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REVIEW

Caregiver Burden in Bladder Cancer Patients with Urinary Diversion Post-Radical Cystectomy and the Need for Comprehensive Nursing Education: A Narrative Literature

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Background: Bladder cancer ranks seventh in global cancer prevalence. Radical cystectomy and urinary diversion are standard for muscle-invasive bladder cancer. Family caregivers shoulder a substantial care burden, affecting their own quality of life, with repercussions extending to patients' health-related quality of life (HRQOL).

Objective: This narrative review aims to highlight the major concerns perceived by the caregivers and efficacy of nurse-led interventions in alleviating their concerns and improving HRQOL.

Methods: A systematic search of the PubMed, CINAHL, and Science Direct databases was carried out to identify studies published in the last 5 years (from Jan 2018 to Aug 2023) that have evaluated the concerns and problems of caregivers attending bladder cancer patients with urinary diversion. Additionally, studies evaluating the efficacy of nurse-led interventions in alleviating these concerns were also searched.

Results: Overall, 6 studies involving 933 BC patients with UD and 1042 caregivers were identified as suitable for inclusion in this narrative literature review. Major concerns identified included psychological well-being, medical assistance needs, and peer support. Significant psychological impact was evident in the caregivers which operated in a dyadic manner. Nurse-led stoma education programs have demonstrated potential in enhancing caregivers' quality of life, although they remain restricted.

Conclusion: Emphasizing caregivers' role and program effectiveness is critical. Our review addresses these gaps, focusing on caregivers' concerns and the impact of nursing education for improved patient outcomes.

Implications for Practice: Holistic and collaborative approach could enhance the overall well-being and quality of life of bladder cancer patients and their caregivers.

Keywords: caregiver, nursing care, nurse-led training, bladder cancer, urinary diversion, quality of life

Introduction

Bladder cancer ranks globally as the seventh most prevalent cancer.[1,2] Optimal management of muscle-invasive bladder cancers (MIBC) involves radical cystectomy (RC) combined with urinary diversion (UD), typically via ileal conduit (IC) surgery.[2,3] Patients undergoing RC and IC face the daily challenge of managing an ostomy, impacting their psychosocial well-being.[4–6] Inadequate preparation post-ostomy can lead to more clinic visits, stoma-related complications, and difficulty coping with negative body image, adversely affecting post-operative quality of life.[4–9] RC plus UD achieves a significant 5-year cancer-specific survival (CSS) rate of up to 76% for MIBC patients.[10,11] Concurrently, years lived with disability (YLDs) have increased over the last three decades.[1–3] Given these CSS and YLDs statistics, the rising number of individuals living with urinary diversion underscores the need to enhance post-ostomy quality of life.

Family caregivers play a pivotal role alongside ostomy patients and their medical/nursing care, forming a crucial part of the healthcare triad for bladder cancer patients undergoing RC plus UD, shouldering a significant burden (Figure 1).[12,13] These

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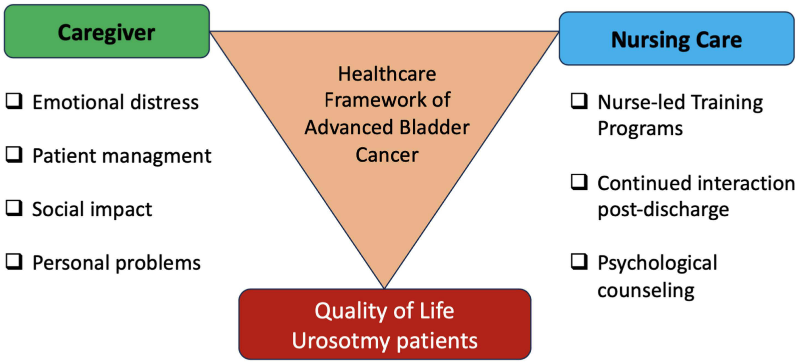

Figure 1 A nursing perspective of healthcare framework of advanced bladder cancer patients undergoing urinary diversion.

caregivers manage not only cancer-related duties but also provide essential support for ostomy care, including nursing tasks, appointment coordination, handling complications, and offering emotional support.[13] Financial strains, including medical costs and potential work interruptions, further complicate their role.[14] Research indicates that family caregivers often experience a diminished quality of life, impacting the health-related quality of life of the patients they support.[14–16] Thus, prioritizing the well-being of family caregivers has the potential to improve the long-term health-related quality of life for these patients, a trend observed in other chronic conditions.

Extensive research on stoma education programs led by medical professionals and nurses consistently shows positive psychological outcomes, including improvements in quality of life (QOL), self-care skills, and self-efficacy.[17–25] These initiatives cover essential patient needs such as effective stoma management, appliance care, dietary adjustments, and addressing sensitive issues like sexuality. Typically conducted in small group settings involving both patients and caregivers, these programs are often facilitated by lay and peer educators.[16–24] Despite the widespread availability of hospital-based pre/postoperative urostomy self-management guidance, patients frequently struggle to maintain this knowledge over time, resulting in ineffective self-care practices.[26,27] Caregivers, often focused on the immediate physical needs of the patient and managing the cancer diagnosis, may inadvertently neglect the reinforcement of stoma education. Furthermore, evaluations of quality of life and program effectiveness typically focus solely on patients, overlooking the critical role of caregivers in the process. Therefore, it is crucial to highlight the inherent limitations of current education programs and the underrepresentation of caregivers in these efforts. Addressing these gaps is essential for enhancing the overall framework of this healthcare triangle comprehensively.

Up to this point, the challenges experienced by these patients have been extensively studied; however, a comprehensive overview of the concerns of family caregivers and their caregiving burden in this specific context is lacking. In this regard, we have conducted an extensive review to analyze and outline these concerns, alongside a crucial evaluation of the role played by nursing education programs and useful recommendations for nursing care.

Methods

Research Strategy

PubMed, CINAHL, and Science Direct databases were employed to locate research studies published in the last 5 years (from Jan 2018 to Aug 2023). The study utilized a set of search terms, which were applied either individually or in combination across all fields. These search terms encompassed "bladder cancer", "invasive bladder cancer", "caregiver", "cancer caregiver", "urinary diversion", "urostomy", "ileal conduit", "nursing care", "nurse led training", "quality of life", "health-related quality of life", and "factors influencing quality of life". Additionally, we identified potential studies by reviewing the references of pertinent articles. Two reviewers conducted a stepwise procedure involving retrieval, organization, and screening to determine which studies met the eligibility criteria. Any disagreements were resolved through mutual consultation. In the reporting of this study, we adhered to the PRISMA criteria guidelines for reporting items for Systematic Reviews and Meta-Analyses, as outlined in Supplementary Table 1.

Eligibility Criteria

Caregivers providing care to bladder cancer patients who have undergone cystectomy with urinary diversion were assessed for their health-related quality of life. The primary focus was on examining how caregiving impacted the well-being, emotional coping, healthcare requirements, and other aspects of caregivers. This study excluded case studies, conference abstracts, letters to the editor, literature reviews, systematic reviews, and meta-analyses. The inclusion criteria also stipulated that studies must be published in the English language.

Data Extraction and Synthesis

The study characteristics and participant details were gathered by extracting information such as the first author's name, publication year, study design, the quantity and demographic composition of participants, and the evaluation tools used. Participant attributes encompassed age, gender, and their relationship with the patient. Furthermore, relevant outcome measures, including psychological well-being, coping mechanisms, and medical requirements, were also obtained. To facilitate organization, the collected data were then structured into a tabular format.

Results

The initial database search, using specific keywords, produced a total of 7359 studies. Following the screening of titles and abstracts and the removal of duplicates, 7308 studies were eliminated. A more comprehensive assessment based on eligibility criteria resulted in the final selection of 6 studies, which included 933 bladder cancer patients (excluding the 9 participants with ileostomy/colostomy in the study by Mohamed et al) with urostomies, as well as 1042 caregivers.[16,19,28–31] The research strategy and process of study selection is illustrated in Figure 2. It's important to note that the study conducted by Masiero et al, did not provide the exact number of caregivers attending to the 382 bladder cancer patients with urostomies.[16] Four of the studies examined the impact of caregiving on the Health-Related Quality of Life (HRQOL) of caregivers for bladder cancer patients with urostomies.[16,19,28,29] While, two studies investigated the effects of nurse-led interventions in improving the HRQOL of these caregivers.[30,31] For further studies and participant characteristics, please refer to Table 1.

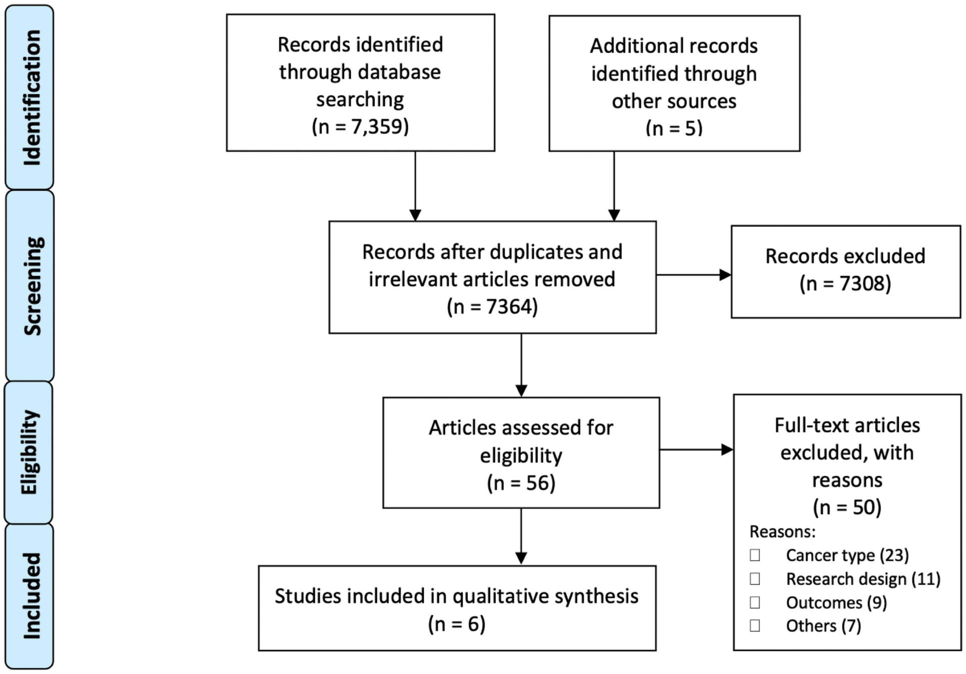

Figure 2 Research strategy and study selection.

Table 1 General Characteristics of the Included Studies and Participants

Study Groups	**Studies Describing Caregiver Concerns**				**Nurse-Led Intervention Studies**	
First author and year	Masiero, M. et al 2021[16]	Renner, S. et al 2023[28]	Mohamed, N.E. et al 2021[29]	Iovino, P. et al 2023[30]	Wulff-Burchfield, E. M. et al 2021[19]	Fan, X. et al 2022[31]
Study Design	Observational study of patients and caregivers	Infodemiology study using social media data	Qualitative, descriptive	Cross sectional questionnaire by interview	Qualitative, descriptive	Randomized controlled trial (RCT)
Country	Italy	United States of America	United States of America	Italy	United States of America	China
Setting	European Institute of Oncology, RCCS, Milan, Italy	United States geolocalized sites	Icahn School of Medicine at Mount Sinai	Multicentre	University of Kansas Medical Center, Kansas City, KS, USA	First Affiliated Hospital of Wenzhou Medical University
Assessment tool	EORT QLQ-C30 and emotion thermometer (ET)	Manual and automatic Methods to extract and analyze several hundreds of social media posts for caregiver unmet needs	Self-designed interview encompassing three major domains: (1) functional and lifestyle changes, (2) emotional adjustment, and (3) postsurgical complications and side effects	Caregiver Contribution to Ostomy Self-Care Index; Depression was assessed with a nine-item Patient Health Questionnaire	Self-prepared questionnaire	Zarit Caregiver Burden Interview (ZBI) and the Simplified Coping Style Questionnaire (SCSQ)
Nurse-led interventions					Preoperative 2-hour Stoma Boot Camp	Internet Plus Health Education (IPHE) versus conventional care instructions
Intervention team					A urology nurse practitioner, an ostomy nurse, and a project coordinator	A urologic surgeon, an enterostomal therapist (ET), a registered nurse (RN), 3 nurse practitioners (NPs), and a researcher of the present study
Patients						
Number	382	262	30	252	16	
Age	67.29 ± 9.23		66.42 (range: 43–86)	70.05		
Male	319 (82.9%)	57 (20.6%)	23 (77%)	69.8%		
Female		54 (21.8%)	7 (23%)			
Undetermined		151 (57.6%)				
Caregivers						
Number	NA	679	13	252	18	80
Age				58.7		44.57 ± 6.39*
Male		19 (2.8%)	3 (23%)	80.6%		34 (42.5%)
Female		88 (13.0%)	10 (77%)			
Undetermined		572 (84.2%)				

(*Continued*)

Table 1 (Continued).

Study Groups	**Studies Describing Caregiver Concerns**				**Nurse-Led Intervention Studies**	
Relationship						
Spouse	63.8%		11 (84%)			48 (60%)
Child	19%		1 (8%)			23 (28.7%)
Parent			1 (8%)			
Siblings	1.8%					
Family members	2.9%					
Friends	0.3%					
Others						9 (11.3%)

Note: *Estimated mean and standard deviation from median and range or interquartile range.
Abbreviations: EORT QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; NA, not available.

Profiling the Concerns of Caregivers

Family caregivers are confronted with an overwhelming situation, starting from the cancer diagnosis through post-operative discharge and the sustained responsibility of ostomy-related care at home. Providing care for these patients demands a substantial commitment of time and energy. Family caregivers of cancer patients, on average, spend around 32.9 hours per week engaging in diverse caregiving tasks.[12] This encompasses tasks like medication administration, arranging clinical appointments, follow-up visits, and routine check-ups, constituting approximately 60% of the medical and nursing care responsibilities.[12] Upon discharge from the hospital, primary care responsibilities for bladder cancer patients are transferred to home caregivers. These responsibilities encompass tasks such as assessing the stoma and the surrounding skin, replacing the stoma bag, and detecting potential complications.[13] Consequently, this substantial caregiving burden has been shown to profoundly impact the caregivers' own quality of life, a consequence that reverberates onto the patients as well.[14–16] In the following sections, we elucidate some of these quality of life effects on the caregivers.

Psychological Well-Being

Several studies present clinical evidence regarding the altered psychological well-being experienced by both these patients and their caregivers. In the research conducted by Masiero et al, they employed an emotional thermometer (ET) comprising five visual analogue scales, ranging from 0 (none) to 10 (extreme), to evaluate emotional distress encompassing stress, anxiety, depression, anger, and the need for help among bladder cancer patients with UD and their caregivers.[16] Remarkable differences were observed at all time points (T0 [1 month before surgery], T1 [2 weeks after surgery], T2 [6 months after surgery]) in emotional total scoring for both patients ($F (1, 596) = 150.307$, $p < 0.001$, $\eta 2 = 0.335$) and caregivers ($F (2, 492) = 152.341$, $p < 0.001$, $\eta 2 = 0.382$). Specifically, elevated distress was evident immediately after diagnosis for both patients (T0: $M = 17.53$, $SD = 11.25$; T1: $M = 3.93$, $SD = 7.96$, $p < 0.049$) and caregivers (T0: $M = 20.46$, $SD = 11.62$; T2: $M = 3.72$, $SD = 9.026$, $p < 0.001$). In a separate study, the key Discussion themes and unmet needs of both patients with advanced bladder cancer (aBC) and their caregivers were assessed through a mixed methods analysis of social media posts.[28] Through the random selection of 423 caregiver posts from a total of 1214 posts written by 679 caregivers engaged in conversations about aBC, a total of 36 distinct unmet needs among these caregivers came to light. Notably, a leading issue centered on the psychological consequences of aBC, encompassing 26.0% (46/177) of the cases.[28] In another investigation that included 13 caregivers and 30 participating patients, 70% of whom had undergone urostomies due to bladder cancer, indicated a substantial emotional impact of watching their loved ones struggle with surgery and stoma care (82%).[29]

A Patient-Caregiver Dyad: The Impact of Psychological Well-Being of Caregiver on the Patient's Quality of Life

Psychological well-being of patient and caregiver was shown to be intertwined in a dyadic manner, impacting each other reciprocally. In bladder cancer patients with UD, Masiero et al revealed that elevated emotional distress in caregivers correlated with poorer HR-QoL and low patient perceptions of QoL and global health, persisting consistently over a 6-month postoperative period.[16] Specifically, emotional thermometer total scoring in caregivers showed positive correlation with HR-QoL at T0 ($r = 0.359^{**} p < 0.001$), T1 ($r = 0.502^{**} p < 0.001$), and T2 ($r = 0.606^{**} p < 0.001$). Conversely, emotional thermometer total scoring in caregivers was inversely correlated with patient perception of QoL (T0: $r = -0.625^{**} p < 0.001$; T1: $r = -0.416^{**} p < 0.001$; T2: $r = -0.604^{**} p < 0.001$) and global health (T0: $r = -0.585^{**} p < 0.001$; T1: $r = -0.463^{**} p < 0.001$; T2: $r = -0.648^{**} p < 0.001$) at all time points. In a separate investigation, Iovino et al examined the correlation between patient and caregiver depression and patient self-care and caregiver involvement in self-care related to ostomy care.[30] They employed the Patient Health Questionnaire, Ostomy Self-Care Index, and Caregiver Contribution to Ostomy Self-Care Index for this purpose. Within the group of 252 patient-caregiver dyads, the findings demonstrated a positive correlation between patient depression and caregiver contribution to self-care maintenance. Conversely, caregiver depression exhibited a negative association with self-care management.

Fear of Coping with Care Challenges and Medical Needs

Studies indicate that family caregivers require increased assistance during the patient's discharge from the hospital. In healthcare facilities, patients and their family caregivers typically receive concise training from medical experts, including tasks like assessing the stoma and peristomal skin, emptying the ostomy appliance, and changing the ostomy appliance. Nevertheless, once they are back at home, caregivers confront difficulties related to ostomy management. This includes challenges in retaining education, particularly when it's provided post-operatively, and they also contend with relatively restricted support from healthcare professionals.[16,26,27] Considering the single visual analogue scales employed in the study conducted by Masiero et al, noteworthy distinctions were identified for the "need help" aspect ($F(2, 126) = 13.281$, $p < 0.001$, $\eta 2 = 0.174$), which exhibited a reduction from T0 to T2 ($p < 0.001$) as well as from T1 to T2 ($p < 0.011$).[16] Similarly, fear and management of patient adverse events (22/177, 12.4%) formed the third most prevalent unmet needs among the identified 36 unique unmet needs within caregivers of aBC patients.[28] Mohamed et al's research, involving 13 caregivers, also revealed that all caregivers were not adequately prepared for the patient's ostomy surgery and how to assist with stoma care.[29] Most caregivers (95%) reported challenges with stoma care. Moreover, 64% of the caregivers described postsurgical complications as major challenges for both patients and caregivers.[29] Moreover, participants (both patients and caregivers) in the research conducted by Elizabeth et al had also expressed concerns regarding stoma care and post-ostomy surgery quality of life, motivating them to engage in a nursing training program.[19] These findings underscore the necessity for enhanced post-hospitalization caregiver support and education programs.

The Need for Support Groups and Peer Interaction

Another aspect that emerged within the realm of caregiving was the keenness to become part of support groups and exchange their experiences with fellow peers. In the research by Renner et al, the recognition of the necessity for support groups and the sharing of experiences among peers (28/177, 15.8%) emerged as the second most prevalent need among the 36 distinct unmet needs identified within caregivers of aBC patients.[28] Likewise, in the study conducted by Mohamed et al, 45% of the participating caregivers advised seeking social support from various outlets, including online cancer support groups.[29]

Others Factors

While existing studies primarily focused on addressing concerns related to caregivers of patients undergoing cystectomy and urinary diversion, it's noteworthy that some of the apprehensions highlighted for urostomy patients could potentially extend to caregivers as well.[16,28,29,32–36] As an example, challenges encompassing daily routines, leisure activities, employment and financial matters, sleep disturbances, sexual issues, family or spouse conflicts, social interactions, and uncertainties regarding the future.[16,32–36] In a study by Mohamed et al, it was reported that 95% of caregivers experienced an impact on their relationships, including their intimate lives.[29] Financial worries were also evident, as a study involving 123 caregivers, 17% of whom were attending to bladder cancer patients with urostomy, revealed heightened economic concerns. The findings suggested pronounced financial strain among caregivers with young children (34%) and those who were older (mean age=56.10 years; SD=10.56).[14] These factors necessitate thorough examination in future research endeavors to enhance the overall quality of life for caregivers.

Role of Nursing and Critical Evaluation of Nurse-Led Training

Given the substantial impact that stoma care has on the well-being of both patients and their caregivers, there is a pressing need for interventions addressing these concerns for both groups. While a limited number of studies have explored the significance of nurse-led training sessions before or after urostomy surgery in bladder cancer patients, the outcomes indicate a positive trajectory in psychological well-being, HRQOL, self-care, and self-efficacy.[19–25] However, the caregivers' quality of life in these training sessions have remained unexamined. Only two studies have reported on the impact of training courses on caregivers' HRQOL.[19,31] An exploratory qualitative study conducted by Elizabeth et al (2021) at the University of Kansas Health System (KUHS) Urology Department aimed to enhance self-management and post-ostomy life for bladder cancer patients.[19] Their Stoma Bootcamp (SBC) education program, devised by a specialized team including a urology nurse practitioner, an ostomy nurse, and a project coordinator, integrated psychosocial care, pre-operative guidance, and instruction by lay and peer educators. Interviews were conducted with a total of 16 patients, 18 caregivers, and 3 program educators, spanning a period from 3 to 18 months post-program. The consensus was that both patients and caregivers found the SBC program to be well-received, effective, and appropriately timed, resulting in a shift from anxious to confident expectations regarding post-ostomy life. Overall, caregivers expressed contentment with the SBC, highlighting their satisfaction in terms of embracing the stoma, developing a comprehensive preparedness for surgery and post-operative care, and mastering practical stoma care skills. Conducted amid the COVID-19 era, another study examined the influence of "Internet Plus Health Education" on the ability of caregivers of urinary stoma patients to cope with care burden and emotional pressure.[31] A total of eighty caregivers were divided into experimental and control groups using randomization. The experimental group underwent digital nursing education (Internet Plus Health Education - IPHE), while the control group followed conventional care. After six months, the Zarit Caregiver Burden Interview (ZBI) and Simplified Coping Style Questionnaire (SCSQ) assessed care burden and emotional pressure. Following the intervention, the experimental group displayed notably increased ZBI scores in comparison to the control group, while the SCSQ scores exhibited the opposite trend ($p < 0.01$). The experimental group also demonstrated a significantly reduced rate of complications (overall incidence: 36.5 vs 7.5, $p < 0.05$), alongside comparatively higher scores on the Family Care Satisfaction Scale (FCSS). This underscores the promising potential of education interventions in ameliorating caregivers' well-being and, consequently, enhancing patient outcomes.

Discussion

It is crucial to grasp the profound impact of caregiving responsibilities on the well-being of caregivers, as this understanding is fundamental for the development of effective support and intervention strategies. Family caregivers shoulder a significant burden, especially when managing ostomies and other care-related tasks. This burden demands attention, as it can jeopardize the caregivers' own quality of life and, subsequently, impact the overall care they provide to patients.

A predominant consequence experienced by patients with bladder cancer and urostomies is the emotional well-being of both patients and their caregivers. The confirmation of a cancer diagnosis induces emotional distress in both parties, further exacerbated by uncertainties surrounding treatment options, associated expenses, disease outlook, and familial care.[37,38] Moreover, after discharge, concerns about the patients' limited knowledge and practical skills that may hinder their ability to provide adequate care add to the escalation of distress and anxiety. In fact, the shock of diagnosis, coupled with apprehension about stoma surgery, has driven patients and their families to participate in interventions like the Stoma Bootcamp, a nursing training session.[19]

An expanding body of research underscores the intricate relationship between the psychological and emotional well-being of caregivers and patients. For instance, studies have shown that cancer patients' use of acceptance coping strategies is associated with a reduction in depression among family caregivers.[39] Conversely, relying on emotional support coping is connected to increased depression in family caregivers and decreased levels of anxiety.[39] Hodges et al have also observed a positive correlation between patient and caregiver distress, underlining the significant impact of one family member's emotional well-being on the other.[40] Furthermore, patients' perception of their cancer symptoms is closely tied to the emotional well-being and physical functionality of their caregivers.[41] Experts have explained this connection by suggesting that caregivers experiencing emotional distress and/or poor physical health might encounter difficulties in effectively supporting patients across various aspects of care.[41,42] This includes attending clinical appointments, administering medical treatments, and assisting patients in understanding medical instructions and making care-related decisions. This relationship has the potential to positively influence a patient's long-term adaptation and resilience to cancer.[37,43] Just as patients and caregivers experience cancer as a dyad, impacting each other reciprocally, their psychological well-being is also intertwined in a similar dyadic manner.[44]

Studies emphasize that family caregivers face substantial challenges upon a patient's discharge from the hospital, particularly in managing ostomies. This includes the need for continuous education and limited post-operative support.[16,26–29] Notably, caregivers in these studies reported difficulties in various aspects of stoma care and coping with post-surgical complications. It is evident that there is a demand for enhanced post-hospitalization caregiver support and educational programs. Caregivers have also expressed a desire to engage in support groups and share their experiences with peers, highlighting the importance of social support.[28,29,37] Additionally, the studies suggest that caregivers contend with a range of concerns, from daily routines and financial worries to intimate relationship challenges, all of which warrant further exploration to enhance caregivers' overall quality of life.[14,16,32–36]

Implications for Nursing Care

Family caregivers shoulder a significant caregiving burden across the trajectory of bladder cancer, from diagnosis to post-operative care. Their involvement is pivotal, yet often overlooked, in the healthcare equation. The psychological well-being of both patients and caregivers is profoundly interconnected, impacting each other's quality of life. The enduring challenges encompass uncertainties, anxieties, and practical concerns, underscoring the need for comprehensive support. Strategies like stoma education programs have shown promise in improving outcomes, but their effectiveness requires ongoing evaluation and caregiver inclusion.

The fear of grappling with post-operative challenges and medical necessities emerges as a significant burden, with caregivers encountering hurdles in retaining education and receiving sustained professional support. Their struggles are further underscored by the prevalence of postsurgical complications and inadequate preparation for stoma care. Moreover, the imperative for support groups and peer interactions is evident, with caregivers yearning for platforms to share experiences and glean insights from their peers. The recognition of these concerns mandates a comprehensive approach to caregiver well-being, warranting focused interventions, enhanced training programs, and the establishment of strong support networks. By addressing the unique challenges faced by family caregivers, we can collectively improve the lives of both caregivers and patients, fostering a more inclusive and holistic approach to bladder cancer care.

Nurse-led training programs have shown promise in improving patients' psychological outcomes, yet caregiver quality of life often goes unexamined. Initiatives like the Stoma Bootcamp have been well-received, fostering confidence and preparedness. A study on "Internet Plus Health Education" during COVID-19 indicated positive effects on caregivers' coping and satisfaction. However, the current research lacks comprehensive exploration of caregivers' concerns. Future efforts should focus on examining the impact of nursing education on caregivers' quality of life, expanding support systems, and addressing physical and psychosocial challenges.

Conclusions

The caregiving responsibilities for caregivers of bladder cancer patients with urostomies significantly impact their well-being, necessitating effective support strategies. Both patients and caregivers experience emotional distress following a bladder cancer diagnosis, exacerbated by treatment uncertainties and caregiving responsibilities. The psychological well-being of caregivers and patients is intricately linked, with each influencing the other's emotional health and ability to manage cancer-related challenges, underscoring the need for professional support. Post-hospital discharge, caregivers face challenges in stoma care management and coping with complications, emphasizing the need for ongoing support and education. Enhancing caregiver support through educational programs and peer support groups is essential to address diverse challenges such as daily routines, financial concerns, and relationship dynamics. Nurse-led programs like the

Stoma Bootcamp and digital health education show promise in alleviating caregiver burden and improving outcomes. In conclusion, our review highlights the gaps in caregivers' perspectives, underscoring the role of nursing education in building a more holistic healthcare framework. Ultimately, the collaborative efforts of patients, caregivers, and healthcare providers are crucial to enhancing the well-being and quality of life of bladder cancer patients and their caregivers alike.

Disclosure

The authors report no conflicts of interest in this work.

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