Original Article

Resilience in Informal Caregivers of Patients with Gastrointestinal Cancer: A Content Analysis Study

Abstract

Background: Resilience is a multidimensional concept that explains why some individuals who face adversity, stress, and health-threatening factors are able to adapt and achieve positive outcomes. This study aims to "explain the experience of resilience in informal caregivers of patients with Gastrointestinal cancer." **Materials and Methods:** This qualitative study was conducted using the conventional content analysis method. Data were collected through semi-structured interviews between March and September 2023. The participants included 11 informal caregivers of patients with Gastrointestinal cancer, selected through purposive sampling. Data analysis followed the three-step method proposed by Elo and Kyngäs. **Results:** The data analysis revealed five main themes, including emotional self-regulation, care competency, spiritual health, social intelligence, and flourishing. **Conclusions:** Informal caregivers, when faced with the caregiving experience, endure and grow through hardships by possessing traits such as optimism, hopefulness, and acceptance, and skills like problem-solving and relationship management.

Keywords: *Caregivers, gastrointestinal neoplasms, qualitative research, resilience*

Fereshteh Mollaei[1], Moluk Pouralizadeh[1], Hamid Sharif Nia[2,3], Nazila Javadi-Pashaki[1]

[1]Department of Nursing, Shahid Beheshti School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran, [2]Psychosomatic Research Center, Mazandaran University of Medical Sciences, Sari, Iran, [3]Department of Nursing, Amol Faculty of Nursing and Midwifery, Mazandaran University of Medical Sciences, Sari, Iran

Address for correspondence:
Dr. Nazila Javadi-Pashaki, Department of Nursing, Shahid Beheshti School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran.
E-mail: n.javadip@gmail.com

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Introduction

Cancer is one of the most common chronic diseases and the main cause of death worldwide.[1] Gastrointestinal (GI) cancer, including colorectal, stomach, esophageal, liver, and pancreases, are among the most prevalent types of cancer globally, with an incidence rate of 18.7%.[2,3] In Iran, GI cancer is the most common type of cancer among men and the second most common among women, accounting for 38% of all cancers.[3] Patients with gastrointestinal cancer have multiple care needs.[4,5] Moreover, they prefer to receive care at home, resulting in family members assuming the caregiving role.[6] Family members who take on the responsibility of caring for a sick relative are referred to as informal caregivers or informal caregivers; they provide non-professional or unpaid care to the patients.[7] In Iran, families, as the most important source of patient support, willingly accept this role and provide the highest quality care.[8,9]

Studies have shown that informal caregivers of patients with GI cancer face numerous challenges, including the lengthy diagnostic process, delivering bad news, managing physical symptoms, changes in relationships, handling the practical aspects of care, psychological consequences, and managing issues.[4,5,10] However, some caregivers have demonstrated the ability to cope with these difficulties,[11] find meaning in life, strengthen interpersonal relationships,[12] return to healthy functioning shortly after,[13] and achieve personal growth.[12] This ability is known as resilience.[14] Resilience is "the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress such as family and relationship problems, serious health issues, workplace, and financial stressors".[15] Resilience explains why some people can adapt and achieve positive outcomes despite facing adversity, stress, and health-threatening factors.[16]

Resilience in informal caregivers of cancer patients is directly associated with positive psychological outcomes[17] and acts as a protective factor against caregiving burden.[16] Resilience positively affects physical and mental health and significantly reduces the risk of depression, anxiety, and stress.[18] According to studies, psychological well-being and healthy functioning are the most common outcomes of resilience.[19] Additionally, the

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study by Silva *et al*.[17] showed a positive correlation between resilience and the general, physical, psychological, social, and environmental domains of quality of life, indicating that higher resilience levels correspond to higher quality of life levels. Therefore, knowledge about resilience can help nursing professionals reduce suffering and enhance positive experiences for informal caregivers, enabling them to provide individualized and comprehensive care.[17] It also helps health professionals develop strategies to improve caregivers' quality of life.[20] If nurses can distinguish between resilient informal caregivers and those at greater risk, they can better support these individuals and reduce the negative effects of caregiving.[21]

There is a critical need for more research on resilience in informal caregivers of cancer patients because focusing on resilience aids in the early identification of caregivers at risk of psychological disorders and the development of preventive programs.[22] This allows health professionals to reflect more on the concept of care and gain a better understanding of caregivers.[23] Resilience is a context-based concept.[24] Therefore, to deeply, comprehensively, and accurately examine this concept, qualitative studies are preferred to capture individuals' real-life experiences related to this concept.[25] This qualitative study is designed to explore the experience of resilience among informal caregivers of patients with gastrointestinal cancer in Iran.

Materials and Methods

This qualitative study was conducted from March to September 2023 using conventional content analysis. The participants were informal caregivers of patients with GI cancer who visited the oncology ward of Razi Hospital, Besat Chemotherapy Clinic, and Razi Specialty Clinic in Rasht, Guilan Province. Sampling method was purposive sampling, with maximum variation (considering age, gender, occupation, and cancer-affected organ). The inclusion criteria were being over 18 years old, being a first-degree family member of a patient with GI cancer, having full-time caregiving experience, not having chronic physical diseases or mental disorders based on self-reporting, and the ability to understand and speak Persian. The exclusion criterion was the voluntary withdrawal of a participant from the study.

After obtaining written informed consent, data were collected through face-to-face, individual, semi-structured interviews. The interviews were conducted by the first researcher in one of the hospital rooms or the caregivers' homes. The duration of the interviews ranged from 35 to 70 minutes. Each interview began with a general question, "Please describe a day from morning to night spent caring for the patient," to create a warm-up. It then continued with questions like "What experiences have you had while caring for your patient (from diagnosis to now)?", "How do you deal with the problems/issues related to caring for your patient?", and "What changes have occurred in you during this caregiving period?" Saturation was achieved after 11 interviews with 11 informal caregivers.

Data analysis followed the method suggested by Elo and Kyngäs,[26] conducted in three phases: preparation, organization, and reporting. In the preparation phase, interviews were transcribed verbatim immediately after completion. Researchers read the transcriptions several times to immerse themselves in the data. During the organization phase, after identifying explicit and implicit concepts, initial codes were assigned to related meaning units. Several subcategories were then created by combining initial codes. Subcategories were compared based on their similarities and differences, leading to the development of categories. Finally, main categories were formed by merging categories. The coding process was independently implemented by all researchers, and categories were extracted through further discussion in regular meetings. MAXQDA 2020 software (version 10) was used to facilitate data management.

To increase the rigor of the study, Lincoln and Guba's four criteria were used.[27] Credibility was enhanced by the researcher's prolonged engagement in the study environments for seven months and continuous interaction with interviewees. Additionally, the analysis process was evaluated by all members of the research team as relevant experts. Dependability was ensured through peer review and multiple meetings with the research team to assess the study's quality and results. For transferability, purposive sampling with maximum variation among informal caregivers of GI cancer patients was conducted, and participants were selected from multiple centers. The researchers achieved saturation with great precision. A detailed description of the study method was also provided. To achieve confirmability, two researchers outside the study were asked to review the study process as external audits. Additionally, an audit trail, including all activities, decisions, data, observations, and data analysis processes, was recorded and maintained.

Ethical considerations

This qualitative study was part of the PhD Dissertation in nursing entitled "Designing and Psychometric Properties of Questionnaire of Family Resilience in Patients with GI Cancer: A Sequential Exploratory Mixed Method Study". To observe the ethical considerations, an approval was obtained under the ethics code no. IR.GUMS.REC.1401.600. Before the study, the researcher explained its main objectives, data confidentiality, and voluntary participation. As well, written informed consent was signed by all participants.

Results

In this study, 11 face-to-face interviews were conducted with the informal caregivers of patients living with GI cancer. The participants were mostly men (54.50%), married (72.70%), with university education (63.70%), self-employed (63.70%), and children of patients (72.70%). Most of the patients had colon cancer (36.40%). The data analysis accordingly established 493 codes, 34 subcategories, 15 categories, and five main categories, including emotional

self-regulation, care competency, spiritual health, social intelligence, and flourishing [Table 1].

1. Emotional Self-Regulation

As the first theme emerged in this study, emotional self-regulation denoted one's capacity to receive emotional responses and adjust them, which contained four categories of optimism, adaptability, self-restraint, and Subjective well-being.

1.1. Optimism

Based on the informal caregivers' statements, much hope for coping with difficult situations could breed optimism for the future and make them much more resilient. In this regard, one of the informal caregivers said that: "*I think much hope has so far made me go through these hard times. It was not demanding as much as it could have been before. I do not mean it is an illusion of getting better, but the hope that soothes me that someone loved gets better before long.*" (Participant K).

As well, one of the main attributes of resilient informal caregivers was thinking positively about the new situations to come. For example, the participants stated that: "*I sought to be very positive, so I kept telling myself that everything will be fine like before.*" (Participant B) or "*As an illustration, I became very happy once I saw that my mother could do some activities by her own despite the fact she was sick. At all events, she could have been much worse than this time*" (Participant D).

1.2. Adaptability

The resilient informal caregivers had some qualities to aid them adapt with many existing circumstances, which included the acceptance of the tough situations. As an example, one of the participants with reference to adaptation to difficult situations replied that: "*If I had failed to adapt to this new role, I undeniably would not be able to adapt to other problems.*" (Participant K).

Table 1: Subcategories, categories, and main categories of experiences of resilience in informal caregiversof Gastrointestinal (GI) cancer

Themes	Categories	Subcategories
Emotional Self-Regulation	Optimism	Hope
		Positive thinking
	Adaptability	Acceptance of the situation
		Adaptation to existing conditions
		Maintaining daily routines
		bouncing back to before condition
		resistance
	Self-Restraint	keeping up appearances
		controlling inner feelings
	Subjective well-being	enjoying caregiving
		Satisfaction with the caring role
Care Competency	Cognitive Skills	Managing problems
		Dealing with the situation reasonably
	Caring Skills	caring knowledge
		functional ability
		self-care
	Spirit of Support	supporting patient
		supporting family
	Commitment in Caregiving	being responsible
		Continuity in care despite conflicts
Spiritual Health	Religious Beliefs	
	Religious Behaviors	
	Seeking Help from Religiosity	
Social Intelligence	Constructive Communication	Communicating effectively with patient
		Effective family interactions
		Desirable social interactions
	Social Perceptions	being grateful
		Understanding the circumstances of others
Flourishing	Inner Transformation	improving their attitudes toward cancer
		Positive mental-psychological changes
		Not getting involved with the trivial issues
	Skills Development	improving emotional support skills
		Improving problem management skills
		increasing relationship management skills

To maintain daily routines, one of the participants said that: "*I inspired myself to keep on my normal life, that is, I have to stay alive and continue in this way.*" (Participant C).

1.3. Self-Restraint

Given the informal caregivers' experiences, one of the major qualities that displayed their capacity in terms of emotional self-regulation was self-restraint. Their experiences accordingly showed that they had enough ability to keep up appearances and control their inner feelings while being with patients and others. In this respect, some participants believed that: "*Even two years after I found out that my mother was sick, I tried not to cry out. I feel sad, but deeply in my heart. I never share my gloomy feelings with my mother and others.*" (Participant D). "*His ostomy bag would always get wet and come off. It seemed to be very uncomfortable. I used to get disappointed when I saw this, but I did not notice it, I did not even react, because it was something natural.*" (Participant E).

1.4. Subjective well-being

Based on the informal caregivers' experiences, enjoying caregiving in light of Subjective well-being could significantly contribute to building resilience among them. In this context, one of the participants stated that: "*This is a positive point to take care of your parent. Well, helping my parents seems pleasing to me*" (Participant J).

The participants also felt satisfied with their role as caregivers, and one of the participants added that: "*I did my duty, I did it very well. In any way, I was able to take care of my mother within this short time, so I am satisfied with myself. As a caregiver, I could successfully finish this course of the disease and help her*" (Participant C).

2. Care Competency

Care competency as a main theme in this study laid much focus on the caregivers' ability to provide care to patients, and included cognitive skills, caring skills, spirit of support, and commitment in caregiving.

2.1. Problem Solving Skills

Based on the findings of the present study, one of the characteristics of resilient caregivers is their problem-solving skills, which indicate their competence in the caregiving role. Accordingly, one of the participants stated: *"I am a person who never gets stuck in a problem. I know this problem has a solution, and I should just look for it."* (Participant J).

Another participant expressed a rational approach to dealing with problems in order to solve them: *"Whenever I feel I can't psychologically resolve an issue on my own, I go to a counselor. I'm not a know-it-all; I might be thinking or interpreting the issue incorrectly."* (Participant K).

2.2. Caring Skills

As evidenced in the participants' experiences, the resilient informal caregivers were endowed with a blend of caring skills, particularly caring knowledge. In this line, one of the participants uttered that: "*I used to study a lot, that is, I searched the web to know what I should do at the moment. I thus tried to personally broaden my knowledge about someone with cancer, the way family members could deal with it, and what information they should have about it.*" (Participant G). Regarding functional ability, one of the participants said that: "*I learned from the nurse in the hospital to change the ostomy bag or dress the wound.*" (Participant E). Considering self-care, one of the participants also pointed out that: "*I am informed about the effects and damages of this chronic disease on myself. Now, I try some methods, such as music therapy, exercise, and going for a walk to relieve my stress.*" (Participant J).

2.3. Spirit of Support

The spirit of supporting patient and family was one of the most important qualities of the resilient caregivers in the present study. In this vein, the participants stated that: "*I spend much time following the treatment for my patient. There are some regimens, bathing styles, toilet services, massages, and moods that I need to manage.*" (Participant J)

Another participant also stated: *"In addition to taking care of my father, I also look after the rest of my family. I try to be a support for all of them." (Participant I)*

2.4. Commitment in Caregiving

The informal caregivers declared that they were in charge of providing care to their patients. One of them said that: "*I am a mother and I should be by my child with cancer. I did my duty well. I feel responsible for her.*" (Participant A).

Besides, some informal caregivers had continued to care for their patients despite their conflicts; for instance, one of the participants mentioned that: "*There is a big age difference between my parents and I. The fact is that they cannot understand me, that is why we are always in disagreement. There were arguments and anger, but this never caused me avoid caring for my mother. I refused to go away.*" (Participant H)

3. Spiritual Health

As another theme, spiritual health referred to personal beliefs and modes of communication with a higher power, and embraced religious beliefs, religious behaviors, and seeking help from one's religiosity.

3.1. Religious Beliefs

One of the qualities of resilient informal caregivers was spiritual health, which could stem from their beliefs and convictions. In this case, the participants revealed that: "*You must be connected to something, have a support, believe in a high power, and ask for help. If you do not believe in it, you will get exhausted.*" (Participant I) or "*I think God loves me, and He is testing me, so I have to go on to see how far God will test me. God loves me to any further extent.*" (Participant A).

3.2. Religious Behaviors

One category under spiritual health in the informal caregivers was resilient behaviors coming from their

religion and religious beliefs. The participants accordingly said that: "*I trust in God. I encouraged myself that the physician was a servant of God, did everything he could, and from now on, I needed to trust in God.*" (Participant A). "*I prayed a lot, may God heal all the sick, my father, too*" (Participant I)

3.3. Seeking Help from Religiosity

The informal caregivers used to get help from their religious beliefs to bear the difficult situations and thus reach peace. The participants accordingly commented that: "*I pray, and then I sit and recite the rosary. I feel very well, I achieve much peace*" (Participant E) or "*Reading the Holy Qur'an helped me when mother was sick, because I already had the background knowledge. It made me calm down, and I was inspired*." (Participant G)

4. Social Intelligence

Social intelligence as one of the main themes represented the caregivers' ability to establish healthy interpersonal relationships with others, which was composed of constructive communication and social perceptions.

4.1. Constructive Communication

The resilient informal caregivers could communicate effectively with patients. For example, one of the participants stated that: "*I used to talk to my sick sister a lot. I told her that I was not suffering from this chronic disease, but I could understand her. It was hard anyway because she had a disabled child and was burdened with medicines and physician visits. Her pain was my pain.*" (Participant E).

As well, they had made effective interactions with other family members. In this regard, one of the participants said that: "*At this time, I tried to give much energy to my mother and the people around, but this was not always one-sided; for example, wherever I had no energy, both family and friends helped.*" (Participant C)

4.2. Social Perceptions

One other attribute of resilient informal caregivers was having social perceptions. Under this category, the study findings indicated that they were grateful. In this case, one of the participants mentioned that: "*Well, I would like to share my success with my mother. For example, my mother looked after me until I turned 17 or 18. She has helped me to reach this stage of life, so I need to compensate for her sincere efforts.*" (Participant C). They could also understand the circumstances challenging those around, viz., family, friends, and medical staff. One of the participants reiterated that: "*I am in a different situation compared to the rest of my siblings. I am single and I live with my mother. It is not fair to make them engaged in taking care of my mother. I really do not expect it, so I am by her side.*" (Participant K).

5. Flourishing

As another main theme, flourishing implied the positive changes among informal caregivers after the caregiving experience, which involved inner transformation and skills development.

5.1. Inner Transformation

The resilient informal caregivers stated that handling the hardships of patient care had led to their growth and flourishing, so they had experienced some changes in their lives, including improvements in their attitudes toward cancer. In this line, one of the participants said that: "*Now, if they tell me that someone has cancer, I never feel afraid, and I am not surprised. I always assume it as a disease with a treatment process. I think it is a chronic condition which needs much more care.*" (Participant C). Regarding positive mental health, one participant stated that: "*I became more resistant. Once a problem occurs, I have enough patience and I put up with it, but I was not so in the early days."* (Participant E). With respect With respect to not getting involved in some trivial issues, one participant added that: *"In the past, some small problems looked very big. For example, I used to buy a lot of clothes. I would be very upset if I had no money at the end of the month to buy a dress, but now I am not so."* (Participant H).

5.2. Skills Development

The informal caregivers were able to acquire numerous skills while caring for patients or even improve them, which included the development of emotional support skills. One of the participants accordingly believed that: "*My father's illness was a positive turning point in my life because I faced a very big challenge at the age of 26 or so, I was able to cope with them well, and I gained many experiences, like dealing with the moods of the patient, my mother, and the people around me.*" (Participant J).

In terms of enhancing problem-solving skills, one participant said that: "*I was not good at crisis management because of the intense love I had for my beloved ones. They were always my weak points, that is, if, God forbid, one of them would get sick or feel bad, I could not manage that difficult situation at all, but now I have really changed, and my family has noticed it.*" (Participant K).

Discussion

This study was to explain the experience of resilience in informal caregivers of patients with GI cancer. Based on the participants' experiences, such caregivers had some attributes, viz., emotional self-regulation, care competency, spiritual health, social intelligence, and flourishing.

Emotional self-regulation was the uppermost quality of these caregivers. As a main theme representing understanding, accepting, and adjusting emotional responses, it was thus a process to adapt to the psychosocial environment in order to achieve evolutionary goals and support one's mental

health.[28] With reference to the participants' experiences, individuals with emotional self-regulation could have some attributes, such as hope, positive thinking, optimism for the future, adaptability to existing conditions, ability to maintain life routines and return to previous situations, and self-control. In this respect, Krok *et al*.[29] (2021) had demonstrated that the spouses of cancer patients as caregivers had achieved positive adaptation to adversity thanks to their hope. As well, Silva *et al*.[30] (2023) had found that positive thinking in informal caregivers of cancer patients had strengthened their resilience, so they had tried to put the situation under control by handling their inner emotions. Some qualitative studies had similarly revealed that resilient people had much hope and devoted attention to positive aspects, so they could empower themselves while facing problems.[31-33] Lima *et al*.[34] (2023), analyzing the concept of resilience, had also found that acceptance, positive thinking, and optimistic attitudes were among the leading attributes of resilient people, giving rise to their ability to regulate emotions. In line with the findings of the present study, Kim and Chang (2022) had confirmed that resilient informal caregivers could accept their role and the existing situation, and then try to maintain their normal life.[35] In times of difficulty and distress, they could thus create peace and strengthen their inner abilities by adjusting their thoughts, feelings, and behaviors; in other words, they could achieve acceptance and adaptation and consequently maintain their functioning in life through this strategy.

Care competency was also identified as another attributes of resilient informal caregivers. The participants' experiences showed that informal caregivers had enough capacity to manage difficult situations logically, support patients and the family, and even practice self-care. They were also committed to patient care and endeavored to broaden their knowledge and reach high performance in patient care. In this regard, Dionne-Odom *et al*.[36] (2021) had reported that resilience in informal caregivers of patients with newly diagnosed advanced cancer was associated with higher readiness for caregiving and potential decision-making in the future. Furthermore, some studies had shown that resilient informal caregivers had the capability to solve many problems.[37] They could increase their care knowledge as they assumed themselves responsible[38] and committed to providing full care for patients,[30] through browsing the web and asking other families in similar situations and treatment teams.[31,35] Analyzing the concept of resilience also showed that having personal competence and problem-solving skills were among the qualities of resilient people.[34] Like the findings of the present study, previous research had suggested that resilient individuals could support patients and other family members, and even take care of themselves.[14,34,39] A systematic review had additionally revealed a significant positive relationship between resilience and self-care.[40] It had been argued that resilient people could view this concept as a solvable challenge and try to find a solution due to their positive attitudes. They also deemed care as a duty, so they could care for the body and mind of patients and themselves by maintaining a spirit of support, and then create a sense of control over difficult situations and gain self-confidence to tackle other problems.

As well, spiritual health was another quality of resilient informal caregivers. The participants accordingly considered themselves connected to a higher power. They had strong religious beliefs and decent behaviors that could help them stand in front of the difficult caring conditions of cancer patients. In its confirmation, Krok *et al*.[29] (2021) had detected a positive relationship between religious order and resilience. In other qualitative studies across the world, spiritual health had been further mentioned as a attribute of resilient people.[33,34,41] A qualitative study in Iran had thus concluded that informal caregivers of cancer patients had surrendered to God's will and relied on their spiritual beliefs in tough situations, so they had reached peace.[31] A systematic review had similarly demonstrated that spirituality and religious beliefs had been introduced as the sources of adaptation in cancer because they could raise a sense of meaning and purpose in life.[42] In contrast to the findings of the present study, Silva *et al*.[30] (2023) had reported no significant relationship between religiosity and resilience, but informal caregivers had tapped this strategy as a factor to strengthen the caregiving process. Religious beliefs and convictions accordingly seemed to act as protective factors, helping people to set valuable goals and find ways to achieve them and then the meaning of life.

Another attribute of resilient informal caregivers in the present study was social intelligence, which meant the ability to establish interpersonal relationships, join a group, pool resources with others and understand them better, and ultimately grow and develop.[43] The study participants also highlighted their ability to communicate effectively and interact socially with patients, other family members, and people around them. Quantitative studies had further shown a significant positive relationship between social support and resilience in caregivers of cancer patients,[44,45] Silva *et al*.[30] (2023) had also found that informal caregivers of cancer patients had been satisfied with their social relationships, so high quality of life was vital for dealing with the existing conditions. In Tandiongan *et al*.[38] (2023), social support had been further introduced as an attribute of resilient informal caregivers. Santos *et al*.[46] (2019) had even discovered in their study of resilience in informal caregivers of patients with malignancy that communication between caregivers and health professionals had been essential when dealing with problems. Resilient people could thus try to be social and seek help from their family and friends in difficult situations[35] because the use of existing social capital could accelerate the adaptive response in many individuals.[32]

One of the other important qualities of resilient informal caregivers in the present study was flourishing, in which people could mostly experience positive emotions as well

as high mental and social performance.[47] Resilient informal caregivers accordingly stated that tackling the hardships of patient care had led to growth and flourishing among them, so some changes, such as improving their attitudes toward cancer, positive mental changes, and not getting involved in trivial life issues had occurred. Other qualitative studies had further shown that people could be subjected to positive changes in themselves after experiencing care, including changing attitudes toward the disease, enhancing their ability for crisis management, becoming stronger and more empathetic, improving physical and mental performance, boosting life values, and strengthening social relationships.[14,31,33,34,48] Resilient individuals were thus seeking for a positive meaning and self-growth in the event of problems, and even have achievements. Along these lines, they could prepare themselves for future challenges.

This study has limitations. One of them is the geographical limitation, which restricts the generalization of the findings. The concept of resilience is context based, and since this study was conducted in Iran, its results cannot be generalized to countries with different cultural and religious backgrounds. Additionally, caregivers whose patients had passed away were not included in the study; they might have different experiences regarding resilience. Furthermore, individual factors such as caregiving stress and the number of hospitalizations of the patient were not considered when selecting participants.

It is suggested that future studies examine the experiences of informal caregivers of other types of cancer and diseases, as well as in different cultures and religions. Additionally, intervention studies aimed at enhancing resilience in informal caregivers and evaluating their effectiveness should be conducted.

Conclusion

As a result, this study helped us understand the experiences of resilient informal caregivers, including emotional self-regulation, care competency, spiritual health, social intelligence, and flourishing. Family-centered care is one of the nursing concepts derived from a holistic perspective in this profession. According to this view, one of the responsibilities of nurses is to assess the health status and functioning of patients' families and provide them with the necessary education. Therefore, understanding the experiences of informal caregivers during the care of a family member informs us about their situation. Thus, understanding their experiences regarding positive concepts such as resilience is very helpful due to its positive effects on the caregiver.

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Conflicts of interest

Nothing to declare.

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