

Caregiving Challenges among Family Caregivers of Patients with Gastrointestinal Cancer: A Content Analysis

Fereshteh Mollaei^{1,2}, Moluk Pouralizadeh¹, Hamid Sharif-Nia^{3,4}, Nazila Javadi-Pashaki^{5,1*}

¹Department of Nursing, Shahid Beheshti School of Nursing and Midwifery, Guilan University of Medical Sciences, Rasht, Iran

²Department of Nursing, Behshahr Faculty of Nursing, Mazandaran University of Medical Sciences, Behshahr, Iran

³Psychosomatic Research Center, Mazandaran University of Medical Sciences, Sari, Iran

⁴Department of Nursing, Amol Faculty of Nursing and Midwifery, Mazandaran University of Medical Sciences, Sari, Iran

⁵Social Determinants of Health Research Center, Trauma Institute, Guilan University of Medical Sciences, Rasht, Iran

*Corresponding Author: Nazila Javadi-Pashaki, Email: n.javadip@gmail.com

Abstract

Introduction: Family caregivers of patients with gastrointestinal cancer face many challenges during the caregiving process, which can negatively affect their health and quality of life. Identifying these challenges is essential for developing effective interventions. Therefore, this study aimed to explain the caregiving challenges encountered by family caregivers of patients with gastrointestinal cancer.

Methods: This qualitative study employed conventional content analysis. Data were collected through semi-structured interviews with 11 family caregivers of patients with gastrointestinal cancer, selected via purposive sampling. Interviews continued until data saturation was achieved. Data management and analysis were conducted via MAXQDA software (version 10), following the approach proposed by Elo and Kyngäs.

Results: Data analysis revealed four main categories, including *non-supportive healthcare system*, *lack of social support*, *care strain*, and *unmet educational needs*.

Conclusion: The findings of this study showed that family caregivers of patients with gastrointestinal cancer face multifaceted challenges during the caregiving process. Identifying these challenges and their underlying sources can inform healthcare system planners and nurses to reduce their burden by providing tailored programs addressing caregivers' needs, along with appropriate training, facilities, and support services.

Keywords: Caregiving challenges, Family caregivers, Gastrointestinal cancer, Qualitative research

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Introduction

Cancer has been documented as one of the four major types of non-communicable diseases (NCDs) and stands as the second leading cause of death globally (1). Among these, gastrointestinal (GI) cancer, affecting the esophagus, stomach, liver, pancreas, and the small and large intestines, is one of the most prevalent types of cancer, with high mortality rates in Iran and worldwide (2, 3). Moreover, the increasing number of cancer cases admitted to outpatient clinics indicates that many patients presenting with cancer symptoms and complications are receiving care at home (4). As a result, care transition from hospital to home has led to a significant involvement of family members in providing daily care services for such patients (5). Therefore, family members as the primary supporters, also called family caregivers (FCGs) or informal caregivers (6), have been in charge of a wide variety of practices, such as patient care,

symptom management, assistance with activities of daily living (ADLs), and emotional support for patients with GI cancer (7).

Given that the need for care often arises unexpectedly, and most family members are not adequately prepared for these responsibilities, FCGs are likely to experience physical and psychological consequences (8), leading to caregiving burden (9), impairing their ability to meet their personal needs. Accordingly, they have to endure a reduced quality of life, heightened anxiety, chronic distress, psychological pain (10), financial problems (11), social isolation, and poor self-care (12). In this regard, the findings of the study by Karimi Moghaddam et al. in Iran showed that family caregivers of cancer patients suffer from high levels of caregiving burden, depression, and anxiety (13). Similarly, Lee found that the stress associated with caregiving acts as a barrier to adopting health-promoting behaviors, including



dietary changes, among family caregivers of patients with GI cancer (14). As evidenced in some qualitative studies, FCGs of patients with GI cancer face a multitude of challenges, such as those related to the diagnostic process (e.g., delayed diagnosis and acute psychological distress associated with frequent visits and tests), receiving bad news, managing physical symptoms (e.g., insufficient knowledge of pain management, ostomy care, and nutrition), Changes in relationships (e.g., reduced social interaction and family disruption), controlling practical aspects of care (e.g., household chores and appointments), psychological consequences (e.g., uncertainty about the future, fear, desperation, shock, witnessing patient pain and suffering, and the imminent risk of death), and managing their own health and personal issues (15-18).

Despite the leading role of FCGs in patient care, they have not yet received sufficient attention from healthcare providers (HCPs). Recognizing the importance of care provided by family members and all related measures is essential, as patients' health conditions are influenced by the quality of the care they receive (10). Healthcare policies should be designed to support FCGs of patients with cancer in maintaining their own health and practicing self-care, ultimately benefiting both the caregivers and the patients (19). Thus, gaining insights into the challenges faced by FCGs and understanding their caregiving experiences can pave the way for developing effective interventions that promote healthy behaviors, planning educational programs tailored to their needs, and facilitating access to support resources (20). Accordingly, the present study sought to explore the caregiving challenges faced by FCGs of patients with GI cancer, using conventional content analysis.

Methods

This qualitative study was conducted as part of a doctoral dissertation in nursing from March to September 2023. It employed conventional content analysis (CCA) to explore caregiving challenges among FCGs of patients with GI cancer. Qualitative data obtained from real-life experiences serve as valuable sources of information, offering insights and novel perspectives related to the target population (21). Among various qualitative approaches, CCA was deemed suitable for analyzing the multidimensional and sensitive nature of the nursing caregiving phenomenon. It facilitates comprehensive data collection and provides practical guidance through the generation of knowledge, insights, and factual understanding (22, 23).

Participants were FCGs of patients with GI cancer referred to the inpatient oncology wards of Razi Hospital, Be'sat Chemotherapy Clinic, and Razi Sub-Specialty Clinic in Rasht, Guilan Province, Iran. Purposive sampling was employed with maximum variation in terms of age, gender, occupation, and the affected body part. Sampling continued until data saturation was reached. Inclusion criteria were being a first-degree family member of a patient with GI cancer, having full-time caregiving experience, and speaking and understanding Persian. Exclusion criteria comprised unwillingness to continue participation and

deterioration of the patient's condition during the study.

Data were collected through face-to-face, in-depth, semi-structured interviews conducted by the first author. Interviews were audio-recorded with participants' consent and held either in hospital rooms or at patients' homes. Each interview lasted between 35 and 70 minutes. Initially, general open-ended questions such as "Would you please describe a typical day spent caring for the patient from morning to night?" were used to establish rapport. Follow-up questions included, "What challenges did you encounter during patient care from diagnosis until now?" and "What changes occurred in your life during this period?" As interviews progressed, other exploratory questions, such as "Can you elaborate on that?" and "Can you give an example?" were employed to deepen the discussion. Data collection continued until data saturation was reached, i.e., no new codes emerged.

The three-phase content analysis process developed by Elo and Kyngäs (2008) was used for data analysis (22). During the preparation phase, interviews were transcribed verbatim and reviewed by the authors multiple times. In the organization phase, initial codes were assigned to semantic units, and related codes were grouped into subcategories through comparison of their similarities and differences. These subcategories were further consolidated into main categories, ensuring maximum homogeneity within main categories and heterogeneity between them. The coding process was further performed independently by all four authors, with consensus reached during group meetings. MAXQDA 2020 software was employed for data management. The reporting phase involved documenting all stages of the inductive CCA process and its outcomes.

The trustworthiness of the study was ensured according to the criteria outlined by Elo and Kyngäs (2020) for CCA-based research (24). Validity was strengthened through prolonged engagement with the research environment and regular communication with FCGs. The analysis process was evaluated by all members of the research team. To enhance reliability, peer debriefing was conducted, and several meetings were held with the research team members to further evaluate and refine the findings. Moreover, transferability was addressed by using purposive sampling to select FCGs of patients with GI cancer from relevant care centers. Confirmability was maintained through documentation of all data, analysis steps, and decisions, thus enabling transparency and verification when required.

Results

The study included 11 family caregivers of patients with gastrointestinal cancer. The main characteristics of the participants are summarized in [Table 1](#). Data analysis identified 13 subcategories and 4 main categories including non-supportive healthcare system (non-therapeutic communication by HCPs, inadequate equipment in hospitals, limited access to medical services), lack of social support (feeling of not belonging to family, lack of empathy from others, lack of access to a supportive social network), care strain (multiplicity of roles, social stressors,

Table 1. Participant characteristicsdoi:

Age (mean)		37
Gender	Female	5
	Male	6
Marital Status	Single	3
	Married	8
Occupation	Unemployed	7
	Employed	4
Education	Lower doi:than a doi:high doi:school diploma	2
	High doi:school doi:diploma	2
	Higher doi:than a high doi:school diploma	7
Relationship to patient	Spousedoi:	1
	Parent	1
	Child	8
	Siblingdoi:	1
Affected body part	Esophagusdoi:	1
	Stomachdoi:	2
	Liverdoi:	2
	Pancreas	2
	Colon	4

psychological stressors, financial stressors, physical stressors), and unmet educational needs (need to increase care knowledge, need to learn care skills (Table 2).

Non-Supportive Healthcare System

As a main category, the non-supportive healthcare system encompassed non-therapeutic communication by HCPs, inadequate equipment in hospitals, and limited access to medical services.

Non-Therapeutic Communication by HCPs

One of the caregiving challenges specified by the FCGs of patients with GI cancer was the poor communication from physicians, particularly regarding delivering bad news. For example, one participant explained: *"We had an appointment with a specialty physician to review the lung scan, but he told my mother about her cancer recurrence without any further explanation, and we were very upset"* (Participant 2). Participants also reported that the HCPs' behavior affected their emotional well-being. One participant asserted: *"In my opinion, nurses' conduct is of utmost importance. They are almost always edgy and do not answer well. Some are kind-hearted and try to make us more cheerful. As a whole, their behavior has a significant effect on our mood"* (Participant 8).

Inadequate Equipment in Hospitals

Another challenge experienced by the FCGs of patients with GI cancer was the lack of equipment in hospitals for patient caregivers' comfort. One participant shared: *"My sister needed a caregiver once she was admitted. I had to stay with her overnight, but there was no chair or bed, so I spread a blanket on the floor and slept. I felt exhausted"* (Participant 5). Another added: *"No one in this healthcare*

system sees caregivers. For example, I wonder how much it costs to have a green space or a café in the hospital yard. Sometimes, I needed to leave the ward for a few minutes, but there was nowhere to go" (Participant 11).

Limited Access to Medical Services

Participants described significant difficulties in accessing essential chemotherapy drugs. One explained: *"Getting the drugs seems to be an immense problem. Many cannot be found, or you have to ask a friend to bring them from Germany or other countries. Sometimes, you have to use the alternatives available, but they are not very effective"* (Participant 3). Moreover, some participants complained about limited access to appropriate medical equipment, as an example: *"Many colostomy bags on the market are faulty; I mean they tear easily, or are not odor-proof. There are some good brands, but they are always hard to find"* (Participant 10).

Lack of Social Support

This main category was associated with the feeling of not belonging to family, lack of empathy from family members, friends, and relatives, and not having access to a supportive social network.

Feeling of not Belonging to Family

Several FCGs reported feeling isolated within their families, emphasizing a lack of support and recognition. One shared: *"I care for my father wholeheartedly, but I expect all family members to support him. For example, my brother could sometimes call and ask if I was tired; he could be here, but I am alone"* (Participant 9). Another FCG declared: *"If I had my father's support or someone to come and take some responsibilities, the care path would be much easier"* (Participant 4). In addition, one caregiver expressed: *"When you take on all responsibilities and see the ungratefulness of your family members who underestimate your care, you feel dejected"* (Participant 1).

Lack of Empathy from Others

Another challenge faced by participants was experiencing a lack of empathy from family members, friends, and relatives. One FCG believed: *"All relatives always let you down. They think that you are treating the patient in a meaningless way with no outcomes. I felt very upset and just turned to God for help"* (Participant 5). Another participant commented: *"No close relatives supported. We did not expect money, but they could have merely called or shared their empathy, but I did not receive it at all"* (Participant 2). Another FCG said: *"Friends and relatives come and visit my daughter, but they only heave a sigh and moan. Most of them make you feel below par"* (Participant 1).

Lack of Access to a Supportive Social Network

A notable challenge reported by FCGs was the absence of a supportive social network that could help alleviate their pain and suffering through shared experiences and mutual support. For example, one participant remarked:

Table 2. Family caregivers' care challenges

Main categories	Subcategories	Codes
Non-supportive healthcare system	Non-therapeutic communication by HCPs	Discomfort with bad news delivery by physicians; nurses' inappropriate behaviors affecting caregivers' emotional well-being
	Inadequate equipment in hospitals	Lack of chairs for caregivers; absence of pleasant environments outside hospitals for mental refreshment
	Limited access to medical services	Unavailability of high-quality colostomy bags; limited access to chemotherapy drugs
Lack of social support	Feeling of not belonging to family	Lack of family cooperation; feeling unappreciated
	Lack of empathy from others	Lack of empathy from friends and relatives; disappointment due to relatives' statements
	Lack of access to a supportive social network	Absence of online groups to share experiences with other caregivers; restricted access to low-cost counseling centers for caregivers
Care strain	Multiplicity of roles	Exhaustion from assuming multiple roles; worries about taking on the roles of a father, a husband, and a son
	Social stressors	Reduced communication with colleagues as a result of job quitting and taking on more duties; Social isolation after reduced communication with friends
	Psychological stressors	Constant anxiety about the patient's future; depression from changes in living conditions
	Financial stressors	Selling property for medical costs; job loss due to full-time caregiving
	Physical stressors	Back pain after increased physical work during caregiving; insomnia owing to full-time caregiving
Unmet educational needs	Need to increase care knowledge	Need to obtain more information about communicating with patients; need to gain more information on nutrition and colostomy bags
	Need to learn care skills	Need to learn how to change colostomy bags; need to learn how to feed patients through nasogastric tubes

"One of my relatives who is now living in Europe told me they attended group counseling sessions, particularly group therapy. They also participated in online groups under the supervision of psychologists and nurses, so they could be in touch. Unfortunately, such services are not available in Iran" (Participant 11). Similarly, another FCG added: "I wish there were NGOs, support groups, or centers where people with similar experiences could find each other. Only someone with the same experience can understand us" (Participant 2).

Care Strain

All participants complained about the heavy burden of caregiving, mostly caused by the multiplicity of roles and the accompanying social, psychological, financial, and physical stressors.

Multiplicity of Roles

The majority of FCGs in this study faced numerous challenges after assuming their caregiving responsibilities alongside their personal roles. For example, one participant asserted: "I am the oldest son in the family. These days, my father is sick and cannot manage the conditions, so I have taken on his duties. I have to think about my brother's future and take care of my mother more than before. My responsibilities have proliferated" (Participant 10). Another mentioned: "My father has died. I have a sister younger than me and a sick mother now. In addition to being the son of the family, I have always been a father at home. I am a farmer, but these days I have to take care of my mother as a duty" (Participant 4).

Social Stressors

Caring for patients with GI cancer often led to social isolation and disrupted employment. One participant, for example, alleged: "I closed my shop for a while because I have to care for my mother round the clock. Sometimes, I don't even have enough time to answer my friends' calls"

(Participant 7). Another participant mentioned: "I used to meet my friends every few days, but now I cancel my plans to take care of my mother. Currently, I feel somewhat isolated" (Participant 3).

Psychological Stressors

The FCGs of patients with GI cancer also encountered many psychological stressors during care. As an instance, one participant stated: "My mind is always busy thinking about the patient. I cannot relax, and I worry about the future of the disease" (Participant 6). Another said: "When you take care of the patient, you are always with them. You see how their mood is affected. You are in a bad mood when you see your loved one has lost her hair because of the treatments" (Participant 2). Besides, another participant added: "Too much stress and anxiety I put up with recently for my father's treatment and future have definitely reduced my efficiency" (Participant 9).

Financial Stressors

One of the main concerns among the FCGs in the present study was the financial problems following job loss to care for the patients, along with the high healthcare costs of the disease. For example, a self-employed participant remarked: "I closed my shop for a while, because I have to be with my mother all the time" (Participant 7). Another participant stated: "Over and above the high costs of the chemotherapy drugs, there are some smaller expenses that may be left unnoticed; for example, the colostomy bag must be changed every four or five days, which costs 1,200,000 Iranian Rial each; it is a great deal" (Participant 10). One participant also pointed out the high costs of some special diets for patients with GI cancer: "The physician recommended meat, liver, and even some special supplements for the patient, but their high costs made my mother tell me not to continue the treatments" (Participant 3).

Physical Stressors

Caregivers experienced numerous physical health problems due to their caregiving duties. In this regard, one of the participants affirmed: *"The physical effort involved in bathing, massaging, and moving the patient hurts caregivers physically"* (Participant 10). Another FCG said: *"I try to care for myself while attending to the patient, but over time, I hurt myself. For example, I sometimes have to go through sleepless nights and come down with headaches due to my mother's acute pain or her poor health condition"* (Participant 11).

Unmet Educational Needs

This main category represented the FCGs' need to increase care knowledge and learn practical skills to care for patients with GI cancer.

Need to Increase Care Knowledge

According to FCGs' experiences, caregivers highlighted a significant gap in their knowledge about caring for patients with GI cancer, which has largely been overlooked. One participant asserted: *"I had no information about patients with cancer and even the disease itself. I did not know about the way family members should behave. No one taught, so I had to look for information on Google myself"* (Participant 7). Another participant stated: *"At first, we were confused; for example, we did not know what foods we should prepare and which ones were good. We received some education in the hospital. In fact, I myself asked for more information, but it was very limited and merely covered general information. I constantly asked questions to gain more understanding"* (Participant 5).

Need to Learn Care Skills

In addition to theoretical knowledge, the participating FCGs expressed a pressing need to acquire practical caregiving skills. A participant described *"One of the biggest challenges was changing the colostomy bag. I had never seen or done it before. I did not know about it. When I was in the hospital, I asked the nurse to teach me how to change it"* (Participant 5). Another highlighted: *"I think they should hold a series of educational classes for caregivers because the education they provide in the wards is inadequate. For someone unfamiliar with medical procedures, feeding the patient via a tube is a failure. I think a two-minute explanation at the bedside does not suffice"* (Participant 6).

Discussion

This study explored the caregiving challenges faced by family caregivers of patients with gastrointestinal cancer. Based on participants' experiences, four main categories of challenges emerged, including *non-supportive healthcare system, lack of social support, care strain, and unmet educational needs*.

A primary challenge identified was the non-supportive healthcare system, which included non-therapeutic communication by HCPs, inadequate equipment in hospitals, and limited access to medical services. Similar findings were reported in a qualitative study conducted in

Denmark, emphasizing the importance of support from HCPs and effective communication for FCGs of patients with cancer (25). Furthermore, Hamedani et al. highlighted the role of the healthcare system in mitigating the challenges among the FCGs of patients with cancer, stressing the need for adequate support and facilitated access to healthcare services (20). The findings of another study in Iran further confirmed that the lack of financial and social support from the healthcare system, along with the challenges caused by caregiving, could lead to caregiver fatigue and hinder their ability to perform ADLs (26). These findings underscore the necessity of recognizing family caregivers as vital, informal members of the healthcare system (27), whose well-being should be prioritized by HCPs to enhance their quality of life and, ultimately, patient outcomes in the long run (10).

Lack of social support, manifesting as feelings of being unsupported and misunderstood by family, friends, and relatives, and the lack of access to a supportive social network, was another significant challenge faced by the FCGs of patients with GI cancer in the present study. In line with these findings, Nemati et al. revealed that long-term caregiving could decrease family support, despite the family's traditional role as a source of safety and patronage for its members in Iran, thereby exacerbating the FCGs' pain, suffering (26), and perceived helplessness (28). Beyond family, FCGs expressed the need for peer support (29), social networks (27), and social acceptance (20). They could accordingly take part in group discussions with those having the same conditions about the ways to cope with their new life conditions (29). Besides, online social support groups could create a sense of cohesion and belonging to the society in FCGs and provide a great opportunity to share information and benefit from emotional support (30). Social support could further improve their quality of life by raising motivation and a sense of belonging through allaying the psychological burden of caregiving. This need could be met by implementing low-cost counseling programs for family members of patients with cancer and creating online social groups under the supervision of hospitals.

Care strain was identified as a prominent challenge for all FCGs of patients with GI cancer in this study, involving physical, psychological, financial, and social stressors experienced during patient care. Most studies on FCGs of patients with cancer align with these findings, reporting moderate to severe caregiving burden (27, 28, 31, 32). For example, a review study in 2020 showed that FCGs of patients with cancer could be subjected to physical problems, including pain, fatigue, and sleep disturbances; mental health issues like depression, anxiety, and panic; social disorders, such as loneliness and isolation; and financial difficulties caused by job loss (10). Too et al. correspondingly mentioned care strain due to multiple tasks, such as bathing patients, dressing wounds, giving medicines, lifting patients, and taking patients outside (27). Among mental disorders, depression and anxiety had high prevalence rates in FCGs, as they were related to care strain

(13). FCGs of patients with cancer also have to spend long hours day and night to deliver care (28), which could lead to job quitting. Furthermore, high healthcare costs, limited insurance coverage, and transportation could force them to sell their properties and undergo huge financial burdens (27). Accordingly, patient care is considered a complex process, requiring extensive preparation and support. Moreover, FCGs are at risk of experiencing harm while providing care; therefore, it is essential to take them into account alongside patients.

Unmet educational needs also emerged as a significant challenge in this study. FCGs expressed the need to improve their care knowledge and acquire practical caregiving skills. Consistent with these findings, FCGs in the study by Nemati et al. reiterated the need for knowledge and caregiving skills as one of their challenges (26). Too et al. also mentioned the urgent need to address information necessities for care among FCGs (27). Vale et al. further emphasized that the lack of caregiving skills and experience could be a primary source of stress in FCGs (28). Access to accurate information about cancer, care, and treatment has also been cited as one of the unmet needs among FCGs (29, 33). Knowledge and skills could play leading roles in patient care. Nevertheless, many FCGs reported not receiving education for this purpose (26). Caring for patients is a difficult and stressful task, and it could become a debilitating process if caregivers do not know the practical principles of caregiving. Therefore, HCPs, particularly nurses, could help reduce the pain and suffering of FCGs of patients with GI cancer by providing sufficient information and teaching caregiving skills at discharge.

Conclusion

The long-term care of patients and their associated challenges significantly impact family caregivers, often disrupting their lives and compromising their health in various dimensions. Given the vital role that FCGs play in the healthcare system, their well-being warrants thorough attention and support. Understanding their caregiving experiences is essential for enhancing the quality of care provided. Based on the findings of this study, it is imperative to prioritize health policies that incorporate the needs of family caregivers into overall health planning. Moreover, providing targeted feedback from the Ministry of Health and Treatment to the government regarding caregivers' welfare needs and required facilities at the community level is essential. Establishing and promoting social support mechanisms, such as caregiver support groups and public awareness campaigns, can also be highly beneficial. In addition, training healthcare staff in effective communication with caregivers and offering educational programs for caregivers on caring for patients with gastrointestinal cancer in hospitals can help reduce the challenges faced by family caregivers, which in turn would lessen caregiver burden.

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Authors' Contribution

Conceptualization: Nazila Javadi-pashaki, Fereshteh Mollaei, Moluk Pouralizadeh, Hamid Sharif-Nia
Data Curation: Nazila Javadi-Pashaki, Fereshteh Mollaei
Formal Analysis: Nazila Javadi-Pashaki, Fereshteh Mollaei, Moluk Pouralizadeh
Funding Acquisition: Nazila Javadi-Pashaki
Investigation: Nazila Javadi-Pashaki, Fereshteh Mollaei, Moluk Pouralizadeh, Hamid Sharif-Nia
Methodology: Nazila Javadi-Pashaki, Fereshteh Mollaei, Moluk Pouralizadeh, Hamid Sharif-Nia
Project Administration: Nazila Javadi-Pashaki
Software: Fereshteh Mollaei
Supervision: Nazila Javadi-Pashaki
Validation: Nazila Javadi-Pashaki, Moluk Pouralizadeh, Hamid Sharif-Nia
Visualization: Nazila Javadi-Pashaki, Fereshteh Mollaei, Moluk Pouralizadeh, Hamid Sharif-Nia
Writing–Original Draft: Fereshteh Mollaei

Competing Interests

The authors and the organizations involved declare no conflicts of interest.

Ethical Approval

The present study was approved by the Vice-Chancellor for Research and Technology of Guilan University of Medical Sciences, Iran [IR. GUMS.REC.1401.600].

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