Current Research Status on the Caregiving Experience and Needs of Family Caregivers of Patients with Gastrointestinal Cancer: Postprint

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Date: 2023-06-12T00:00:00+00:00

Abstract

This article reviews the caregiving experiences and needs of family caregivers of patients with gastrointestinal tumors. The caregiving experiences mainly encompass three dimensions: excessive psychological burden, diminished physiological function, and restricted social functioning. Caregivers' needs are primarily manifested as a strong desire for knowledge and skills in caring for gastrointestinal tumor patients, as well as needs for emotional and social support. This article also systematically summarizes supportive intervention measures for these caregivers, recommending that nursing professionals should attend to caregivers' negative psychological issues, harness positive psychological effects, help strengthen their social support systems, and meet their psychological support needs, thereby improving caregiving quality.

Full Text

Abstract

This paper reviews the care experiences and needs of family caregivers of patients with gastrointestinal cancer. The care experiences of these caregivers mainly include three aspects: excessive psychological burden, decreased physiological function, and limited social function. Their needs are primarily concentrated in the thirst for knowledge and skills in caring for gastrointestinal cancer patients and the demand for emotional and social support. This article also summarizes intervention measures to support family caregivers of gastrointestinal cancer patients and suggests that nursing staff should pay attention to caregivers' negative psychological problems, leverage positive psychological effects, help caregivers strengthen their social support systems, and meet their psychological support needs, thereby improving the quality of care.

Keywords: Gastrointestinal tumors; Family caregivers; Care experience; Care needs; Intervention measures

1. Care Experience of Family Caregivers of Gastrointestinal Cancer Patients

Care experience refers to the real feelings caregivers undergo while caring for patients. Family caregivers of gastrointestinal cancer patients experience complex emotional experiences during the perioperative period, with both positive and negative aspects, though negative experiences predominate, creating significant pressure and burden across physiological, psychological, and social domains.

1.1 Psychological Overload

Worry about disease prognosis: Studies have shown that concern about the disease and prognosis of gastrointestinal cancer patients is a primary factor causing excessive psychological burden in family caregivers. Ringborg et al. found that family caregivers experience heavy psychological load due to intensive caregiving work and worry about surgical outcomes. In a qualitative study on the physical and mental state of caregivers of gastric cancer patients nearing discharge, caregivers described: "I constantly worry whether my family member' s gastric cancer will recur after surgery, and I' m afraid the tumor will metastasize elsewhere." "Recently, I often have wandering thoughts, feeling empty and confused every day, with many things on my mind, feeling very anxious, and tossing and turning at night unable to sleep." Jeon et al. demonstrated that this uncertainty-related worry and anxiety is most severe among middle-aged family caregivers, likely because they bear more responsibilities in life, society, and family.

Fear of emergencies: Family caregivers express fear and helplessness about potential "emergencies or long-term complications" that may occur at home. This fear stems partly from lack of disease-related knowledge, as one caregiver noted: "The only possible emergencies at home I can think of are changes in blood pressure and blood sugar. What complications might actually occur after gastric cancer surgery? How should we prevent and respond to them? I really don' t know, and I' m worried I can' t handle it." It may also arise from caregivers' acquisition and application of caregiving skills. Taleghani et al. reported caregivers describing: "What should I do if belching, acid reflux, or vomiting occur after discharge? How should I handle complications or stomach discomfort? Just thinking about it makes me panic and feel completely at a loss."

Pain of concealing the diagnosis: In caring for gastrointestinal cancer patients, family caregivers experience distress regarding whether to disclose the malignant diagnosis. They face contradictory feelings and uncertainty about appropriate communication, leaving them particularly helpless. In a qualitative study on caregiving needs of postoperative gastric cancer patients, one family caregiver mentioned: "We have to pretend everything is fine in front of him, but I' m actually under tremendous pressure with no one to talk to. I' m afraid he can' t accept the truth, so I made up a less serious condition and told him it' s a gastric ulcer." Another described: "I always act relaxed and fine in front of him, and I even prepared two sets of medical records specifically to deceive the elderly. I don' t know if this is right or wrong, but I' ll hide it as long as possible."

1.2 Physiological Function Decline

Studies indicate that only a small percentage of gastrointestinal cancer family caregivers rate their health as good, with most experiencing various degrees of discomfort and fatigue. Caregiving activities negatively impact caregivers' health, leading to declined health status. In reports on living with jejunostomy feeding tubes after esophagogastric surgery, Halliday et al. documented physiological burdens including weight loss, decreased immunity, increased smoking and alcohol consumption, overeating, insomnia, and headaches. Mosher et al. found that while physiological stress comprises a smaller proportion of total stress compared to psychological and social stress, caregivers' physical health receives insufficient attention and warrants greater emphasis. Taleghani et al. reported one gastric cancer caregiver' s description: "I feel my own health is not good either, but I' m not clear about what' s wrong or how serious it is. Meanwhile, I worry that caring for my family member is too exhausting and I won' t be able to hold up."

1.3 Social Function Limitation

Long-term caregiving leads to negative emotions that affect caregivers' harmonious relationships with others. Caregivers describe conflicts between work and caregiving responsibilities: "The conflict between my own job and caregiving is hard to reconcile, forcing me to stay home to care for the patient most of the time." Shih et al. found that some working caregivers lost their jobs due to caregiving, reducing income and increasing financial burden, which creates enormous psychological pressure. Leow et al. described how social interaction becomes limited: "Most of my time is spent accompanying family members, wanting only to be with them, unable to pursue my hobbies and activities." Research indicates that up to a certain percentage of gastrointestinal cancer patient family caregivers ultimately quit their jobs due to caregiving tasks. During caregiving, conflicts sometimes arise between caregivers' and patients' needs, as described: "To care for my father, I almost have no time or energy for my own studies" and "I have gallstones that often hurt badly, but considering my family member just had surgery, I don' t want to have surgery myself, as it would trouble the family again."

2. Needs of Family Caregivers of Gastrointestinal Cancer Patients

2.1 Health Information Needs

Research demonstrates that gastrointestinal cancer family caregivers have strong needs for caregiving knowledge, seeking information on diet and nutrition, postoperative complication prevention, disease prognosis, emergency management, and rehabilitation care. Studies show caregivers lack access to caregiving knowledge when caring for postoperative gastric cancer patients, with a significant percentage eagerly seeking guidance on post-discharge rehabilitation knowledge, particularly regarding home care guidance. Caregivers lack deeper caregiving knowledge and have relatively greater demand for health education content that solves practical problems, necessitating targeted health education based on their needs. In one study, a caregiver mentioned: "Medical staff instructed us on some relevant knowledge and dietary precautions, but for other unclear issues, we buy magazines or search on our phones." Another expressed: "It' s unclear what will happen later or how long he can live. The hospital can' t keep him indefinitely, so how should I care for him after discharge? How should I handle discomfort symptoms?" Research indicates most family caregivers have not received relevant professional training or skill guidance, leaving them unable to address various caregiving problems, which further exacerbates caregiving burden. One caregiver described: "Last winter, my father couldn' t get out of bed. We worried about pressure sores from prolonged bed rest, but besides medication, we understood nothing and didn' t know if there were any good solutions."

2.2 Social Support Needs

Psychological research considers social support an important buffer and predictor of caregiving burden. To better adapt to the caregiving role, family caregivers crave external support and assistance. They hope to find reasonable ways to vent emotions while receiving encouragement and care, as expressed: "I always feel blocked inside. If there were a dedicated place where we could talk and vent together, that would be good." Studies show social support negatively correlates with caregiving burden—higher social support levels correspond to lower burden. Research also demonstrates caregivers urgently need guidance and help from medical professionals through phone follow-ups, home visits, and health education lectures.

3. Support Measures for Family Caregivers of Gastrointestinal Cancer Patients

3.1 Intervention Measures Based on Health Education Theoretical Models

Zhang et al. applied a narrative intervention model to spouses of advanced gastric cancer patients in a week-long intervention study, using patient-spouse dyads as the implementation unit. The intervention comprised four stages: inner awareness, storytelling, experience sharing, and cognitive restructuring, effectively reducing anticipatory grief and improving coping abilities. Wei et al. applied continuous nursing theory based on standardized health education templates to family caregivers of esophageal cancer patients for a period, significantly reducing adverse emotional reactions and improving caregiving ability ($P<0.05$). Zhang et al. developed a family empowerment intervention for primary caregivers of esophageal cancer patients during the perioperative period based on empowerment theory, featuring one-on-one bedside health education daily for about 30 minutes across three phases: admission, perioperative, and pre-discharge. Results showed comprehensive caregiving ability scores significantly higher than the control group ($P<0.05$). This approach emphasizes caregiver emotional expression, encouraging them to voice concerns, establishing WeChat communication platforms among patients for emotional support and psychological counseling, discussing solutions with patients and caregivers, providing written care plans, and guiding implementation while offering timely instruction, encouragement, and praise to enhance caregiving confidence and competence.

3.2 Caregiver Participatory Enhancement Measures Based on Modern Information Technology

Recent studies show that utilizing modern information technology—such as mobile apps, WeChat, QQ, social networks, and wearable devices—to establish interactive health education platforms can enhance family caregiver competence. Research demonstrates that establishing a "concurrent care" WeChat public platform and groups, combined with phone follow-ups, effectively improves quality of life for both gastric cancer patients and their caregivers. Other studies explored telephone, QQ, or WeChat-based interventions for primary caregivers of digestive system cancer patients, providing information support, emotional support, interpersonal coordination, and caregiving problem solutions for 15-30 minutes per session, significantly reducing caregiving burden scores in the intervention group ($P<0.05$). Research indicates "Internet+" applications in medical services offer numerous benefits and have become a social trend, with patients, caregivers, and nurses all emphasizing the indispensability of "Internet+" continuous care platforms for recovery and improved family caregiving capacity.

4. Summary

Family caregivers of gastrointestinal cancer patients undergo complex emotional experiences, commonly experiencing excessive psychological burden and impaired physiological and social functions. They relatively lack knowledge and skills for caregiving and hope their emotional and social needs receive attention and support. Developing nursing intervention strategies based on health education theoretical models and modern Internet information technology represents the primary method for reducing caregiving burden and enhancing caregiving capacity. Combining "Internet+" models to achieve innovative and diversified intervention content and forms warrants further exploration and research.

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Note: Figure translations are in progress. See original paper for figures.