and the researcher has sufficient experience regarding the family of patients with mental disorders and can communicate with participants by the trust. To be assured on that data are presenting experiences of participants, investigating findings with participants was used. In addition, it was tried to explain methods used in the study carefully and in detail, so that the readers of the article can follow the process of the current study. The researcher tried by caring in wisely selecting the integration of methods of data gathering such as deep conversation, keeping a note in the field, reminding writing, and also co-analysis of data, cooperation analysis, and simultaneously all the members of searching team and regular comparing of data and classes regarding similarity and disparities, allocation of sufficient time to perform interviews and feedback of encodings to all the participants, and also using comments of some of them in abstractive stages of the work to achieve real data.[24]

RESULTS

The age range of participants was 28–50 years old, and the number of children was between 1 and 8 ones. The education level of four of them was elementary and six of them were diploma. Except for one who was employee, the rest were housewives, and all of them had the role of caring for the diseased spouse [Table 1]. At the first stage, 920 primary themes were extracted. Then, the themes were compared to each other and were integrated and separated based on similarity and resemblance, which its result was decline in primary themes into 230 themes. After clustering, 31 concepts were extracted, and finally, from the total interviews, the main category of frustration with four additional categories and 13 subcategories were flourished from the data.

The main category formed in this study is "frustration". This main category includes four additional categories "gradual extinction," "disappointment," "forgotten," and "financial disconnection." These women are frustrated in the description of living with spouse with mental disorder [Table 2].

Gradual extinction

Women, due to enduring problems and life responsibilities, neglected the preservation of their health and well-being and providing their primary requirements. Therefore, gradual extinction is one of the main concepts of women's experience in caring for spouses with mental disorders with three subconcepts of "role relocation," "self-neglect," and "early aging."

Role relocation

Women caring for their diseased husband due to accepting caring of their spouse in home and accepting his/her responsibilities in life are faced with roles beyond their real role as one woman in life. One of the participants says that:

"My husband did not implement paternal role, but I did not let my children to feel lack of the father, I have sold the gold I had before for expenses of university of my children, now my smaller girl is ill and has problem in gut, her father is not aware of it at all, and she should undergo surgery, and all the tasks are by me."

Table 1: The demographic data of the participants

Duration of life	Number of children	Type of illness husband	Education	Age	Common
20	6	Schizophrenia	Under the diploma	46	1
17	3	Dipole	Diploma	31	2
4	3	Depression	Under the diploma	32	3
28	4	Schizophrenia	Under the diploma	46	4
10	2	Dipole	Diploma	28	5
30	5	Schizophrenia	Under the diploma	40	6
27	2	Dipole	Diploma	47	7
12	1	Forced obsession	Diploma	37	8
35	8	Anxiety disorder	Diploma	56	9
18	2	Schizophrenia	Under the diploma	35	10

Table 2: The main theme and subthemes from the data

Main theme	Subtheme	Initial subtheme
Frustration	Gradual extinction	Role relocation
		Self-neglect
		Early aging
	Disappointment	Misery
		Obligate life
		Disturbance and distress
		Loneliness
	Forgotten	Noncomprehensive treatment system
		Isolation and seclusion
		lack of a support
	Financial disconnection	Lack of governmental support
		Economic disturbance of the family
		Working of woman and the children

Self-neglect

Living with a diseased spouse leads to major changes in daily and physiologic and instinctive needs and health status and life pattern is vigorously affected, and therefore, leads to affection by diseases and decrease in health level and life quality. For instance, spouse of one of the patients says that:

"I am absolutely depressed. I have diabetes, my blood sugar is high due to my nervous problem, my blood sugar is not decreased, my blood sugar is always 400, 500, the doctor prescribed me medication, but I am not comfortable with them since I should eat and sleep all the time and then I discontinued them."

Feeling premature aging

Due to enduring numerous physical problems and emotional and mental stress in this woman facing such husbands, they express decrease in self-esteem which manifests as a premature aging. One of the participants says in this regard:

"Sometimes I am speaking, the neighbors, the relatives tell me why I am becoming so?! You are becoming old early, why are you so, you are not so, why your face is so? I also feel that I am becoming old early…"

Disappointment

Experience of women regarding living with their spouse shows that status of their mood is worsening and they are disappointed and hopeless toward their future and their children, and they are disturbed and tired of the numerous distress of living with their spouse, and loneliness makes them upset. Disappointment is four subcategories of "misery," "obligate life," "disturbance and distress" and "loneliness."

Misery

The female participants of this study talked about feeling miserable due to lack of hope regarding husband and confusion for the future of themselves and their children. One participant says in this regard:

"When he is hospitalized, I am really calm, I feel comfortable when he is not at home, it's like I'm just born, I breathe more easily, and when he comes back, everything goes bad again."

Compulsory life

These women know an obligation to live with their husband while describing her lives, as instance:

"Well, I have not a family, my parents died in earthquake, my brother and sisters have their own tasks, so I had to continue living with my husband."

Disturbance and stress

Emotional problems of children and impressionability of them by father's behavior, negative atmosphere, and disturbed and stressful environment of home, and intolerance and worry and impatience of the spouse make the inflamed and unquiet environment in the house. One of the participants stated as so:

"One of my children who is 15 years old self-harmed her/himself, and hit her/himself, and when see blood he/she becomes quiet, he/she was not so before, I said, the words of the father makes him nervous, I have taken him/her to doctor for about 3 months, he/she is consuming medication, the doctor said, that he/she is affected, and must consume medication or he/she must be also hospitalized."

Loneliness

These women had not emotional and intimate relation with their husbands due to the disease of the husband and its outcomes, and this emotional deprive brings them mental pressure and leads to that she feels being apart from everybody. The lack of family communications and emotional deprive leads to disappointment. As said by one of them:

"We have had communication before, visited relatives, but now, we did not go even at the new year holiday, sometimes, we say that why the relatives do not visit use, how should be if your sister comes and take you to caring you."

Forgotten

Wives of men with disease had not required and sufficient information regarding the disease of her husband, which it was stated sue to lack of training by treatment systems and mental health specialists, and on the other hand, due to worry about judgments of others regarding themselves and their husbands, they limit their relations, therefore know themselves as forgotten. Most of them explain on lack of supporter, and these issues lead that these women feel to be forgotten. Forgotten includes three sub-themes, "not being comprehensive of the treatment system," "isolation and seclusion," and "lack of a support."

Not being comprehensive of the treatment system

The participants know the treatment system inefficient due to the existing weaknesses. Dissatisfactory of treatment system is mostly due to lack of true training and announcing and inappropriate coverage of insurance. For example:

"I have not seen a doctor, even the day of discharge, nobody visited me, and did not want to talk to me even the nurses of training department, I asked by my own several questions on what should I do or not."

Isolation and seclusion

Disruption in social relations due to the attitude of others toward these individuals and feeling abandonment by these women leads to isolation and seclusion, which is reflected in their expressions:

"I have not been anywhere for a long time, If I want to go, it would be just for my children, I go to my mother's home alone, I don't go anywhere, I don't go anywhere, I don't like to go to weddings, if I go, I would be depressed, I don't like to go mourning ceremony, I don't like to go party, wherever I go, I like to come back soon, if I go somewhere I think that everybody is talking about me."

Lack of supporter

High costs of treatment due to the long trend of mental disorders and lack of full coverage of insurance make this family know themselves abandoned and without any support. One of the women explains this issue so that:

"I have suffered many discomforts, sometimes I have not bread for 3 days to feed my children, but I have not told anyone, god willing, I prefer to borrow from bakery rather than saying my relatives or my husband's relatives. Well I have no support."

Financial disruption

Financial problems and costs related to medication and treatment, lack of insurance, lack of supportive centers, and also lack of ability of the husband to work forces the women and their children to work to overcome economic problems. However in the current economic status of the society, these women endure many financial difficulties. Some of these women are also faced with many problems regarding daily subsistence, and thereby these women are faced to financial disruption. Financial disruption includes three sub-themes of "lack of governmental support," "economic disturbance of the family," and "working of woman and the children."

Lack of supportive systems

These women expect more from governmental systems to support them in facing problems. One of the participants says:

"I have not been supported by anywhere, I have gone to welfare center and they told me that if they record a file for my husband, and encode him, they have numerous patients with neurological disorders, we could support 154 individuals out of 900 persons, and they had been here for a long time, and if you come, not your subsidy will be increased nor anything else… when I come back home I explained on such supports?! The people should be died to get support!!"

Family economic disturbance

One of the most important and fundamental problems of this community is living with their spouse, which in the abnormal economic status of the country leads to the incidence of many economic contention for these families for example:

"Swearing to god, you cannot believe that since my husband is unemployed; I overcome my debts too difficultly, I called a teacher this evening whom the school manager introduced to me to borrow money from her for just 500 T, god willing,

I have a check for 5.5 million, I am wondered how I can pay 800 T every month as debt, whatever we had I have paid for our debts."

Working of wife and children

The disability of husbands to afford living expenses makes most of the women to work to afford the primary needs of themselves and their children, and children of these families are highly involved in this issue.

"I worked in people's house previously, but now I really can't physically, my husband comes with me and then, nobody may want me to go to their house with a man, now the boys had quit education to work, if though they can get work, one of my girl who has not child yet said to me to work in people's house instead of me, and give the payment to me since we are have financial problems."

DISCUSSION

Family is a unique system, which any changes in members affect other members.[7] The presence of patients in the family environment makes changes in the system, construct, and relations among family. The findings showed that women with psychologically diseased husbands are faced with numerous challenges and experience disappointment due to many personal and social pressures. They are not only faced with personal problems regarding the disease of their spouse but also deal with problems caused by a lack of support and care system in society. Such women are affected by some types of self-forgetfulness, which this causes physical and mental problems. The role of these women in home and family is changed and they are responsible for all the needs of the diseased spouse's life, which this leads to self-forgetfulness and subsequently feeling mature aging. This finding is in line with the findings of other studies which investigated the experience of women in the role of caring her husband.[25,26] These findings emphasized on that the family of mental patients are affected by many mental diseases by accepting the responsibility of caring their patients,[22] which this decreases life quality of these families.[3-13]

Feeling loneliness, disappointment, hopelessness, and abandonment are of outcomes observed in family of psychological patients and especially individuals who play the role of caring of these patients, and almost all the studies conducted in this field showed it as various names but similar concepts.[27] Another issue which exacerbates isolation is the insufficiency of knowledge in treating with psychological patients.[28] The insufficiency of knowledge is observed even in the family of the patients and also in society.[29] This knowledge insufficiency leads to labeling to these families which this is a factor to increase isolation and seclusion, which can modify incorrect mental thoughts regarding these diseases by spreading general programs of training regarding psychological disorders.[12] The most important obstacle to the success of the individuals with mental and behavioral disorders is name-calling and discrimination associated with it, which to defeat it, public announcing programs for training and informing society regarding nature, and intensity, and effect of mental disorders is needed, and more positive attitude and behaviors should be substituted.[30]

Economic difficulties caused by disease in the family for other members in addition to the flourished concept in the current study is almost an inseparable theme of the most studies in such issue in various cultures,[31] and since the mental disease has a chronic and resurrecting nature, family deal with this problem always. If supportive services of social insurance are insufficient in society, economic problems will also increase.[32]

CONCLUSIONS

The needs of patients and their family are complicated and always changing, therefore, continuing caring is of most important. This issue requires change in systemize the current level of caring. Most challenges, including caregiver disease, defect in training, and financial frustration is caused by insufficient support of the health system. Training of families and correct policy-making can decrease the enforced damages to families.[33]

Incidence of events affect the balance of individual, family, and social system, and the roles of individual are changed in these dimensions. At the time of occurring of a problem, the family should be considered as a whole and the system with components that interact with each other. Continuous caring and pain and suffering which are enforced to the patient, as well as the family, can lead to family trouble. Lack of sufficient identification due to awareness and insufficient supports and mental pressures delays the initiation of the treatment. After receiving primary treatment due to no cooperation by men and high costs, the treatment trend is disrupted, and lack of comprehensive systems of follow-up exacerbate the disease and enforcing high physical and mental pressure to the family.

Studies in this regard point to this tip that disability and suffering caused by disease and living with psychological patients is accompanied by disturbances and stress for

the caregivers, and this issue changes life quality and their health. Suffering from pain, self-neglect, high costs of treatment, loss of calmness in life, feeling of loneliness in defeating with disease's outcomes, and lack of sufficient skill and knowledge in facing to disease and lack of support by treatment systems and insurance exaggerate this issue more than before, and the individual feels isolation and seclusion and disappointment. In order to provide thorough caring for psychological patients, wide spectrum of services are required that caring for the spouse and family is of most important.

Conflicts of interest

There are no conflicts of interest.

Authors' contribution

RZ and MA conceived the study and determined the methodology, collected and analyzed the data. RZ took the lead in writing and organizing the manuscript. All authors reviewed the final manuscript before submitting for publication.

Financial support and sponsorship

Nil.

Acknowledgement

The authors of the article consider it necessary to thank and appreciate all the wives of the mentally ill patients of the 22 Bahman Qazvin Educational and Medical Center who helped us in this research.

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