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Integrative Power of Illness: A Qualitative Study of Cancer Patients

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Abstract

Our aim of this study was to explore the constructions of cancer patients about their everyday interactions using an interpretive-qualitative approach. We wanted to know how cancer patients understand their condition and the challenges they face in family and everyday relationships. Accordingly, a basic qualitative research method was used, and interviews were conducted with 21 cancer patients and their caregivers. Participants were selected through the purposeful sampling in Ahvaz City, Iran. The collected data were firstly transcribed and then analyzed by the grounded theory coding analysis. The findings were represented in five main categories included: pressure on relatives, the limitation of relationships, helpful awareness, personal development, and the integrative diagnosis. According to the findings, cancer patients experience many fluctuations to adapt to the disease. During the interaction with family members and other people, patient experiences change in the actions and daily routine while, at the individual and family level, they experienced the limitation of relationships.

Keywords

cancer, social relationships, interactions, patient's family, integration, qualitative method

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Integrative Power of Illness: A Qualitative Study of Cancer Patients

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Our aim of this study was to explore the constructions of cancer patients about their everyday interactions using an interpretive-qualitative approach. We wanted to know how cancer patients understand their condition and the challenges they face in family and everyday relationships. Accordingly, a basic qualitative research method was used, and interviews were conducted with 21 cancer patients and their caregivers. Participants were selected through the purposeful sampling in Ahvaz City, Iran. The collected data were firstly transcribed and then analyzed by the grounded theory coding analysis. The findings were represented in five main categories included: pressure on relatives, the limitation of relationships, helpful awareness, personal development, and the integrative diagnosis. According to the findings, cancer patients experience many fluctuations to adapt to the disease. During the interaction with family members and other people, patient experiences change in the actions and daily routine while, at the individual and family level, they experienced the limitation of relationships.

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Introduction

Cancer as a major general health problem has involved millions of people around the world. The cancer diagnosis and treatment process, such chemotherapy has physical and psychological pressures on individuals. On the other hand, the diagnosis and treatment process can affect social roles and functions, family activities and relations. A large literature now attests to the fact that cancer is a stressful experience that may affect multiple aspects of psychological adjustment, including emotional and social well-being, body image and physical functioning (Thornton & Perez, 2007). Cancer may affect role patterns and responsibilities, social activities, and the general emotional equilibrium (Manne, 1998). Imposed pressure is effective on patients and their caregivers economically, socially, physically, and psychologically and sometimes causes family crisis (Weitzner, 1999). It also affects the relationship between the patient and his family or at least changes their routine daily life as, they try to deal with this illness and react to the threats (Awadallah, 2006). The current study seeks to gain a deeper understanding of this field in the continuation of the existing literature. For this purpose, we have targeted the discovery of communication mechanisms without the limitations of other studies such as cancer, gender, focus on appearance, etc., and we have tried to achieve a socio-relational understanding. Research of this type, which also has a qualitative aspect, has been seen much less. This study investigates the history of patients from the beginning of the disease to the stages of treatment and recovery. In this way, people involved in disease, such as the patient's family and treatment staff can better regulate their behavior with the patient according to what is going on in different stages of the disease. In fact,

understanding what happens at each stage of the disease is effective in better organizing the situation of patients and those around them.

Review of Literature

Several studies are available about cancer patients' lives and relationships. By studying the existing background, a comparison can be made between them and the current study. Heidari (2009) found that family is the main source of emotional support of patients. Although it has also shown its dimensions, it has done so with a quantitative research method, limiting it to five specific sources. In the current study, however, in addition to family relationships, data collection is also open to the opportunity to explore lesser-known groups. Fasihiye-Herandi et al.'s (2011) findings showed long-standing problems in social-emotional dimension and lack of enough psychological, economic and social support of them. They conducted a qualitative study on cancer however, and contrary to our research, it is limited to women with breast cancer. Rajeeian and Godarzi (2016) concluded that access to social supports has effects on adaptation and resistance to disease. They concluded that social support is effective in adaptation and disease resistance.

Arshee et al. (2015) reported positive and meaningful relation between care-created pressure and general function. The scope of their study is limited to the families of children with cancer and is methodologically different from the present study. Clarke and Fletcher (2003) found that parents must train the child, and on the other hand they don't have enough knowledge and skills. They focused their study on the relationship between parents and children with cancer. Mackenzie (2014) examined the mechanisms of regulation and management of conditions different from this study in relation to mothers with a specific type of cancer. Senden et al. (2015) studied life experience of old cancer patients and evaluated the interaction between family caregivers and the way they confront with cancer diagnosis and treatment, while the current study has consistently followed this issue from the onset and diagnosis of the disease to the stages of recovery and treatment. Wittenberg et al. (2017) reported that family-centered cancer care givers require the notice of communication challenges caused due to the family caregivers to help nurses to match with caregivers. This study is very close to our research; however, its focus is more on practical suggestions for nurses. Our study has tried to promote new forms of communication mechanisms without emphasis on a specific group. The results of Ullgren and colleagues (2018) showed that family caregivers are like the affairs of health professionals at home and provide supports, motivation, and social activities along with health care. Xiaoyun and Fenglan (2020) presented a quantitative study and focused on psychological aspects that easily reveal their differences with this study.

The diagnosis of cancer and its treatment has a major impact on both patients and their family caregivers (Kayser et al., 2007). Cancer affects the patient and, the patient's partner, children, extended family, friends, and entire network of support. However, these effects are not sudden and do not happen suddenly. The patient and relatives must constantly adapt to new conditions. It is a process that is unpredictable and constantly changing.

Understanding the impact of cancer on relationships is important because cancer occurs in an interpersonal context (Thornton & Perez, 2007). The diagnosis and treatment of cancer affects not only the patient, but also their significant others, including family and friends (Manne, 1998; Thornton et al., 2004). Interpersonal relationships play a key role in how people adjust to a life crisis (Wimberly et al., 2008). Interpersonal relationships are important to examine because the cancer survivor's social relationships play a crucial role in their social and psychological adjustment to cancer. Since the family is the first source of care and support for a member with the disease, the type of family attitude towards the disease and its disorders

has a special impact on patient care (Friðriksdóttir et al., 2011). Also, family caregivers have a positive effect on their patient adjustment and play a pivotal role in managing various aspects of patient care (Lim et al., 2017).

Data acquired via various methodologies suggest that many people diagnosed with cancer report high levels of relationship quality over the course of survivorship (Thornton & Perez, 2007). Most of what we know about the interpersonal processes involved in adjustment to cancer is restricted to the dyadic relationship. More systematic research assessing the impact of cancer on relationships with other family members and friends is needed to clarify

how interpersonal processes are affected by the cancer experience. In the current study, we try to find the meanings and social reactions of patients and their families. Also, we study the consequences of cancer in the patients' life by focusing on their interpretation and experience. The questions that we followed were: How does a cancer diagnosis affect interpersonal relationships as perceived by cancer patients? How they respond to the situation?

Self- of the Researchers

We have been interested and have practiced qualitative research methods for many years. Afrasiabi has taught qualitative research methods for 10 years at the Department of Sociology in Yazd University by focusing on grounded theory and basic (generic) qualitative research methods. One of us (Kasra) lived with cancer for years and won the battle in the first year of her master of Sociology program. By starting her masters at Yazd University, her interaction and personal involvement with patients allowed to us to know more about their feelings and challenges. After some student-teacher dialogues, we designed a qualitative study that now we are writing about.

Methods

Method

The current study was conducted using the basic (generic) qualitative research method. Qualitative researchers conducting a basic qualitative study would be interested in (1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences (Merriam, 2016). The overall purpose is to understand how people make sense of their lives and their experiences.

Participants

Semi-structured interviews were conducted with 21 male and female cancer patients and their caregivers, including 12 women, four men, and five of the patients' caregivers. The interview was conducted among patients who had undergone a major part of their treatment in Ahwaz (Iran). The patients were between 20-65 years old and the caregivers, who were all women, where between 19 and 42. Participants were selected by a purposive sampling method. Among different types of purposive sampling, the snowball sampling method was utilized. In the first instance, some of the participants were selected by means of related networks or according to their familiarity and previous relationship with Kasra. Then, each of them led the researcher to other patients and their families and helped him to communicate with them and form new interviews.

Ethics

The interviews were conducted taking participants consent. Written and oral permission was obtained from them to participate in the study. They were also notified when their voices were recorded, and they were also assured that their information would be kept confidential, using aliases, and storing data on a dedicated hard drive. Trustworthiness was considered in the text of the interview and the interviewees were given sufficient authority to withdraw from the study. They were also told that they could be informed of the overall results of the study if they wished. To complete the findings and further reassurance, contact with participants was maintained until the end of the analysis. The interviews took place over three months and were recorded with the consent of the participants. Next, the interviews transcribed. The interviews were conducted in the hospital room with the permission of hospital officials. The interviews with the patient caregivers were conducted on the hospital campus. Before any interview, the research purpose, subject and method were explained to participants. Verbal informed consent was obtained from each participant, and all were asked to choose a pseudonym to protect their identity. As mentioned before, one of the researchers (Kasra) had a patient's background in Cancer Clinic, and this experience helped us to make a personal connection. So, the study approved by IRB review. All the participants gave their informed consent to participate after receiving both oral and written information about the study.

Data Collection

Interviews included questions such as: Can you tell us a little about the impact of cancer on your daily routine? How did your relationships change after you become aware of your disease? How do you try to deal with your illness? How is the relationship of others with you? For this purpose, the data were qualitatively analyzed, and three steps of open coding, axial coding and selective coding were performed on them. The result was also review and re-analyzed through continuous scrolling between encrypted data and steps.

Data Analysis

The data collected were transcribed and analyzed using grounded theory coding analysis (Charmaz, 2014). Units of meaning were words, sentences, and parts of sentences. Interviews were coded using an inductive iterative process. Segments of interviews were sorted into categories until the categories accounted for all the variations in the data. Codes were refined and reformulated by gradually incorporating more interviews into the coding structure. Selective coding and relationships between the categories were refined, and main categories were identified and arranged into broad emergent by similar concepts.

Credibility

Credibility establishes whether the research findings represent plausible information drawn from the participants' original data and is a correct interpretation of the participants' original views. For this purpose, we were in touch with the patients and caregivers for six months. Entering in the field, selecting hospitals, and taking formal procedures from hospital and communicating by our first participants, took place over three months and the next three months were spent for interviews. Lived experience by cancer by one of us (Kasra) helped to better communicate with patients. During the past years, she was struggling with the cancer and fortunately has won the battle! Also, the researchers achieved the results by paying attention to the principles of analysis in the grounded theory, integrating the method with the

findings to gain a better understanding of what was happening, and multiple and flexible analyses. In fact, by considering the inductive nature of the qualitative method and spending time to extract concepts and categories in the three main steps of the research, it became possible to understand the details.

Findings

At initial coding, 38 concepts and 4 categories were constructed. The main categories included pressure on relatives, the limitation of relationships, helpful awareness, and personal development. Finally, "integrative power of illness" constructed as core category. The concepts and categories reflect a kind of encounter with the disease that becomes meaningful through the communication network (especially the family relationships) and in an active process.

Pressure on Relatives

The diagnosis changes the role and responsibility of patients and close relatives, and the old roles take on new forms. Dimensions of the pressure included suffering in company with uncertainty and increasing responsibilities, withdrawal of job and other activities, intolerable treatment and its effect, caregivers' suffering, financial problems. Indeed, the measure and type of the categories change according to the role of patient in his family. Caregivers' concerns must also be mentioned. It is impossible to put all the roles and responsibilities of patients to caregivers who have their own responsibilities and difficulties.

Fariborz, a cancer patient, believes the most of his pressure is emotional. Also, the sophisticated condition imposed on their family especially the parents is painful:

My mum and dad endured so much pain. Actually, my mum got at least 7-8 years older than before. I was sorrier for them than me. It's better to be sick but not do nursing. Now they are nursing me. So, they are more bothering than myself.

Treatment process and its consequences makes the patient hate any kind of treatment and medical institutions. Cancer treatment has its own difficulties and suffering. The course of treatment is long and is associated with digestive disorders, sexual problems, fatigue, and decreased motivation. According to Maryam:

Sometimes I can't stay on my feet for the first few days after I leave, then I get a little better. But now I think I cannot clean the house for the holidays, and the doctor told me not to lift anything heavy after the surgery. My other limitation is that I have trouble having sex and I have pain during intercourse like in my early marriage. But I did not tell my doctor, I am bored. There is a specialist in our city, but I am tired. I'm afraid to go to a specialist, tell me to go to a gynecologist. I'm bored. Now there is a subcutaneous injection. I have to inject them every morning. I have to go to the clinic and then be hospitalized.

The first, these statements may seem personal. However, it should be noted that the patient's problems have direct and indirect effects on family relationships and relatives. Physical and mental disability of Maryam and other patients deprives them of the possibility of simple activities. The difficulty in playing the patient emotional or social roles is also a pressure on those around him.

The Limitation of Relationships

The limitation of relationships was a key theme for patients and their families in response to the diagnosis. They diminished their past relations provisionally and confined themselves to family and close friends. Also, they mentioned some issues such as believing in short time of disease and keeping others in the dark about their health statuses; thus, their reason for limiting their relationships is stated. Faranak as a cancer patient says:

In our city, our old women and old men call this disease the disease of death. And they behave badly as if a person is dying, so my wife's family told me you are young, and we do not want anyone to know. We should not tell others.

They also prefer to diminish the communication network for some cultural reasons including negative viewpoint to the disease, over curiosity of the people about the disease, and their boring questioning.

Faranak tries to hide the disease from relatives with cooperation of her husband and families. She says:

There are some people that shouldn't know about your weak point. For example, I didn't tell my sister-in-law that I have a cancer. She doesn't know. I cut my relationship with her for a while. Because she can't accept it. I tried no one knows about it; even my sisters-in-law. Even my husband said: so, what? if she knows about your disease, she can't do anything for you. So, there is no need to tell her about our defect." I say to myself this is a short period in my life that I struggle with and determinate it and will be finishes one day. When I cure five or six years later, if someone come to me and ask me hey you had a cancer are you OK now? It may weaken my spirit. Most individuals don't have the capacity to hear about this disease so there is no benefit in telling them.

The patient, with cooperation of her family, manages and controls his relations depending on their needs. Maybe the patient disconnects from some individuals completely but temporarily. It is to some extent related to a patient's conservatism, ethnic customs, life situation and city (even a small or big town) and its culture, and the behavior of close and far relatives. The perception and behavior of individuals are involved in awareness of the disease and continuous of communication.

One of patients does not like these relationships during her treatment, according to Arezo: "Some strangers' questions upset me. Stranger people, whom I never called, and we had no contact with, now call and ask how I am."

Faranak says:

From the beginning, both my family and my husband's family decided not to tell anyone because our city is a small and these issues cannot be accepting in our culture. That is, when they find out that someone has cancer, they feel that his death is certain. I do not have any problems. I'm living, I'm fighting. but acceptance is still not so good. They are very abusive. their pity is misplaced. It bothers a lot.

Also, Korosh believes:

From I came to the hospital, we tried not to be noticed by those around us as much as possible, however, we lived in such a way that we tried not to spread these things among our families. In my opinion, there was no problem, but well...

Helpful Awareness

Usually during treatment, the attitude of the patient and his caregivers change over time and increases awareness. The participants need reliable information about cancer treatments. more information about cancer and treatments can reduce the patient's fear of cancer often have a positive effect (although this is not always the case) Soraya talks about her mother's disease and therapies (chemotherapy):

At first, I had a negative point of view about her disease, but now it's better. Though it's a hard situation yet, we had to accept it. We thought chemotherapy is a horrible machine, which is very difficult. Now that we see the process of chemotherapy, we have less anxiety and fear.

It must be noted that this knowledge is not only related to cure and medical issues, for example, academic knowledge, also much of it, is related to the social science on individuals in dealing with the disease. It is important for all persons in the communication network. Patient, family caregivers, medical staff and other individuals share in this interaction need such knowledge. Effective factors include social experiences, flexibility of individuals, community culture and ideas. Samira says:

At first, I couldn't believe that cancer can be cured. I thought I would die. Cancer is horrible. I did everything to have high moral, positive energy ...No...at all I couldn't believe and accept, but then I trust in god and accept it gradually.

Fariborz says:

When the first time of treatment was over, my family came to the conclusion that this disease is not a disease that has no cure. Ten years ago, if someone got cancer, everyone would say, "Well, he got cancer, he's dead." That is, no one hoped for someone who would get cancer. Cancer drugs were not so strong, there was no medical progress and no public awareness. But now these three are side by side, both its condition and its surgery and the type of medicine available. If everyone is together and there is no particular bad luck, the chances of cure are very high. The family gradually increased their knowledge in this field. I mean, I have two sisters with my parents, if you ask them, they are all encyclopedias about cancer. In general, I read the nursing books that I took to my mother's house, one by one, and she says that if I go for a master's degree exam now, I will know better than you. So over time, the disease became normal for them.

Therefore, training and trying to better understand the disease through study and communication with the patient, could improve coping with the conditions.

Personal Development

The life story of a cancer patient begins with his awareness of the disease, but there is no definite end to it. Cancer has many ups and downs for the patient, and this condition may continue for a long time after successful treatment. Suffering from illness changes one's worldview. A kind of growth and personality development are existed due to this view and silence. Thereupon, new decisions are taken. This change of perspective may occur in any therapeutic setting. The patient may have already started treatment and even all or part of it may be over and a new course may begin.

Arezo has decided to behave differently because of the things that have happened to her:

Before, I was affected by sad events like sad songs, sad films, labor children... but the disease changed my personality, my worldview, my thoughts ... It's an amazing disease...you think if you pass this process, you'll change your manner.

In addition, there is a concept related to how to deal with illness, especially severe illness, which is not necessarily academic knowledge and is related to the patient's decisions, goals, moods, and experiences. For example, their high patience and flexibility with a different view of the situation. Fariborz says:

I was the one when I chose a goal, I didn't complete it. I had never tried to catch my goals. But the disease taught me to struggle. I decided to complete a goal. If I had this behavior about the disease, I would leave the treatment. This disease taught me to struggle and try to achieve a certain goal.

Accordingly, the experience of cancer and difficulties in accommodation, led to attitude changes in attitudes to self, others, and the universe.

Discussion

According to the findings, the patient and their family encounter many fluctuations and difficulties. Usually, the onset of a disease is associated with inappropriate physical conditions and unknown symptoms, which is a prelude to a special experience. Therefore, a new form of relationship forms between the patient and his relatives. So, they adapt themselves to the new situation in various ways. One of their most important concerns in such a situation is how to control the conditions, the unknown status of the new situation and the fear of personal and social identity changes. The diagnosis brings a kind of anxiety for the patient and his family. Indeed, some part of the emotions can be matched by Camper's theory about power - dignity. According to Camper, each emotion can be linked to power. For example, the loss of the base, the deprivation of financial and symbolic resources provokes anger and mobilizes the energy needed to fight the disruptive factor (Camper, 1991).

Now that a person is in an unknown position and often has no clear idea about a new identity or, has an idea that is not pleasant, he makes negative assessments and thus shows new emotions that contain a message of struggle and confrontation with the new conditions. The condition is consistent with the results of Clarke and Fletcher (2003) that indicates the patients have new responsibilities and concerns while their knowledge and ability in this field is not enough to cope with the new situation. As a result, the patient's critical position at this stage requires care and more time spent by their family and friends. In this regard, they try to consider

the patient's needs through the creation of a positive interaction and responsive as far as possible. They change their relationships based on priorities and preferences (and considering the new conditions). Trying to regulate the relations in the desired direction inevitably creates volatility in relationships. Creating close intimate groups helps the patient to regulate and shape relationships in such a situation.

There upon, the form and content of social communication change. It is also same to the results of Wittenberg (2017) which focuses on communication challenges in family-based cancer care, and its positive effect to accommodate other groups (such as nurses).

Based on priorities and preferences and considering the new conditions, patient, and the family, make changes in their relationships that are as beneficial as possible for both them and the family. The attempt to regulate relations in the desired direction create fluctuations in communications. This is consistent with the tuning of feeling with special situations by Hochschild (1983). This kind of communication developments can sometimes be seen in diminishing the communication network. These results are consistent with the findings of Rajeeian and Godarzi (2016), which have proved the relationship between social support and its impact on adaptation and resistance to disease. However, according to our findings, the supporter and the form of communication is also important. Moreover, the patient's suffering and also the effect of physical activities and physical battles resulting from treatment and disease are consistent with body phenomenologist and related theories (Turner, 2005).

In this regard, French philosopher Merleau-Ponty (1948) avoids considering the body as a passive and static product of social structures and instead considers it as a field of experience. As a result, it is only recognizable as the way in which the body lives. So, according to the patients' experience about their body and its meaning during the treatment period, we understand the effects of the body and its transformations on their social life. Here, as Merleau-Ponty (1948) points out, the body becomes the subject of experience and goes beyond the passive and static product. As a result, any change in the body affects the social, economic, and cultural affinity.

Cancer survivors who are asked to reflect on the impact of cancer on their significant relationships, report that the changes associated with the cancer experience are largely positive rather than negative. Data acquired via various methodologies suggest that many people diagnosed with cancer report high levels of relationship quality over the course of survivorship (Thornton & Perez, 2007). In fact, positive changes in relationships with others is one of the most frequently cited domains of benefit-finding by cancer survivors across virtually all cancer diagnoses, with between 50% and 85% of cancer survivors endorsing this change (Stanton et al., 2006; Thornton, 2002). How the cancer patient and the family respond to the diagnosis will depend on how each family had functioned in the past (Lange, 2005). Families that can talk about this disease and the changes it will bring typically cope better than families in which each member deals with problems alone or makes all the decisions by a member (Lange, 2005).

Studies have suggested that adjustment to cancer is better in a family environment with the characteristics of cohesiveness, open expression, and absence of family conflicts (Friedman et al., 1988). Individuals and communities respond to cancer as well as other diseases according to their culture, norms, and values (Mohseni, 2003) At the individual and family level, the new situation caused by the disease creates many problems for the individual and his family (Courtens et al., 1996). In this way, how the people around and the patient deal with the disease is very important.

The specificity of the cancer experience on one hand, and the lack of familiarity with cancer on the other hand, increases the need for educating people. As cancer can affect every individual from any family and it is not particularly specific, how to deal with the disease during the post-exposure period is very important. Research findings suggest that cultural review is needed in the face of cancer (Afrasiabi et al., 2020); modifying behavior negative and

ill-considered misconceptions about the disease are needed to better respond to the illness and reduce stress and mental harm to patients. Since cancer puts the family and medical institutions with their different perspectives together, to facilitate the treatment process, each one's understanding of the perspective, and the demands and other needs for the better advancement of the treatment process, can be beneficial.

Moreover, creating spaces for communication between patients and their families with those who have experienced the illness and improved can be effective in helping the family and the patient to use their experiences to strengthen their mood and help themselves.

Cancer brings together family and medical institutions with different perspectives. To facilitate the treatment process, more familiarity with each perspective, attention to other needs to better advance the treatment process can be helpful. For this reason, education is important by providing educational brochures to families that address social issues in addition to illness and treatment. It is also important to have training for different people active in the medical staff by assistants or even to provide appropriate curricula during the study and to pay more attention to these interactions. Desensitization of the medical institution is one of the problems that cause discomfort and complaints to patients. The lack of constant consultation with patients was one of the issues that some patients emphasized. To strengthen the support wards, medical and non-therapeutic consultations, as well as more attention of physicians to the mental condition of patients, there is a need that is felt. Also, creating spaces for more communication between patients and families with people who have experienced the disease and regained their health, to use their experiences can be effective in strengthening the mood and helping the family and the patient (Afrasiabi et al., 2020).

One of the interesting points in the research process may be implicit discoveries. That we realized the difficulties in the lives of female patients that the disease was only part of, and that could be a topic for future research. The fact that sometimes the disease is in a lower category than other problems, and this shows the depth of the problems of women, especially in traditional societies. Difficulties that sometimes marginalize the bitterness of cancer or imposes additional pressure on the patient. (Afrasiabi et al., 2020).

One of the limitations of the research is the physical and mental condition of the participants in the research (patients and families). Review of illness memories, treatment steps, and challenges that have been or still are. It is not pleasant for people, and it is usually difficult for them; This made the interview difficult for the researcher.

The researchers tried to provide a qualitative analysis to create a communication to help this transferability between the research content and the readers. For this purpose, continuous analysis was performed, and the results of the research were shared with the interviewees.

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