

Access this article online
Quick Response Code:

Website: www.jehp.net
DOI: 10.4103/jehp.jehp_943_20

Care burden dimensions of informal caregivers having patients with bipolar disorder (challenges and alternatives) (qualitative study)

Mehdi Kargar, Seyed Aliakbar Faghihi¹, Mahin Nazari²

Abstract:

BACKGROUND: Taking care of patients with bipolar disorder (BD) makes critical challenges for their informal caregivers (ICGs) and forces them to tolerate considerable burden. This qualitative study explored the dimensions of ICGs' care burden (CB) based on their own experiences and the patients' therapists.

MATERIALS AND METHODS: This is a qualitative study which was conducted based on conventional content analysis through semistructured and in-depth interviews. Purposive sampling was used to select the participants including 13 ICGs and 14 therapists (2 psychiatrists, 10 psychiatric nurses, and 2 clinical psychologists). Interviews were audiotaped, transcribed verbatim, and analyzed using Graneheim's 2004 principles.

RESULTS: Qualitative analyses yielded three major themes: "challenges associated with the nature of BD," "challenges related to the ICGs," and "challenges related to interventions." The categories of the first theme entailed "individual-oriented characteristics of BD" and "social-oriented characteristics of BD." The categories of the second theme consisted of "social stigma," "psychiatric problems and helplessness of ICGs," "financial costs related to providing cares," and "insufficient self-efficacy of ICGs in cares provision." The categories of the last theme included "educational interventions" and "organizational interventions."

CONCLUSIONS: This study showed that the burden of ICGs have individual, social, and organizational aspects. Every one of them impacts the severity of their burden remarkably. The depth of the therapists' experiences has a significant role in designing the interventions to reduce this burden. The present investigation emphasized the constitution of a comprehensive framework related to all factors affecting burden in a developing country.

Keywords:

Bipolar disorder, care givers, qualitative research

Introduction

Bipolar disorder (BD) is known as a chronic and disabling problem, specified by recurrent episodes of mania, hypomania, and depression.^[1] It makes a considerable burden on patients and their informal care givers (ICGs) who are supposed to take care of the patients out of clinical environments without receiving any wages.^[2]

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

Many patients have constant mental symptoms and relapses specified by recurrent manic psychotic rounds. Nowadays, taking care of BD patients makes important challenges for their ICGs. Some of these challenges include financial problems, leisure time limitation, and disturbance in daily activities, (occupational affairs and social relations).^[3,4] However, determination and measurement of care burden (CB) is hard.^[5]

How to cite this article: Kargar M, Faghihi SA, Nazari M. Care burden dimensions of informal caregivers having patients with bipolar disorder (challenges and alternatives) (qualitative study). J Edu Health Promot 2021;10:282.

Department of Health
Education and Promotion,
Faculty of Health, Shiraz
University of Medical
Sciences, Shiraz, Iran,
¹Clinical Education
Research Center, Shiraz
University of Medical
Sciences, Shiraz, Iran,
²Department of Health
Education and Promotion,
School of Health, Shiraz
University of Medical
Sciences, Shiraz, Iran

Address for correspondence:

Dr. Mahin Nazari,
Department of Health
Education and Promotion,
Faculty of Health, Shiraz
University of Medical
Sciences, Shiraz, Iran.
E-mail: manazari@sums.
ac.ir

Received: 02-08-2020
Accepted: 19-02-2021
Published: 30-07-2021

Previous studies indicated that CB causes social isolation, financial restrictions, and the problems related to health for ICGs of BD patients.^[6] More than 50% of these ICGs suffer from mental distress significantly and psychiatric disorders in comparison with normal population.^[7-9] They also face social discrimination and disturbance in daily activity.^[10] Having limited time for social interaction and leisure time and allocating any spare time for their own physical health and emotional welfare are the other challenges which they face seriously.^[11,12] Furthermore, the comorbidity of BD with substance abuse provides additional burden for ICGs,^[13] so that it affects their family life negatively.^[14]

Despite high number of studies conducted with regard to CB of BD patients' ICGs and the interventions performed for its reduction, there have been few investigations in which the lived experiences of ICGs and therapists have been explored, at least, in Iran.

On the other hand, quantitative studies are criticized to provide hypothesized definition for the researched problem and disregard the ICGs' and therapists' experiences deeply.^[13,15] Therefore, this qualitative study was conducted to explore the challenges related to CB tolerated by ICGs of BD patients' and recognize the basic alternatives and interventions conducted for them based on the experiences of the interviewed ICGs and therapists.

Materials and Methods

Setting and participant

This qualitative study was conducted in Shiraz University of Medical Sciences in Iran. The participants were recruited through purposive sampling method. Inclusion criteria of patients' ICGs included having one family member diagnosed as a known BD case, individual tendency for participating in the study, lacking any physical or mental disease, having telephone line, and at least 6-month history of care giving. The last criterion was determined based on the viewpoints of three psychiatric faculty of members working in Shiraz University of Medical Sciences. Exclusion criterion of ICGs included the possibility of disturbing patients care process due to participating in interview.

Inclusion criteria of the therapists included their tendency to participate in interview, having, at least, 5 years of experience of working with BD patients, and certificates in psychiatry, nursing, and psychology majors. Exclusion criteria of the therapists included their dissatisfaction to continue the interview. The studied cases included 13 ICGs referring to one of the psychiatric centers managed by Shiraz University of Medical

Sciences and 14 therapists (2 psychiatrists, 10 psychiatric nurses, and 2 clinical psychologists) [Tables 1 and 2].

Data collection and analysis

The data were collected by semistructured and in-depth interviews, memos, and reminders. All conditions of interviews including their duration, goal, and confidentiality of the cases' information were described before the interview. Definite appointment was set in advance. Verbal consent was achieved from participants before interviews. The duration of interview was determined based on different factors such as preparation of interviewee, environmental conditions, and the process of interview. Interview duration was fluctuated between 20 and 60 minutes. The participants were asked to participate in another interview to explain more details if necessary. The questions were designed based on the principles of semistructured interviews. Some examples of questions are as follows: "would you explain your own experience of living with your family member suffering from BD?" and "if providing cares makes any problem for you, please describe them in detail?" The examples of the questions asked in therapists' interviews are as follows: "please describe your personal experience about the challenges which the ICGs face with in taking care of BD patients" and "what problems do you face personally in interacting with ICGs of patients when they ask you how to take care of them?" Every audiotaped interview was transcribed immediately after its termination. The audiotaped interviews were listened by the research team repeatedly to achieve the main concepts. The transcriptions of the interviews were also reviewed two times by the research team members. In some cases, it was necessary to clarify some parts of interviewee's statements through telephone calls. Conventional content analysis method was used to analyze data.^[11] In addition, data analysis process was done based on Graneheim's 2004 principles.^[16]

Table 1: Demographic characteristics of interviewed informal caregivers

Number	Age	Gender	Educational level	Time episode of care giving
1	52	Male	Elementary	5
2	48	Male	Elementary	7
3	45	Male	Diploma	3
4	60	Female	Elementary	15
5	50	Male	Elementary	12
6	42	Male	Diploma	8
7	48	Male	Diploma	5
8	45	Female	Diploma	6
9	35	Male	Diploma	5
10	40	Female	Diploma	6
11	49	Male	Guidance School	7
12	42	Female	Postgraduate	7
13	50	Male	Elementary	6

Table 2: Demographic characteristics of therapists

Number	Age	Educational level	Gender	Occupational position	The duration of working as a therapist (year)
1	35	Psychiatrist	Male	Assistance professor	12
2	37	Psychiatrist	Male	Assistance professor	17
3	45	B.S. in Nursing	Male	Head nurse	12
4	45	M.S. in Nursing	Male	Clinical nursing supervisor	19
5	42	B.S. in Nursing	Male	Head nurse	15
6	44	B.S. in Nursing	Female	Head nurse	16
7	43	B.S. in Nursing	Male	Head nurse	16
8	41	B.S. in Nursing	Female	Head nurse	12
9	35	B.S. in Nursing	Male	35 nursing staff	11
10	42	B.S. in Nursing	Female	Head nurse 42	14
11	45	B.S. in Nursing	Male	Clinical nursing supervisor	22
12	45	B.S. in Nursing	Male	Staff nurse	15
13	45	M.S. in Psychology	Male	Clinical psychologist	17
14	35	M.S. in Psychology	Male	Clinical psychologist	5

The meaning units including the participants' statements and the related aspects of the major concepts were identified. The codes of the research were achieved by summarizing and combining the meaning units which were closely related to each other. Monitoring the differences and similarities of the extracted codes, based on their meaning closeness and frequencies, lead to categorize the interviews' contents into subcategories and main categories. This process lead to produce major categories and subcategories.^[17,18]

Rigor

The credibility of the data was proved by the triangulation method through using a professional team to monitor the data. Moreover, semistructured interviews, note taking during interviews, and long-term involvement of the researchers with the data and their clinical experience in mental health (20 years) were used for data credibility.^[18] Moreover, the data dependability was evaluated by peer- and member-checking.^[17] The results were presented to two qualitative study researchers. They revised the achieved data based on the goal of investigation and affirmed them. However, the viewpoints of other researchers and documentation of the results reinforced the confirmability of the data. Finally, some factors such as comprehensive description of topics, participants, content, data collection and analysis, and the study's limitations strengthened transferability of the data. This was done to make it possible for other researchers to use the research process of present investigation in their own studies.

Ethical consideration

This project was affirmed in Shiraz University of Medical Sciences (Iran) with the following ethical code: IR. SUMS. REC.1398.646. The goal of the study was described to the participants before interviews to regard ethical considerations. The interviews were mostly done in Ebnesina Hospital as one of the

psychiatric centers managed by Shiraz University of Medical Sciences. Furthermore, the participants were allowed to withdraw the study whenever they wished. They were also assured that their data kept confidential.

Results

The demographic characteristics of the participants are presented in Tables 1 and 2. The participants included 13 ICGs and 14 therapists (2 psychiatrists, 10 psychiatric nurses, and 2 clinical psychologists). Three major themes related to CB of ICGs with BD patients were recognized through semistructured interviews. They consisted of (1) challenges associated with nature of BD, (2) challenges related to ICGs, and finally, (3) the experiences of ICGs and therapists about any designed interventions which they have witnessed to conduct recently to impact CB of ICGs [Table 3].

Challenges associated with nature of BD

This category included most of natural characteristics of BD noticed in psychiatric references. It consisted of two main subcategories: individual- and social-oriented characteristics of BD.

Individual-oriented characteristics of BD

The interviewees stated the existence of some individual characteristics related to the identity of BD which increased ICGs CB. Some of these characteristics included decreasing occupational function, lack of motivation for adhering to treatment, extravagance especially in financial affairs, aggression, and hyperactivity.

One of the therapists expressed his experience as follows (Therapist 1):

"One of the most important signs of these patients is losing money when they should not do so. This can put

Table 3: Themes extracted from data achieved through interviews

Theme	(A) Challenges associated with the nature of BD	
Category	Individual-oriented characteristics of BD	Social-oriented characteristics of BD
Subcategory	Natural characteristics and symptoms of BD	Marriage
Examples of codes	Medication non-compliance Irregular medication use Taking the medications beyond physician's order Opioid and stimulants abuse Overuse of prescribed medications Substance abuse Relapse Recurrent hospitalizations Reurrence of manic symptoms Reurrence of depression symptoms	Verbal and physical aggression toward ICGs Physical conflicts with others Insulting to others rudely Regarding marriage as a therapeutic alternative Spouse' unawareness about disease characteristics Lack of financial independence Inability to do occupational duties Losing job due to aggression
Theme	(B) Challenges related to ICGs	
Category	Social stigma	Insufficient self-efficacy of ICGs in cares provision
Subcategory	Being seen in a different way in formally social and familial groups	ICG's low literacy
Examples of codes	Social relations decrease Decreasing friendly relations with others Social isolation Fear of being isolated Anti-depressant medication consumption Anti-anxiety medication consumption Referring to psychiatrists Depression and anxiety Hopelessness of complete treatment of patient Uselessness of treatments Recurrence of patient's admission Getting used to wrangling in home Helplessness and nihilistic feelings Inability in admission costs payment Inability in medication costs payment Costs of admission and medication provision Costs of ICG's unemployment Having no fixed income Being time-consuming of patient admission on employer Unawareness of therapeutic methods Insufficient medication literacy Dissatisfaction of employer Limited time for care giving Daily problems Lack of motivation to continue the treatment	Poor therapeutic and personal self-efficacy
Theme	(C) Challenges related to interventions	
Category	Educational interventions	Organizational interventions
Subcategory	Educational methods and content	Social services
Examples of codes	Using group discussion Using individual and group psychological consult Using face to face in education Using virtual education Medication information Therapeutic methods Alternatives to decrease relapse Ways of communicating with other people	Lack of good psychiatric services Lack of social working Lack of sufficient police contribution Shortage of therapeutic and educating staff Therapists' inattention to ICGS Limited education time Limitation of nurse force High number of ICGs and patients

BD=Bipolar disorder, ICGs=Informal caregivers

high economic burden on family and it is due to lack of insight into their own problems. They have no insight of their disease, for example, when they are in manic phase. This can highly lead to disrupt the family. Usually they are possible to wrangle with family physically and verbally. Because they believe that patient can't decide properly, but the guy thinks that he can control the situation."

One of the nurses said (Therapist 7): "One reason can be the nature of the disease. The nature of mental illness is the root of its recurrence specially for BD. Though the patient takes medication, the disease worsens and the signs reveal, and this is nature of disease. And the poor family which should tolerate them!"

A psychologist stated his experience about this challenge (Therapist 14): "Sometimes patient shows no cooperation for treatment and hospitalization, because he disbelieves in his own problem and the problem rises during transferring to hospital by family, when he is so irritated."

Another nurse stated about aggression and its impact on ICGs CB (Therapist 5): "These patients got aggressive, all this burden affects ICGs' life and it would be with them. If we use frustration word, it means that the difficulty which the family has to tolerate. Actually taking care of them is so hard and all family life is affected. They ruin their life entirely."

Medication incompliance

This concept was reported massively in interviewees' statements as one of the most important challenges in BD patients' remedy. It makes considerable burden for ICGs. One of the interviewed nurses stated (Therapist 10): "Well, the problem is that those ones who get better after some time, they become, we say, non-compliance. It means the medication which he should take, he says I am ok and he does not consume them and challenge he makes, between care giver and patient is due to this point that patient feels he's in a euthymic condition and his mood is normal. So, he does not need to take medication. And the care giver knows that this medication should be taken in one or in two years It is the start of wrangle between family and patient. ICG feels anxious whenever patient quits his medication."

One of the ICGs said (ICG 3): "They don't take their medication in a way that they are ok with just two or three pills, but they are careless and refuse to take the medication. When he agitates, no medication, even ten times more than that, responses at all. And I got frustrated again."

Another ICG expressed his ideas about this matter as follows (ICG 12): "Apart from the medication which they

take, they don't should abuse drugs. They should not use cigarette. If he takes more than ten pills but abuses drugs and cigarette, perhaps half of his medication affect him, and I can't stop him, I should remind him like a little kid. I tell him you didn't take your pills this morning, you didn't take your pills at noon, you didn't take your pills at night my dear! Sometimes, he abuses drugs and I follow him, despite I should not do so, because it is useless for him. One specialist said it is useless. I give him his pills, I said if I don't give them to him, he may worsen, his disease got back."

On the other hand, these patients abuse some medications by their own and it can deteriorate CB of their ICGs. Because the risk of poisoning with overdose of medications are high and this upsets ICG all the time. They feel anxious when they know that their patients may fall in another problem due to medication abuse. An ICG said (ICG 4): "If I do not look into his medication use, he may abuse them. Then, I have to be worry of his sudden death if he take them more than doctor prescription."

One of the psychologists stated his experiences (Therapist 9): "One of the problems of the ICGs is the medications suggested by others. Usually as they've been taken in the ward or by other patients. Usually, the families and patients recommend each other that this pill was ok for me or for my child and you can use it too. It was effective and the patient and family should have this knowledge that the type of disease is different and the medication which got effective for someone could be useless for another one. It confuses ICGs."

Substance abuse

This challenge disturbs the treatment process and their rehabilitation severely. One of the ICGs said (ICG 5): "They are mental patients, but their main problem is addiction. If drug use got controlled, they can be treated. Our awful days starts when he fall into addiction."

One of the ICGs said (ICG 10): "His doctor told me he should not use drugs at all and these medications at the same time. If he takes ten pills but abuses opioids or cigarette, all done for him is useless!"

Relapse

It is also one of the most important challenges of BD patients making for their ICGs and therapists. One of the psychiatrists said (Therapist 4): "Those ones who stop their medication use, 50% of them after 5 months and 80%–90% after 1 year and a half, have the chance of relapse. ICGs should tolerate the problems from the first point!"

One psychiatrist stated (Therapist 2): "In BD, the chance of relapse whether in depression phase or manic phase is

always high. So the guys living with them should be wait for the phases of depression and mania which can disturb the care givers more and the responsibilities which they have, surely higher than usual and force them to take life responsibilities which are not supposed in normal conditions. This can increase their burden and lead to their depression and tiredness within care process."

One of the nurses talked about the relapse of this disorder (Therapist 10): "The number of relapse is so high according to the type of disorder. I mean that we see a manic patient have been admitted one time every year at least. One reason can be the nature of disease. The family is under pressure again and again!"

One nurse said (Therapist 3): "The identity of mental disorders including bipolar, especially, is related to relapses sometimes despite the patient takes the medication happens, you know, it is the nature of mental disorder. The second issue is limited family support in a way that sometimes, they let the patient go and he doesn't take the medication. And they don't have good care giver, they don't take the medication on time and the disorder relapses. So, putting away the medication causes relapse. Another issue is economic problem. Sometimes families don't take the patients to the hospital for next follow-up due to economic problems and this situation causes the patient not to be visited and his medication got less or more and he doesn't get the balance and this causes relapse. Another problem that is very important is the families' unawareness of the disorder identity and its type and that is related to the disorder signs. Families are really educated so few or education in treatment course and after discharge in follow-ups that the patient refers, are not enough."

One nurse stated his experiences about this matter (Therapist 9): "Every relapse leads to more CB for families and how they take the patient to the hospital or how they make him stable or how they find the doctor. Absolutely, every episode of relapse increases CB so much."

Verbal and physical aggression toward informal caregivers

BD patients especially in manic episode show mostly some behaviors which lead to verbal and physical aggressions toward other people, especially their ICGs. These behaviors cause considerable conflicts in home and lead to severe disturbance in family.

One of the ICGs said (ICG 15): "When he becomes talkative no one can stop him. He talks so aloud that he irritate. We can tolerate to some extent and he wrangles. Sometimes, when he finds something close to himself, he throws it away towards us. One time, he threw a dish

towards my face that if I did not get down my head I would have been injured awfully."

One of the nurses stated his experiences about this issue (Therapist 10): "Actually living with bipolar patients that may do every deed in anger is terrible. One time, one of them kicked his wife in the ward in front of me which we could take his wife away by difficulty. She was close to be injured seriously." In fact, aggression and the inability of controlling the impulses in mania episode can increase CB of ICGs.

Social-oriented characteristics of bipolar disorder

Marriage

Most of the ICGs believe that marriage can be a big challenge for them. Even, some of them regretted to do so. An ICG stated her experience of getting married with a BD patient as follows (ICG 10): "If I knew that he was sick, I wouldn't have married him. They can't be a good couple. They are not normal most of the time. They have to let others to know their condition before marriage! If I knew, I would not have fallen myself into this disaster."

One of the patients' spouses said (ICG 11): "Sometimes I have decided to divorce. But I have not done it for my kids. I can't tolerate him anymore. It's very difficult to live with a guy who is not a good couple."

One of the nurses said about this issue (Therapist 5): "Actually, it can't be said that marriage is a good solution for these patients. Because marriage is a big stress. Now, a patient with all these problems, how he can support a family. I have seen many guys in trouble after getting married with them."

However, few ICGs believed that marriage can be an alternative to solve their problems. One of the ICGs whose patient was single in 52 years old said (ICG 13): "If I thought those days like today, if he got married, perhaps he wouldn't have been in this way. At least, there would have been someone who could 24 h be with him. We have our own jobs, we have families, we have our own business."

Unemployment and lack of financial independence

This factor is a key element in increasing the CB of ICGs. It can enhance the impact of previous challenges. The economic costs of this disorder are divided into direct and indirect ones. Direct economic costs included any cost of treatment, hospitalization, and relapse. The indirect costs include any financial problems made by patients' unemployment and their inabilities in doing their personal, familial, and social responsibilities.

One ICG stated her belief about occupational disqualification and lack of financial independency of

her patient as follows (ICG 16): "In my opinion. As a mother, if the chance for working is provided, I think he will recover. Because, now you do all your effort, specialists do their efforts, that the patient got healthy after hospital. But when he comes back home, every thing is like before. The patient coming home, after 1 or 2 weeks, he frustrates. He depresses, what can do the family? They can do nothing. They have to be hospitalized. This makes me so depressed."

An ICG stated her experience about her husband unemployment (ICG 12): "When he is depressed, he has no income and he stays at home. When a man has no income, so a beggar can go and does his job but we can't do that. It's really hard for us. We can't tell our problems to anyone. When he is manic, he gives all things to others. For example, his friends say he is a normal guy, he's very generous. For example, he doesn't pay for 2 or 3 months of his house rent but he pays others' rent. He doesn't pay his loans but he pays unpaid loans of others."

The challenges related to informal caregiver

The study of the interviewees' experiences showed that there were some challenges affecting ICGs' CB related to the conditions of ICG themselves.

Social stigma

Living with a BD patients provides social stigma for ICGs. One of the ICGs stated the impacts of having a BD patient and its impact on his social life as follows (ICG 9): "If someone wants to propose my daughters, if they know that their father has this problem, they regret. I have two daughters, one of them studied Law and another one studied Mechanics. Actually when the suitors got that he is ill, they say if we get married with them, perhaps, we will have to support our wife's family."

The dimensions of social stigma importance are so considerable that it threatens family foundation. One nurse expressed his experience about this issue as follows (Therapist 12): "Social stigma which they receive, sometimes causes family to break down and if the man is ill, his wife may ask divorce. Sometimes, it makes problems for the society and it causes conflicts in society and their CB is very high."

Psychiatric problems and helplessness

The experiences of the interviewed participants indicated that a part of CB was resulted by giving cares to BD patients, so that it could lead to mental problems and hopelessness for ICGs. This could impact their quality of life considerably. One ICG said (ICG 18): "I am an insane guy! Like the persons who got frustrated. What can I do? Nothing! I am breaking down. My boys work, my daughters do so. My husband goes out. I got alone with him! Maybe you don't believe, when he is in this

way, I break down totally and I can do nothing for him. I just can say prayer. I can't do anything, I got frustrated."

One ICG said about this challenge (ICG 11): "When I remember now, I am close to crying, because they are not hurt actually, the others disturb (.she's crying.), but mentally, we are awfully involved. When I went to clinic with him, the doctor prescribes medication for me to take, because it was mentally very awful."

Financial costs of cares

All the mentioned factors and the continuity of care process put heavy costs including financial ones on ICGs' shoulder which its handling is so hard for most of them. One of ICGs said about his experiences (ICG 10): "Their medication costs were very high, 200 thousand Tomans, they have also clinical tests. We paid so much but it was useless. He does not get better."

In fact, the care costs can be a big challenge for some ICGs in a way that they can't afford them. This impacts the care process and can lead to relapse. An ICG stated his experiences as follows (ICG 4): "He has no income. My husband supports living just by a retirement pension, I have six kids. It's hard to make a living by this high care expenses."

Insufficient self-efficacy of informal caregivers

One important factor which can affect CB of ICGs is the perceived insufficient self-efficacy, based on the experiences of the studied interviewees.

An ICG stated (ICG 12): "I can't stop him not to abuse drugs. He makes problems for me and himself. He is 45 and I can't control him. After 1 or 2 weeks, he got that he's jobless and has no fun. He irritates and again got to the first point. He shelters to drugs again!"

An ICG said (ICG 6): "When he is depressed, we should be beside him at home completely, I mean we can't let him be free by his own, because he may commit suicide and so, you should be with him and you confused, cry and he comes with you no where. He likes to be alone. When he is depressed. When he is optimistic, he goes out all the time with his friends and relatives. If he is allowed, he likes to be out of home even in nights and you should take him to home by force."

A psychiatrist expressed his experiences with regard to work with ICGs (Therapist 20): "Another issue about suicide is that suicide makes aggression in care givers that they feel disqualification. It means I am not a good father, because I could not take care my kid well or I'm not a good mother or a couple. So, care givers become aggressive and feel to be disqualified which is not possible to compensate because the guy was dead by suicide and he/she can't say that you were a good father

or mother. So, he/she tolerated heavy guilt feeling and shamefulness due to this disqualification up to the end of life."

One ICG said (iCG 2): "I have no specialty. I can do nothing! Doctors and specialists prescribe for me that please provide this medications and give him. I provide them all by any means."

Another ICG expressed his experiences as follows (ICG 5): "Well, I don't know so much of medication. Yes, perhaps if I knew soon or if he took one or two pills, he wouldn't have been as bad as today."

The challenges related to interventions

In addition to the challenges affecting CB of ICGs, there are some interventions conducted for them to reduce their CB. Based on the experiences of the interviewees in the present study, conducted interventions included educational and organizational challenges impacting CB of ICGs by different ways.

Educational challenges

Educational methods and content

Since the interviewed therapists had invaluable experiences in educating ICGs, they presented their own practical experiences to decrease the CB of ICGs. They expressed the challenges existed in educating of BD patients' families.

One nurse stated the importance of education in reducing ICGs' CB (Therapist 4): "If educational issues are done well, whether before, during and after hospital admission, it has positive effect. I mean the more this education is done well by staff, the more it is effective. I mean if education is done well for medication and disease remedies and generally, the cares during hospital treatment and follow-ups after discharge from hospital, it can absolutely be a key element. It can also have impact on CB. But this is done incompletely in our system."

One of the ICGs said about this subject (Therapist 5): "If we consult with you, you can help and tell us how we should treat these guys and how they recover. You can do a lot for us. You and those specialists work hard and if you don't do that, we can do nothing!"

Another ICG said about this issue (ICG 10): "If you set some sessions when a patient got discharged, you let us know how he should be taken care, how he would be treated so that he keeps his hopes and how he finds his goals, we appreciate you."

The experiences of the participants illustrated that using different methods of education to train the ICGs for reducing their CB can be more effective. A nurse

expressed his experiences with regard to utilize various educational methods (Therapist 7): "Absolutely educational groups can be very effective so much. They can encourage each other, participate in these groups and use their each other's experiences in taking care of their patients. This decreases the care pressure of family. So, we conclude that group education which both family and patients take part, are absolutely more effective than individual ones."

Another therapist stated his ideas about this subject (Therapist 9): "It seems that face to face education for patient and families and educational pamphlets are given to patient and family, are ok. But face to face education, when they are educated by nurses or hospital staff and psychologists, are very more effective."

One nurse expressed his idea about virtual networks in educating ICGs (Therapist 6): "If someones whether through virtual networks or telephone consults are educated, it can be very fruitful, I myself have the experience of that. Actually the families of schizophrenic patients that I have educated, they call me sometimes and ask me help them even after some years."

With regard to the content of ICGs' education, the interviewed therapists expressed different concepts. One of the nurses said (Therapist 120): "If the families receive good psycho education and more information about the disease, what factors induce the disease, what factors make it stable and in what conditions the medication can not be given or sometimes our patients take Lithium and this medication has relative toxicity in high doses and can be dangerous, it can all help families so that before getting worse the disease or stopping their medication, they can recognize the signs and refer more rapidly."

A psychologist expressed his idea about this subject (Therapist 14): "Education is done in different issues which one of them is anger control and patient poor impulse control in acute phase of disease which is mainly for preventing from self injury or hurting other people. Some education should be given about the power of adjustability with new conditions. The importance of medication use and doctor prescription are the matters that happen in ward. Another issue is the long term treatment period and this point that medication takes time to show its effectiveness properly."

Shortage of therapeutic and educating staff

The lack of human sources for educating ICGs is a considerable challenge for reducing CB. One of the psychiatrists expressed his own experiences with regard to limited number of educators for ICGs as follows: "One of our main problems is the shortage of human forces. When you have a lot of patients, as a therapeutic

staff beyond your ability, some things is lost absolutely. Necessary education is not provided, patient's words are not listened as expected. Usually, when you visit the patient in clinic and you are psychiatrist, it's possible that you visit 30 or 40 patients in 5 or 6 h whereas in developed countries usually in a single day, psychiatrist visits five or six patients. So, shortage of human forces is absolutely one of the main problems that exists in all medical, nursing and social settings."

Organizational interventions

Based on the conducted interviews, it was revealed that there was some organizational challenge which can affect CB of ICGs massively.

Social services

These services can assist ICGs in critical situations to decrease their CB. In fact, as community-based services, they try to accelerate the process of treatment and this can reduce CB of ICGs indirectly. These services include home visit, insurance coverage, hospitalization, judiciary, and social working services.

One of the therapists said about these services and their importance in decreasing CB (Therapist 11): "Social services like 115 Emergency Line can help them with bringing the patient to the hospital or the police can also help them. I remembered when I worked on my thesis, families' patients didn't know that emergency ambulance could help them or the police station near their home. Even if they are threatened by their patient, they can be helped by judiciary references and they bring their patient to the hospital. These are alternatives that through social services can be given to them and the mental pressures which are on families by these services or some nursing services can be reduced."

One nurse expressed his experiences (Therapist 5): "When they face any problem, they ask me guidance. Just tonight, one of the care givers came here and was visited by the doctor and went back home. Even this education was so important that he has not admitted in hospital from then on. So, educational program and telephone consult and home consults and home visits can decrease very much families' mental burden that they tolerate."

Medical insurance and supplementary insurances do not support the health services totally because of some challenges such as patients' substance abuse which are out of their coverage. This can make serious problems for ICGs, because substance abuse is so common among BD patients.

A nurse expressed his experience as follows (Therapist t1): "At the present that I'm talking to you, insurances just cover a definite number of admission days and if the

patient uses it, no insurance covers the costs. Well, that is a miserable for the poor family! They should pay heavy cost without insurance coverage, their patient is bipolar but abuses drugs. Insurance staff comes and says he is coming for addiction withdrawal and I, as a supervisor nurse could do nothing for the family. You can't imagine what awful wrangling got happened here for family."

A psychiatrist said (Therapist 3): "We have some insurances that they don't help as expected in fulfilling the patients' needs. Sometimes the medication which patient responds, got so scarce and insurances have no coverage for them."

Discussion

This qualitative study was conducted to modify CB of ICGs having BD patients and the alternatives designed to decrease this burden based on the experiences of ICGs and therapists. The findings of the present study demonstrated that ICGs' CB was modifiable by three major themes including challenges associated with the nature of BD, challenges related to ICGs, and interventions designed to reduce CB.

The first theme was related to the challenges associated with nature of BD. It was divided into individual and social characteristics of BD which affect ICGs' CB. Clinical characteristics of BD were related to mania and depression phases. Individual characteristics of this disorder affecting CB of the interviewed cases included medication incompliance, drug abuse and stimulants, relapse, and verbal and physical aggression.

These factors provide high CB for ICGs physically, mentally, and socially. It was shown in a qualitative investigation that spouses of BD patients expressed the characteristics of this disorder as the main determinants of their CB.^[19] This is accompanied with the present study's results. Poor medication compliance is a big challenge impacting CB of ICGs considerably. Sajatovic *et al.*'s study illustrated that major reasons of medication incompliance included the patients' concern of medication side effects and lack of insight into their own problem.^[20] The participants of the present study mostly believed that the main reason of the incompliance was the lack of patients' insight of their own disease. Hajda *et al.*'s study confirmed the role of medication incompliance and poor self-care efficacy in ICGs' CB.^[18] Sajatovic *et al.* found in their research that there was close correlation between medication incompliance and therapeutic relations, because when the psychiatrists assess the treatment progress continuously and reinforce their own relations with the patient, medication compliance was improved.^[17]

Patients' drug abuse is one of the main challenges causing CB for ICGs. The results of this study demonstrated that a considerable part of ICGs' energy, time, and concern spent to control the patients' behaviors related to drug abuse. However, most of their strenuous effort was in vain. Different studies have illustrated considerable overlap between drug abuse and high CB of ICGs.^[13,21] The relapse of symptoms is another challenge which has an important role in accelerating CB of ICGs based on the experiences of the interviewees in the present investigation. Various studies have shown ICGs' concern of patients' relapses.^[22-24] Nevertheless, a research indicated that if medication was combined with individual cognitive behavioral therapies, the relapses would have been happened less than expected.^[25]

In addition, the participation of ICGs in treatment process is regarded as a valuable measure in controlling relapse of mental disorders.^[26] Although the characteristics of this disorder affect ICGs' CB, verbal and physical aggression of the patients is a remarkable challenge playing a crucial role in the level of CB. The management of aggression and suicidal risk is very difficult for ICGs.^[27,28]

Poor self-care efficacy of BD patients in doing their own care affairs is one of the main challenges of ICGs which increase their CB considerably. Based on the findings of Arun *et al.*, lack of sufficient self-care efficacy, life skills, communication capabilities, and also disqualification to support their own living lead to develop ICGs' CB.^[19] This develops social dimension of ICGs' CB.

According to the results of this research, marriage, inabilities of doing familial responsibilities, and lack of financial independence were social-oriented characteristics of BD which accelerated ICGs' CB. The study of Kumar *et al.* modified the role of mental disorders in leading patients to take their familial responsibilities inefficiently and make them more dependent to their care givers for supporting them financially.^[27]

The second theme related to ICGs' CB included the challenges associated with the ICG themselves. Social stigma is a critical challenge for the patients and ICGs. The participants in the present study stated that this concept resulted in delaying treatment and decreasing ICGs' relations with other people remarkably. Taghva *et al.* affirmed the importance of social stigma of BD. They found that cultural and social backgrounds in Iran were two contributing factors in expanding social stigma.^[28]

Meanwhile, the attitude of stigmatizing mental patients is rooted from the culture of society. However, psychiatric centers have made some efforts to reduce social stigma by combining this centers into other therapeutic institutions.^[29-31]

The results of this investigation demonstrated that most of ICGs suffered from some mental problems such as depression and anxiety related to long-term care giving. This makes it necessary for them to refer to psychiatrists and take medication. The families of BD patients tolerated high level of anxiety within their patients' manic phase due to their unpredictable behaviors. In addition, it was revealed that there was positive correlation between ICGs' CB and the severity of their patients' acute symptoms.^[21,32]

The participants expressed their experiences of frustration in the process of patients' rehabilitation to regain a part of their previous function. This affected the process of care giving provided by therapists and can lead to reduce the quality of their services. This is consistent with the results of another study revealing helplessness as the most common form of CB experienced by ICGs.^[33] One of the aspects of ICG's CB is economic issue related to treatment costs. Because BD impacts patients' occupation, personal function, and social capabilities.^[21] This leads ICGs to endure financial pressure related to their patients' expenses.

Insufficient self-efficacy of ICGs in providing care process can be caused by their lack of sufficient knowledge about treatment process and patients' medication. This poor knowledge and ICGs' poor personal capabilities for following up the treatment of BD patients are contributing reasons in increasing patients' CB.^[34]

The last theme of the present study included the designed interventions for ICGs' CB. Type of interventions and educational methods and contents had an important role in decreasing ICGs' CB. Group discussion, face-to-face consultation, and virtual education were the most effective types of education, which could be efficacious in ICGs' CB reduction. Using different educational methods based on limitations, available facilities, and general conditions of ICGs were known as the main criteria to choose the method of interventions performance.^[35,36] It was illustrated that psychiatric services were not qualified enough based on ICGs' needs when information transmission and some chances to provide support have been evaluated.^[37] The participants of the present study expressed repeatedly ICGs' needs to receive social services such as insurance coverage, judiciary referrals, and police support. However, they confessed that these services were insufficient in emergency situations and hospitalization. The conducted study in China has shown the same results.^[13] The experiences of ICGs' patients have indicated that they were ignored by social services tremendously.^[38,39] The present investigation provided a considerable opportunity to mix the experiences of ICGs and therapists with regard to the burden tolerated by ICGs. This can lead to design interventions to reduce ICG's burnout.

Strong points

The strong points of the present investigation were as follows: conducting a qualitative study by a researcher with more than 20 years of experience in mental health and vast access to the ICGs and therapists having lived experience with BD patients. In addition, the format of writing has been tried to illustrate every theme as deeply as possible. This is derived from the policy of this journal in writing style.

Limitation

The stigma which the ICGs suffered from leads them not to state their experiences as openly as expected based on their own statements.

Conclusions

The results demonstrated that their CB is impacted by different factors. Individual characteristics of BD are important sources of CB, which seems to be unavoidable. In other words, CB is an inseparable part of giving care to BD patients as much as other chronic health problems. These characteristics consisted of verbal and physical aggression, medication incompliance, substance abuse, and relapse. Social aspects of BD including marriage and financial insufficiency were known as two important sources of CB for ICGs. Another contributing factors which are believed to increase CB of ICGs include challenges related to ICGs themselves. Social stigma, psychiatric problems and their helplessness, financial costs related to providing cares, and insufficient self-efficacy in providing cares for their patients are the sources of ICGs' CB.

The last factors impacting ICGs' CB are the interventions and measures conducted to reduce their CB. The interviewees' experiences revealed that educational interventions should be used through different educational methods and contents to maximize their impact on ICGs' CB. The shortage of skillful and trained educational staff is known as the significant educational challenge in the present investigation. However, it is shown that organizational interventions had a very vital role in decreasing their CB. Lack of social services is a considerable challenge in respect of organizational measures affecting ICGs CB. Meanwhile, it seems that it is not possible to modify the definite cause and effect chain for determining the associations among these factors.^[40] Designing educational and organizational interventions for ICGs to empower them in providing cares are two serious recommendations to lessen CB. In addition, it should be noted that these interventions have to be multidimensional, so that they can tackle different challenges against ICGs CB.

Financial support and sponsorship

This research was supported financially by Shiraz University Of Medical Sciences.

Conflicts of interest

There are no conflicts of interest.

References

1. Pakpour AH, Modabbernia A, Lin CY, Saffari M, Ahmadzad Asl M, Webb TL. Promoting medication adherence among patients with bipolar disorder: A multicenter randomized controlled trial of a multifaceted intervention. *Psychol Med* 2017;47:2528-39.
2. Bond K, Anderson IM. Psychoeducation for relapse prevention in bipolar disorder: A systematic review of efficacy in randomized controlled trials. *Bipolar Disord* 2015;17:349-62.
3. Vallarino M, Rapisarda F, Scott J, Vecchi T, Barbato A, D'Avanzo B. Experiences of mental healthcare reported by individuals diagnosed with bipolar disorder: An Italian qualitative study. *Community Ment Health J* 2019;55:129-36.
4. Poole R, Smith D, Simpson S. Patients' perspectives of the feasibility, acceptability and impact of a group-based psychoeducation programme for bipolar disorder: A qualitative analysis. *BMC Psychiatry* 2015;15:184.
5. Maassen EF, Regeer BJ, Regeer EJ, Bunders JF, Kupka RW. The challenges of living with bipolar disorder: A qualitative study of the implications for health care and research. *Int J Bipolar Disord* 2018;6:23.
6. Ganguly KK, Chadda RK, Singh BT. Caregiver burden and coping in schizophrenia and bipolar disorder: A qualitative study. *Am J Psychiatr* 2010;13(2):126-42.
7. Pirkis J, Burgess P, Hardy J, Harris M, Slade T, Johnston A. Who cares? A profile of people who care for relatives with a mental disorder. *Aust N Z J Psychiatry* 2010;44:929-37.
8. Amir E. New developments for family caregivers in the context of mental health in Canada. *Can J Commun Ment Health* 2015;34:143-9.
9. Berk L, Jorm AF, Kelly CM, Dodd S, Berk M. Development of guidelines for caregivers of people with bipolar disorder: A Delphi expert consensus study. *Bipolar Disord* 2011;13:556-70.
10. Papastavrou E, Charalambous A, Tsangari H, Karayiannis G. The cost of caring: The relative with schizophrenia. *Scand J Caring Sci* 2010;24:817-23.
11. Möller-Leimkühler AM, Wiesheu A. Caregiver burden in chronic mental illness: The role of patient and caregiver characteristics. *Eur Arch Psychiatry Clin Neurosci* 2012;262:157-66.
12. von Kardorff E, Soltaninejad A, Kamali M, Eslami Shahrbabaki M. Family caregiver burden in mental illnesses: The case of affective disorders and schizophrenia – A qualitative exploratory study. *Nord J Psychiatry* 2016;70:248-54.
13. Messer T, Lammers G, Müller-Siecheneder F, Schmidt RF, Latifi S. Substance abuse in patients with bipolar disorder: A systematic review and meta-analysis. *Psychiatry Res* 2017;253:338-50.
14. Aghakhani N, Lopez V, Cleary M. Experiences and perceived social support among Iranian men on methadone maintenance therapy: A qualitative study. *Issues Ment Health Nurs* 2017;38:692-7.
15. Wainwright LD, Glentworth D, Haddock G, Bentley R, Lobban F. What do relatives experience when supporting someone in early psychosis? *Psychol Psychother* 2015;88:105-19.
16. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105-12.
17. Lee Mortensen G, Vinberg M, Lee Mortensen S, Balslev Jørgensen M, Eberhard J. Bipolar patients' quality of life in mixed states: A preliminary qualitative study. *Psychopathology* 2015;48:192-201.
18. Hajda M, Prasko J, Latalova K, Hruby R, Ociskova M, Holubova M, et al. Unmet needs of bipolar disorder patients. *Neuropsychiatr Dis Treat* 2016;12:1561-70.

19. Arun R, Inbakamal S, Tharyan A, Premkumar PS. Spousal caregiver burden and its relation with disability in schizophrenia. *Indian J Psychol Med* 2018;40:22-8.
20. Sajatovic M, Levin J, Fuentes-Casiano E, Cassidy KA, Tatsuoka C, Jenkins JH. Illness experience and reasons for nonadherence among individuals with bipolar disorder who are poorly adherent with medication. *Compr Psychiatry* 2011;52:280-7.
21. Arias F, Szerman N, Vega P, Mesías B, Basurte I, Rentero D. Bipolar disorder and substance use disorders. Madrid study on the prevalence of dual disorders/pathology. *Adicciones* 2017;29:186-94.
22. Blixen C, Perzynski AT, Bukach A, Howland M, Sajatovic M. Patients' perceptions of barriers to self-managing bipolar disorder: A qualitative study. *Int J Soc Psychiatry* 2016;62:635-44.
23. Granek L, Danan D, Bersudsky Y, Osher Y. Living with bipolar disorder: The impact on patients, spouses, and their marital relationship. *Bipolar Disord* 2016;18:192-9.
24. Lal S, Malla A, Marandola G, Thériault J, Tibbo P, Manchanda R, et al. "Worried about relapse": Family members' experiences and perspectives of relapse in first-episode psychosis. *Early Interv Psychiatry* 2017;11:1-6.
25. Bauer R, Spiessl H, Helmbrecht MJ. Burden, reward, and coping of adult offspring of patients with depression and bipolar disorder. *Int J Bipolar Disord* 2015;3:2.
26. Omranifard V, Yari A, Kheirabadi GR, Rafizadeh M, Maracy MR, Sadri S. Effect of needsassessmentbased psycho education for families of patients with schizophrenia on quality of life of patients and their families: A controlled study. *J Educ Health Promot* 2014;3:125.
27. Kumar P, Sharma N, Ghai S, Grover S. Perception about marriage among caregivers of patients with schizophrenia and bipolar disorder. *Indian J Psychol Med* 2019;41:440-7.
28. Taghva A, Farsi Z, Javanmard Y, Atashi A, Hajebi A, Noorbala AA. Strategies to reduce the stigma toward people with mental disorders in Iran: Stakeholders' perspectives. *BMC Psychiatry* 2017;17:17.
29. Bhugra D, Sartorius N, Fiorillo A, Evans-Lacko S, Ventriglio A, Hermans MH, et al. EPA guidance on how to improve the image of psychiatry and of the psychiatrist. *Eur Psychiatry* 2015;30:423-30.
30. Saberi Zafarghandi M. Some of the challenges of mental health and addiction in Iran. *Iran J Psychiatry Clin Psycho* 2011;17:157-61.
31. Davis M, Balasubramanian BA, Waller E, Miller BF, Green LA, Cohen DJ. Integrating behavioral and physical health care in the real world: Early lessons from advancing care together. *J Am Board Fam Med* 2013;26:588-602.
32. Sajadi S, Raheb G, Maarefvand M, Alhosseini KA. Family problems associated with conduct disorder perceived by patients, families and professionals. *J Educ Health Promot* 2020;9:184.
33. Bauer R, Gottfriedsen GU, Binder H, Dobmeier M, Cording C, Hajak G, et al. Burden of caregivers of patients with bipolar affective disorders. *Am J Orthopsychiatry* 2011;81:139-48.
34. Lobban F, Taylor K, Murray C, Jones S. Bipolar disorder is a two-edged sword: A qualitative study to understand the positive edge. *J Affect Disord* 2012;141:204-12.
35. Chatzidamianos G, Lobban F, Jones S. A qualitative analysis of relatives', health professionals' and service users' views on the involvement in care of relatives in Bipolar Disorder. *BMC Psychiatry* 2015;15:228.
36. Maskill V, Crowe M, Luty S, Joyce P. Two sides of the same coin: Caring for a person with bipolar disorder. *J Psychiatr Ment Health Nurs* 2010;17:535-42.
37. Tamizi Z, Fallahi-Khoshknab M, Dalvandi A, Mohammadi-Shahboulaghi F, Mohammadi E, Bakhshi E. Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study. *J Educ Health Promot* 2020;9:12.
38. Tranvåg O, Kristoffersen K. Experience of being the spouse/cohabitant of a person with bipolar affective disorder: A cumulative process over time. *Scand J Caring Sci* 2008;22:5-18.
39. Rowe J. Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *J Psychiatr Ment Health Nurs* 2012;19:70-82.
40. Zhou Y, Rosenheck R, Mohamed S, Ou Y, Ning Y, He H. Comparison of burden among family members of patients diagnosed with schizophrenia and bipolar disorder in a large acute psychiatric hospital in China. *BMC Psychiatry* 2016;16:283.