

ORIGINAL PAPER

Management of the patient with urostomy: Caregiver needs during the three months after discharge. A qualitative study

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Summary *Objective: To examine caregivers' experiences and training needs after radical cystectomy with urinary diversion for the first three months following the patient's discharge.*

Methods: This study applied a phenomenological design approach through open-ended interviews and descriptive analysis.

Phenomenology applied to empirical research requires researchers to explore the empirical facts narrated by participants. This study followed the Consolidated Criteria for Reporting Qualitative Research guidelines, a 32 – item checklist for interviews and focus groups. The study population included caregivers of bladder cancer patients, admitted to three Italian hospitals. Data were collected between March 2020 and March 2022.

Results: Fifty-two caregivers of patients who underwent cystectomy with urinary diversion from three Italian hospitals (41 males and 11 females) participated to the study. The data analysis converged in the identification of three themes – with sub-themes – that included various aspects of the caregiver's lived experiences: 1) living with the burden of being indispensable, for the family member, 2) feeling abandoned by institutions, 3) tiredness and less willingness to look after the relative due to work burden.

Conclusions: Our study demonstrates that the caregiver of a patient with bladder cancer and urostomy in the first three months of hospital discharge is very worried and stressed. Despite the training program received in hospital, the caregiver does not recognize the newly acquired skills and has difficulty applying them. Further study would be required.

KEY WORDS: Bladder cancer; Caregiver burden; Quality of life; Urostomy.

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INTRODUCTION

A bladder neoplasia is a malignant tumour that forms in the bladder wall (1). Worldwide, it is the ninth most common tumour and the most frequent of the genitourinary tract (2), while it accounts for (3, 4) per cent of all malignancies (American Cancer Society). It also ranks fourth among all malignant tumours affecting men and eighth among those affecting women (3). According to the Italian Society Cancer Registry (AIRT) every year among

men, bladder cancer accounts for 70.7 cases per 100,000, while women account for 16.3 cases per 100,000 and it accounts for 3.6 per cent of all cancer mortalities (4.9 per cent men and 1.8 per cent women). The main risk factors include age, gender (men are considered to be at higher risk), smoking, exposure to chemicals; certain drugs used in cancer treatment, such as cyclophosphamide; chronic bladder inflammation such as urinary infections or cystitis; family history (4).

There are various types of treatment including open, laparoscopic, and robotic surgery, immunotherapy, chemotherapy, and radiotherapy (5).

Surgery is the primary treatment for bladder cancer. Depending on the patient's clinical need, bladder cancer surgery may include removal of the tumour from the bladder wall by cystoscopy (TUR-V) or removal of the entire bladder (radical cystectomy).

Patients undergoing radical cystectomy may be candidates for bladder and urinary tract reconstruction or urinary diversion surgery. Patients undergoing radical cystectomy (RC) and ileal conduit must learn to manage an ostomy that requires daily care, manual skills and must cope with the psychosocial impacts that accompany urostomy placement. Maintaining patients' good quality of life (QoL) depends largely on the caregiver's preparation and management skills (6). In this regard, before and after surgery, nursing and medical staff teach the patient and caregivers how to manage the new physical condition (4).

The caregiver's role is of crucial importance; they will be entrusted to follow their relative's assistance at home, throughout the complete clinical and rehabilitation process (7). Unfortunately, many caregivers are not adequately prepared to cope with the physical and psychological changes of post-cystectomy life and this leads to worsen the patients' quality of life (8).

The aim of this study is to examine caregivers' experiences and training needs after radical cystectomy with urinary diversion for the first three months following the patient's discharge. Our study is the first of its kind in Italy, and it focuses exclusively on the three-month period at home, following discharge.

MATERIAL AND METHODS

Design

This study applied a phenomenological design approach through open-ended interviews and descriptive analysis (9, 10). According to *Mortari* (10), phenomenology applied to empirical research requires researchers to explore the empirical facts narrated by participants. The research questions focused on caregivers' experiences while caring for a family member with bladder cancer, who underwent radical cystectomy surgery with urostomy, during the 3 months following discharge. The study followed the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) guidelines, a 32 – item checklist for interviews and focus group (11). This research was approved by the *Ethical Committee of SS Antonio e Biagio e Cesare Arrigo Hospital, Alessandria, Italy* and data collection took place between March 2020 and March 2022.

Participants

This study employed targeted sampling. The study population included caregivers of bladder cancer patients, who underwent radical cystectomy surgery with the creation of an urostomy in three Italian hospitals, willing to share their experiences after their family member's hospital discharge. A minimum of 10 caregivers from each hospital were invited to participate, and recruitment continued until data saturation. Caregiver recruitment took place at the hospital during patient discharge to facilitate collection of the caregivers' experience in the daily management of the disease during the three months following discharge. The inclusion criteria were knowledge of the Italian and English language, as well as experience in home care giving. The physicians and nurses in charge and working in the hospital unit made the initial contact with caregivers at least 48 hrs. before researchers, to ensure that the potential participants had enough time to consider their involvement (12). Caregivers also received a leaflet, outlining the study's principles and inviting their participation. We agreed on this approach, as it was felt that presence of the patient could jeopardise the participant's willingness to be open about some of the more negative aspects of caregiving and thus impact on our aim of obtaining in-depth and richly diverse experiences from the caregivers. Participants provided written informed consent prior to enrolment, and they provided written informed consent to have their anonymized data presented or published.

Data collection

The study setting was represented by the following hospitals: *AOU Policlinico Bari, Puglia; Azienda Ospedaliera Alessandria, Piedmont; Clinica Città di Alessandria, Piedmont*. The data was collected through a semi-structured open-ended interview; according to this type of interview the caregivers were able to describe their experiences according to how and what they thought essential to share. The interviews were conducted by RF (male, Phd MSN, RN), TB (female, PHD, MSN, RN) and (CB male RN, MSN). The interviews were in part face-to-face within the hospital and in part by telephone. Each participant chose between the two methods according to their personal needs. For the caregivers who choose face-to-

face interviews, a room within the hospital facility was available to maintain the confidentiality and the serenity necessary to share their story. The interviews were audio-recorded and verbatim transcribed by the interviewer. A total of 52 interviews were conducted (the time ranged from 30 to 60 minutes) (Table 1).

Data analysis

All Interviews were transcribed verbatim by NVivo 12 and subsequently reviewed by nurse research scientists TB (RN PhD) and FR (RN, PhD). Interviews were analysed using *Colaizzi's* (1978) descriptive analysis framework revisited by *Mortari* (2019), which included the following steps: (1) in-depth reading of the transcripts to gain a deeper understanding and meaning of what was being said, by three researchers (TB, FR, CB); (2) extraction of meaningful descriptions provided by participants (TB, FR); (3) re-formulation of meanings into sub-themes and themes (TB, FR); (4) construction of themes' descriptions of empirical-phenomenological qualities (TB, FR); (5) sharing results with participants for verification (TB, FR); (6) integration of the results into a complete description, i.e. the definition of general statements to summarise the participants' lived experience. *The Qualitative Research Data Analysis Software NVivo* (12) was used for data management.

Table 1.
Caregiver semi-structured interviews.

Did the healthcare staff regarding the postoperative management of your family member, provide useful explanations and advice?
At discharge, did you have any doubts about the management of the necessary guardianship for your family member?
Has your life changed from before surgery? Could you describe what your typical day is like now?
Have you ever thought about going to the accident and emergency unit (A&E) in case of difficulty?
What are the major difficulties encountered in the three months following discharge?

Table 2.
Caregiver socio-demographic characteristics.

Characteristics Caregivers n = 52	
Age	Range 27-73
Gender	
Male	41
Female	11
Educational level	
Elementary	28
Lower intermediate	15
Upper intermediate	7
Bachelor's degree	2
Occupation	
Employed full time	26
Employed part time	7
Unemployed	3
Retired	16
Relationship with patient	
Spouse	34
Daughter	6
Son	12
Home	
Same	42
Different	10

RESULTS

Fifty-two caregivers of patients who underwent cystectomy with urinary diversion in three Italian hospitals (41 males and 11 females) participated in the study. Their socio-demographic characteristics is shown in Table 2.

The data analysis converged in the identification of three themes – with sub-themes – that include various aspects of the caregiver's experiences: 1) living with the burden of being indispensable, for the family member, 2) feeling abandoned by institutions, 3) tiredness and less willingness to look after the relative due to work.

Theme 1: Living with the burden of being indispensable to the family member

This theme describes the burden the caregiver experiences after discharge. Returning home and managing the family member alone, causes insecurity and increases the burden of the caregivers and awareness of their own abilities and limits. Disease management involves the development of skills that the caregiver did not previously possess. Returning home after discharge involves taking full personal custody of the family member, increasing the burden of responsibility. Replacing professional healthcare staff involves the fear of making mistakes and causing harm. Two subthemes have been identified, a) "I am not a healthcare professional" and b) "I am afraid of making mistakes."

Sub-Theme 1a: "I am not a healthcare professional"

During hospitalization, the patient identified and named his caregiver, who participated in an educational training program that included several meetings with doctors and nurses to plan for possible difficulties to be faced while managing the stoma at home. The caregivers in hospital feel secure and are confident that they are capable of coping with the post-discharge process. At home, however, the situation does not reflect the same feelings: "The problem is that at home I don't have the opportunity to compare myself with someone who understands I'm alone" (C6CF), "I am not a nurse and I do not know what to do sometimes I get anxious ... I am afraid of making mistakes" (C2RS)

Sub-Theme 1b: "I am afraid of making mistakes"

"In the hospital I felt protected and when I looked after my family member, I had no hesitation. I knew there was someone always ready in case of difficulty" (C9RE); "Even though I understand what I have to do, the emotional side stops me" (C4AS); "It would be enough for me to look at the doctor's eyes and I would have the strength to go on" (C11ET); "My family members look at me and monitor me; they think I can make mistakes at any moment" (C8AP).

Theme 2: Feeling abandoned by institutions

The second theme describes the condition of feeling abandoned and the stress that the carer feels after hospital discharge. The distancing from healthcare staff causes not only fear but also a sense of strong insecurity. Loneliness decreases the awareness of one's own abilities and increases the possibility of making mistakes. A sub-theme was identified: "the network does not exist".

Sub-Theme: "The network does not exist"

At home, the caregiver starts an adaptive phase and tries

to implement all the operational instructions they have learnt from the healthcare professionals. In most cases the caregiver changes their habits and moves into the home of the family member they are caring for to avoid leaving them alone. From the interviews it emerged that after a week or so the caregiver tries to contact the family doctor to discuss the hospital discharge letter and new treatments to be administered.

"One must remember that the doctor if he answers..... does so at set times and first one has to talk to the secretary..... I hope I never get sick after 7 p.m. otherwise I will have to go to the Accident and Emergency Unit" (C21NM); "You must go to the District....there, they will order you the supplies.....but I need them now, so how will I manage?" (C24OP); "The general practitioner told me to be patient.....it takes a few daysthen I try phoning the hospital but even there it's like winning the lottery. The phone rings but nobody answers.... I try again until the switchboard tells me to hold..... again!!!!.....if I can't speak to anyone by tomorrow, I'll go to the hospital." (C26UN); "My brother told me don't worry, I'll try to call or go in person and ask what we should do....." (C14LP),

Theme 3: Tiredness and less willingness to look after the relative due to work

This theme describes the caregiver's mood and work difficulties during the three months after discharge. They must cope with a new organisation, which in most cases means a lack of free time as they must take care of a family member, in need of assistance. Such a situation can be a source of enormous stress for the caregivers, who, in addition to their work, must worry about an equally tiring and demanding subsidiary activity. Two sub-themes are identified: a) tiredness and b) sense of responsibility.

Sub-Theme 3a: Tiredness

The thought of being the only family member caring for the patient causes a sense of fatigue that in the long term impairs daily life. Symptoms such as insomnia and asthenia arise, leading to irritability

"I hardly sleep at night and I'm nervous during the day... I didn't think taking care of my mum was so demanding... I don't know if I can do it much longer!" (C31TM); "I no longer have time to do anything.....my life is centred on my mother's needs and she calls me all the time.....I am tired!" (C36VL)

Sub-Theme 3b: Sense of responsibility

"Every morning I get up with the thought that I have to go to work... I pray that nothing happens at home otherwise how can I manage? I can't leave work and I don't know who to call..." (C2NM); "The problem is that M. doesn't need continuous care but if a tube comes out and I'm not there he gets scared and who knows what happens... it happened once, a few hours passed... and then we had to go to hospital" (C14UN).

DISCUSSION

Caregivers caring for family members with bladder cancer who have undergone cystectomy and urinary diversion carry a burden. Many of them are not adequately prepared to cope with post-ostomy life, and they reported that these difficulties often led to a reduced quality of life for the family member as well (8, 13). Our study con-

ducted in Italian hospitals on caregiver experiences, notes some similarities with other studies conducted in other countries. Similar difficulties and problems are mentioned such as the need for communication, an increased network, burden and caregiver stress (1, 7).

Our study reinforces themes highlighted in other studies that cite the importance of good caregiver health education during the family member's hospitalization and identifies a weaker development of community-based services compared to the rest of Europe (12). It also reinforces the concept about the sense of duty felt by caregivers and emphasizes the need to obtain some free time for relaxation and leisure to continue caregiving subsequently (8, 14). The originality and strength of this study is to investigate caregivers' difficulties in the first three months after discharge. There are no studies in literature investigating this context. The first months reveal all the doubts and critical issues of caregivers and are the ones most at risk of improper hospital admissions. It emerged from the study themes, that in addition to the training program, an active network and more effective communication with healthcare staff, even after discharge, are crucial.

CONCLUSIONS

Our study demonstrates that the caregiver of a patient with bladder cancer and urostomy in the first three months after hospital discharge is very worried and stressed. Despite the training program received in hospital, the caregiver does not recognize the newly acquired skills and has difficulty applying them. The lack of an active network and effective communication causes insecurity and subsequent hospital re-admissions. There were no substantial differences within the three hospitals for study performance. However, this study has not analysed the different approaches among different informal caregivers and financial status. Therefore, further study would be required.

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