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Care experiences and challenges of inpatients' companions in Iran's health care context: A qualitative study

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ABSTRACT

Among the clients of nursing services, family members, as patient companions, serve as both caregiver and care receiver, such that specialized care is delivered by nurses and primary care is delegated to the patient companion. Hence, care experiences of all patient companions are not the same. The aim of this study is to investigate the care experiences of inpatients' companions at hospital. This work is a qualitative study conducted according to epistemological methodology. The participants were 13 patient companions who were selected according to purposive sampling. Data were gathered throughout in-depth, unstructured interviews and then analyzed according to Colaizzi method. Overall, six themes were generated in this study, consisting of caregiver's burnout, burden of care, resistance against tension, caregiver's care function, needs, and organizational barriers. The findings demonstrated that the patients' companions are faced with numerous stressful factors during their patients' hospital stay, and hospitals' negligence of the companions' information and support needs to deal with complexities of care has led to increased burden of care among the companions. Meanwhile, the companions' dissatisfaction with health care delivery may bring about adverse outcomes. Therefore, hospital authorities should pay special attention to the status of patient companions as informal the caregivers and support sources of patients.

Key words: Experience, Patient companion, Care, Epistemiology

INTRODUCTION

Care is considered to be an important constituent of nursing by majority of nurses and nurse researchers and is equivalent to nursing practice. Care is a basic need of human and the underlying constituent of nursing profession [1].

Anyone can be a caregiver (companion). Caregiver may be a family member, friend, or other community members. They can care for their patients sometimes in the short term and occasionally for a long time. However, caregiving is mostly regular, continuous, and unpaid. Although caregiving and support can be positive experiences, caregiver's role is likely to become challenging and demanding[2]. Therefore, among the clients of nursing services, family is considered to be both a caregiving and a care-receiving unit [3]. The presence of family members at hospitals to serve as informal caregivers has entered health literature since 1980 [4]. In the USA, over 22 million people play the role of informal caregiver [5]. Seventy five percent of these people are women [6]. Caregiving is defined differently in different cultures. In Iran, patients are cared for in houses and hospitals mainly by their family members because

of the strength of family status [7]. In Iran, families have reported lack of nursing staff in different categories to be the main reason for caring for patients by family members at hospitals [8], such that specialized care is delivered by physicians, nurses, and social workers [9] and primary care is delegated to patient companions. As informal caregivers, family members assist the patients in doing daily routines including nutrition, movement, and taking medications [10].

In many African countries, such as Malawi, that suffer from inadequate staff in health care system, in some hospitals, patients' family members are hired to deliver primary care to the patients including nutrition, basin fetching, medication monitoring, prevention of falling, supporting, caring for wound, and bathing [11]. Patients' companions tend to spend a great deal of time at hospitals as their patients stay in the hospital [8]. Hospitalization of a patient causes certain problems for his/her family which interfere with their supportive role [12]. In the recent years, the experts of health care have acknowledged that the relationship and interaction between treatment team and patient's family at hospital is a necessary constituent of primary care [13]. However, it is noteworthy that negligence of the needs of patients' families and delegation of excessive burden of care to these families can lead to certain side effects such as feeling incapable and inefficient, stress, anxiety, depression, fatigue, and feeling lonely in caring for the patient [8]. Currently, most of the needs of patients' families in hospitals remain unmet. This is a complicated issue worldwide according to the findings of the studies conducted in Europe, Canada, and the USA [14,15].

Hospitals focus mainly on patients' health and may pay inadequate attention to the patients' companions. In other words, paying attention to the patients' companions causes satisfaction and furthered comfort among them; in contrast, paying no attention to the companions and treating them disrespectfully, unfairly, and discriminatorily in hospitals causes dissatisfaction and furthered anxiety in them [16]. In addition, all the health care services deliverers who deal with companions have acknowledged that these people need emotional support, understanding, kindness, honesty, and timely and comprehensible information exchange [17].

This causes relief of stress and development of abilities to take part in caring for the patient, which in turn causes facilitation of the patient's recovery [18]. In the current health care system, the caregivers merely play the role of signers in making treatment-related decisions [19], which causes anxiety and feelings of being invisible and disregarded in them. Even, the caregivers may feel that their presence at hospital is unpleasant to hospital staff [20], which can be due to lack of understanding and disregarding the companions' caring role [21]. The care experiences of family caregivers are different in different families [22]. Hospitalization of a patient is considered a big challenge for his/her companions. In Iran's health care system, the status of patient companion has not yet been defined and the inpatients' companions have several care experiences and difficulties. Therefore, it can be argued that the knowledge about the experiences of the patients' companions is particularly important and necessary to help them persist in caring for the patients.

Regarding the significance and, as far as we searched, a need for qualitative and quantitative research on this issue, and since the findings of the studies conducted in other countries cannot be generalized to Iran's healthcare system because of being obtained in different structural and cultural conditions, then we conducted this study to investigate the care experiences of inpatients' companions at a hospital in Iran.

MATERIALS AND METHODS

This qualitative study was conducted according to epistemological methodology to explore the care experiences of the inpatients' companions in Imam Ali (*PBUH*) Hospital of Andimeshk County affiliated with Jundishapur Ahvaz University of Medical Sciences in 2015-2016. Epistemology is a way of thinking about *what is the meaning of people's experiences?* and *how are these experiences?* and is closely associated with hermeneutics. This approach seeks to use real-life experiences as an instrument for better understanding of people's experiences from social, cultural, and political perspectives.

The database of this study was the inpatients' companions who were the main caregivers of these patients and were enrolled into this study. The information setting was Imam Ali (*PBUH*) Hospital of Andimeshk County. The inclusion criteria were: being the companions of the inpatients' at the hospital under study and providing informed consent to participate in the study and talk about their care experiences. Moreover, to observe ethical considerations during the study, the measures below were taken:

1. The researcher gave necessary and sufficient explanations about himself and the study procedure and purposes to the participants;
2. The researcher did his best to observe the rights of the participants throughout the study and therefore asked them to provide informed consent to participate in the study if they volunteered to do so. Besides that, the participants were told that they can withdraw from the study at any time.
3. The participants were ensured

that the data on them would be dealt with as confidential and the findings would be published as anonymous. For this reason, a number was assigned to each participant in data transcription step to refer to them anonymously throughout data analysis and findings reporting; 4. At all steps of the study, the principles of honesty, confidentiality, accuracy, and faithfulness were observed and at the completion of the study, the participants were informed about the findings; 5. Moreover, the Ethics Committee of the Isfahan University of Medical Sciences approved the study protocol and the Head of the Health Care Network of Andimeshk County provided the formal permission to conduct this study in the hospital determined to be the study setting.

In this study, the researcher achieved data saturation through conducting in-depth and unstructured interviews, lasting for 40-60 minutes on average, with 13 inpatient caregivers (seven women and six men) with mean age of 31 years at the hospital. The interview started with a general question about the care experiences of the caregivers. Before the interview, the interviewees provided the permission to record the interviews and agreed to be interviewed in the room that had been determined for interviewing.

All interviews were completely recorded on cassette and transcribed word by word by the researcher after several times of listening. Then, the transcripts were compared with the recorded data on the cassette. The participants were encoded according to the time of the interview with them. First, an interview was analyzed and then the next one was conducted.

The approaches to investigate accuracy and authenticity of data in qualitative research are different from those in quantitative research [23]. After analyzing each interview, the researcher referred to the participants to investigate the accuracy of the data and, if necessary, make changes [24]. Throughout the study, the researcher sought to avoid any prejudgements about the phenomenon under study before and after the interview. Seven-step Colaizzi method was adopted to analyze the data. First, the contents of the interviews were studied several times to comprehend them so as to sympathize with the participants and then the primary codes were generated.

Afterwards, the codes were categorized. To confirm the authenticity of the categories, the initial protocols were referred to. Next, the results were combined to describe the phenomenon under study and revised to generate clear and unambiguous concepts. Finally, the results were given to the participants to give comments on their authenticity. The results were considered to be accurate if the participants confirmed their accuracy.

Findings

Overall, 234 codes, 14 subthemes, and six themes were generated from the interviews. The themes were caregiver's burnout, burden of care, resistance against tension, needs, caregiver's care function, and organizational barriers.

Table 1: Themes and subthemes of inpatient companions' care experiences at hospital

Main themes	Sub concepts
caregiver's burnout	Persistent tension and behavioral disorganization and fatigue
	Caregiver's burnout
	Caregiver's physical exhaustion
Burden of care	Caregiver's dealing with care complexities
	Change in caregiver's roles and responsibilities
	Forced sacrifice
Resistance against tension	Feelings and emotions
	Beliefs
caregiver's care function	Physical support of the patient
	psychological support of the patient
Needs	Need for support and sympathy
	Need for knowledge
Organizational barriers	Medication- and treatment-related problems
	Hospital negligence

Caregiver's burnout

A theme generated from the participants' statements was caregiver's burnout in dealing with a family member's acquisition of disease and assuming the role of caregiver and companion for him/her at hospital. This theme consisted of the subthemes below:

Persistent tension, behavioral disorganization, and fatigue: The participants talked of behavioral disorganization in dealing with tension and fatigue. The findings demonstrated that the companions responded to hospitalization of their patients differently. The responses, evident in their behaviour, included worry, anxiety, confusion, brainstorming, shock, and frustration.

The participant no. 1 said: "...Mainly because I didn't know what's wrong with him, I got anxious and stressful. I lost my self-esteem at that moment. [Because of] being worried about [the problem] that of course my patient is critically ill, or he could no longer live a normal life and we should always look after his health, I felt disappointed..."

Caregiver's burnout: Caregiver's burnout was one of the subthemes generated from the participants' experiences. The caregivers developed burnout as a nervous reaction associated with the patients' bad temper, stubbornness, and depression and exhibited as lowered tolerance and subsequently anger.

The participant no. 6 said: "Since my patient is old and crippled, I have to do all his works and spend much time caring for him. When I go to home from hospital, I'm so much tired that I get impatient. [It] has also influenced my life, I have to hurry always to provide ideal circumstances for my children and they don't think that they are not paid attention. At the same time, I'm acquiring nervous problems..."

Caregiver's physical exhaustion: Some of the companions reported to acquire certain complications including low back pain, leg spasm and pain, headache, insomnia, and caretaking-induced physical weakness.

The participant no. 9 said: "...well, when you have a loved one hospitalized, in addition to being under mental pressure, your body is also affected. You got anorexia, insomnia. You acquire so much physical weakness and burnout so that you feel that you yourself also need treatment"

Burden of care

Burden of care, referred to as care pressure in some references, is one of the negative outcomes of caretaking. The care pressure, as the source of stress, threatens the caregivers' health domains seriously. Burden of care consisted of the subthemes below:

Caregiver's dealing with care complexities: Dealing with care complexities was one of the experiences of the caregivers. The caregivers talked of becoming engaged in caretaking and attending hospital, caring for two inpatients simultaneously, the associated influence on life, and assuming a heavy, stressful responsibility.

The participant no. 2 said: "... my child's hospital stay has affected my whole family's life really. [Until] now, my husband hasn't gone to work for a week, I have a four-year-old girl that has become displaced. We had to take her to her grandmother's home. She also caught a cold [and] should take medication. I'm worried about her. I'm always preoccupied. Now, what are my girl and husband doing? ..."

Change in caregiver's roles and responsibilities: The inpatients' companions remarked that when they were present and assumed the role of the inpatient companion in the hospital in addition to other roles, they experienced changes in previous roles and responsibilities. In this regard, the participant no. 8 replied: "... I can no longer think about myself at all. Even, I was faced with problem in my job. I have to do my paperwork at night instead of sleeping. From morning to sunset, I'm in the hospital to care for my mother ..."

Forced sacrifice: Regarding being engaged in the bitter process of caring for patients, many of the participants reported that through assuming the tiring role of caring for the patients, they had to abandon most of their personal affairs and dedicated themselves to the patients. The participant no. 4 said: "... with these conditions ongoing, I feel I'm not for myself. In the hospital, as if I'm my father's guardian. Although I'm sad, I have to keep my looks ..."

Resistance against tension

Another theme generated in this study was resistance against tension, consisting of two subthemes: Caregiver's beliefs and feelings and emotions.

Feelings and emotions: Feeling to be inefficient and burden, having dichotomous feelings, being worried about other companions' ongoing conditions in the hospital were the companions' emotional responses. The participant no. 9 said: "... we always sit behind the ICU door for some hours and really this is agonizing for a companion whose loved one is on that side of the door. As if you're in limbo. However, you feel close to him and get comfortable, but there is no way to see him and indeed, there is limitation ..."

Beliefs: Despite hard and stressful conditions due to the family member's disease, presence at the hospital, and the associated difficulties, the companions become hopeful and feel mentally comfortable relying on their beliefs and a more solid relationship with God. The participant no. 9 said: "... one night we held Salavat termination ceremony for him at home. When after the ceremony we came to the hospital with his son to visit him and his son called him, he blinked quickly and for a moment opened his eye. I really feel that my prayer has been answered ..."

Caregiver's care function

Care function refers to the caregiver's ability to comply with or adapt to the changes caused throughout the patient's hospital stay to resolve the patient's problems throughout the disease course. The caregivers' care function in hospital consisted of two subthemes: physical support of the patient and psychological support of the patient. The companions assisted the patients in doing all of daily routines and took care of them.

Physical support of the patient: The participants reported to experience caretaking of the patients, assisting the personnel in changing dressing, feeding the patient, aiding the patients in physiotherapy and rehabilitation, and other care. The participant no. 5 said: *"... I, throughout these 16 days of my presence at the hospital, myself bathe my mother on the bed, diaper her off, empty her urine bags, feed her, and aid her in physiotherapy. I try to satisfy all her requests so that she is not mentally shattered ..."*.

Psychological support of the patient: When a patient stays in hospital, it is stressful for him/her to wait for recovery and the period following the acute stage of the disease. In addition to supporting their patients physically, the companions provided psychological support for them. In this regard, the participant no. 5 reported: *"... this condition has also affected my mother, her mood has been lowered, and she thinks she has disturbed my life. I try to satisfy all of my mother's requests so that she is not mentally shattered. I keep myself glad and behave in a manner to make her mood better, as well ..."*.

Needs

Needs assessment is a multidimensional subject which is related to certain concepts such as planning for and foreseeing purposes and destinations. Having knowledge about the needs is a main criterion to deliver different services and to implement diverse plans to further well-being and comfort in target populations. Hence, the subthemes of the need for knowledge and the need for support and sympathy were generated.

Need for support and sympathy: The participants talked of the need for mental and psychological support, the treatment team's sympathy, and social and spiritual support to cope with care-related problems and to reduce care-induced tensions.

The participant no. 4 said: *"... I'm under much pressure. In the hospital, really one of the servants, when on shift, understands me. He assists me much. Really he gives me positive energy. I don't feel alone any more..."*

Need for knowledge: Having knowledge and obtaining information about the process of recovery contribute significantly to reducing the companions' stress. The participants complained about having no appropriate information on the disease diagnosis, the recovery process, and the methods of appropriate services delivery. The participant no. 3 said: *"... when doctor comes to visit, he doesn't spend much time, doesn't let me ask my questions about my child's recovery process. Indeed, I don't know at present, which stage of recovery process is my child in? They told me he's got pneumonia. I was scared. What does it mean? Lest my child gets a hard-to-treat disease. I got confused. Lest I lose him. Until a nurse explained to me and showed me a brochure on my child's disease, I was relieved ..."*

Organizational barriers

Undoubtedly, any organizations seek ultimately to gain success. The realization rate of this process can be measured by certain indices such as flexibility, solidarity, speed, and innovation. In this study, the organizational barriers were divided into two subthemes: medication- and treatment-related problems and hospital negligence.

Medication-and treatment related problems: The participant no. 8 said: *"... To provide a series of drugs that are really expensive, I have to provide [from] free [market]..."*

The participant no. 5 said: *"... Just, after 12 hours [waiting], they told us they didn't have facilities for surgery of the mother and the public. They should be sent to the province capital. After a great deal of time waiting, we were sent to another hospital. Constantly, they sent us from one ward of the hospital to another. No one was accountable to us. As if they even didn't know what they are held accountable for ..."*

Hospital negligence: Hospital is considered a pivotal and main healthcare center in health system and healthcare services are mainly delivered by hospitals, particularly in Iran. The companions reported that the hospital authorities ignored them.

The participant no. 4 said: *"... they told me that at present you should not feed your father such that when taking food for other patients, [he says] I'm no longer given food, as if I don't exist at all, no facility is available for the companions. I have to sit on a hard chair beside my patient..."*

DISCUSSION

The most significant challenge that the inpatients' companions reported to experience in this study was the tension and stress due to dealing with different care-related issues and dimensions such as burden of care, caregiver's care function, caregiver's burnout, organizational barriers, and resistance against tension. The caregivers made efforts to cope with the disease of the family member relying on individual beliefs, emotions, and feelings, and needed knowledge, support, and sympathy of the treatment team to reduce behavioral disorganization in dealing with such tension. However, the hospital's negligence of the companions' needs intensified their burden of care.

Care-induced burnout is an assimilating condition that may severely affect the caregiver's perception of physical health and life satisfaction [25]. Assuming the caregiving role and being the inpatient's companion caused many problems for the caregivers. Lavdanitn et al [26] argued that family, as the patient's companions, usually spend a great deal of time in hospital during the relative's hospital stay. Therefore, the caregivers occasionally experience intrinsic tensions due to a change and an obvious tension is caused in the family members' behavior such that if the family's needs are left unidentified and unsatisfied, they cause distress. The participants in this study reported to exhibit burnout as anger, psychasthenia, and depression. Similarly, Chang et al [27] found that the caregivers who spent more hours caring for their patients tolerated greater care pressure and had lower levels of mental health. Epsten-lubow et al [28] demonstrated that the inpatients' caregivers were more predisposed to depression compared to outpatients' companions. Moreover, a number of the companions reported to acquire certain complications such as low back pain, leg spasm and pain, headache, insomnia, and care-induced physical weakness while they were caring for their patients at the hospital. Kukri et al study [29] demonstrated that 24% of family members acquired physical symptoms such as headache, hypertension, gastric pain, anorexia, weakness, and fatigue following hospitalization of one of their family members.

Haley study [30] demonstrated that over 60% of first-degree relatives are the wives and children of the patients. This population has been reported to suffer from information, economic, social-individual, and mental difficulties but they complained mainly about physical problems [30]. Physical symptoms can be muscle pain and mental symptoms include stress, worry, or depressive mood disorder [31].

In addition to talking of care-induced burnout, the companions pointed out the burden of care due to assuming the role of companion. The burden of care has been referred to as care pressure in some references. Indeed, the burden of care is mental, physical, and social distress which develops in the caregiver due to caretaking of the patient. Bugg et al [32] conducted a study to investigate the levels of stress experienced by the caregivers of patients with stroke within the first months after incidence of stroke in Scotland, which demonstrated that 37% of the caregivers experienced great care pressure six months after stroke. The burden of care was one of the negative outcomes for the caregivers. Hospitalization of a patient caused his/her companions to be faced with the care complexities and the changes in their roles and responsibilities. In this regard, Esbensen and Thomé study [33] demonstrated that most of the informal family caregivers of patients with chronic disease, as a family member, felt that they lost their individual freedom due to holding themselves accountable to the patients. In Katz et al research [34], different figures were reported for turnover, daily engagement, delayed going to work, and early retirement among the caregivers of chronic disease patients. In addition, Kukri et al [29] reported changes in the life of family members while one of them stayed in hospital. Furthermore, most of the participants in this study reported to sacrifice and ignore themselves for the progression of the patient's recovery process. In reality, they had to show altruism and sacrifice themselves. Similarly, Maruiti et al study [35] showed that families feel tired of caring for their ill family member, ignore their own rest-related and nutritional needs, and *only* think of support of their ill family member.

In this study, the companions were able to manage the tension due to the patient's hospital stay more efficiently relying on their beliefs, feelings, and emotions. Consistently, Mauk et al [36] argued that since religion and spirituality are considered one of the important human dimensions from holistic care perspective, which contributes significantly to feeling healthy and enjoying well-being, and religious beliefs affect the health levels of the patient and his/her family members as well as self-care behaviors, then having knowledge about and recognizing religious beliefs is important and ethical response to this knowledge requires understanding of spiritual-religious concepts as a constituent of the health system interventions. Chrisin et al [37] remarked that people with religious beliefs are more resistant in facing stresses and emotional problems. Inevitably, people respond to life events and circumstances emotionally. Indeed, emotional state is an instant experience of a specific emotion such as anger and fear that is induced in response to circumstances and situations [38]. Emotion contributes both positively and negatively to how it is that people do learn, recall, think, evaluate, and take risk [39]. An investigation of emotions effect on risk taking concluded that emotions can lead to different risk taking in processing information for decision making in different people [40].

Another aspect of the participants' experiences in this study was care function, such that they supported their patients physically and psychologically. Among formal caregivers, family members are most important for caretaking of the patient. In this regard, Qidwai *et al* [41] argued that family members can well emotionally help dependent people do their daily routines such as cleaning, walking, and eating (nutrition). Besides that, Mokhber *et al* [42] stated that many patients need to be constantly cared for. The caregivers are both emotionally (mentally) and physically interconnected to the patients and hence play a very important part in the recovery process of the patients.

To care for the patients appropriately, the companions needed knowledge, support, and sympathy which were not provided by the personnel satisfactorily. Moretta *et al* study (2014) confirmed the caregivers' urgent need for information and support, and the caregivers' informal feedback showed that the educative and informative programs delivered to them were perceived as useful [43]. Mouini *et al* study [44] demonstrated that families considered education and support to be their main requirements. Furthermore, Ramsey study [45] reported that the better the patients' families are understood by the ward personnel, the more satisfied they are.

In this study, organizational barriers was one of the generated themes that was categorized into medication- and treatment-related difficulties and hospital negligence. Nowadays, the quality of services has been increasing in importance, and can be considered an essential strategy that assists organizations in gaining optimal outcomes in a competitive market and is adequately profitable in the long-term. Improving the quality of services is a big challenge facing serving agencies to satisfy the expectations and gain the satisfaction of their customers [46]. Astedt-Kurki *et al* [47] have reported that in the recent years, modern hospital technologies have not considered support of the patients and families are not adequately supported [47]. Moreover, Astedt Kurki *et al* [48] reported that 45% of the families needed nurses' assistance and 3.1% of them did physicians' assistance in caring for the inpatients. The findings indicated that this need was not appropriately satisfied and even many of the responsibilities were imposed on the families. It should be noted that it is necessary to support family caregivers, to provide them with physical comfort, and to consider their primary needs. Although psychosocial and physical environments are considered separate, they exert reciprocal effects on each other [49]. The buildings of healthcare centers are not usually designed according to the families' needs and the hospitals' accommodations such as furniture are not comparable to the houses' [47]. Therefore, hospitals can take measures to gain organizational success in competitive arenas through detecting their strengths and weaknesses precisely [50]. Altogether, the patients' companions feel that their needs remain unsatisfied in most cases and lack of propitious response to the needs is due to lack of understanding, unsatisfactory examination of situation, and negligence of the value of the companions' caring role. It can therefore be argued that the companions are a very reliable source of information to evaluate the quality of care delivered in the hospitals. However, the companions' dissatisfaction with the healthcare services delivered leads to adverse outcomes. Hence, hospital authorities should pay special attention to the patients' companions as the informal caregivers and support sources of the patients.

CONCLUSION

The findings of this study confirm that the patient's companion is considered to be an informal system and support source in delivering primary care, either mandatorily or voluntarily, to the patient during the whole disease course in the hospital. Notably, the patients' companions spend a great deal of time being present at hospital to care for the patient physically and psychologically. This is a stressful, tiring, and damaging experience and causes burden of care to exhibit as the changes in the caregiver's roles and responsibilities throughout struggle with care complexities. As a result, the patient's companion is forced to ignore one's own needs, sacrifice oneself, and show altruism for the patient's recovery.

Therefore, hospitals' negligence of the companions' needs, medication- and treatment-related problems, and lack of social support and appropriate training cause physical exhaustion and burnout in the companions. The companions are susceptible to these stresses and exhibit a series of distractions, such as anger, frustration, fear, and anxiety, in dealing with tensions. Therefore, the feelings, emotions, beliefs, and needs of the inpatients' companions should be figured out to assist them through appropriate planning and interventions such as holding training sessions according to their needs and providing them with appropriate knowledge, familiarizing them with available sources of social support, especially spiritual domain and instrumental support as physical or respite assistance through training assistants to care for the patients, providing necessary facilities such as accommodations, including construction of caregiver house in the hospitals, and paying attention to them as the participants in delivery of healthcare services to help them cope with the changes induced by a family member's hospital stay .

A limitation of this study can be lack of addressing individual differences and mental preoccupations of the participants throughout the interviews that might affect their responses.

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