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Original Scientific Paper

QUALITY OF LIFE OF OSTOMATES – A QUALITATIVE STUDY

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SUMMARY – Facing a malignant disease, surgery and creation of an intestinal stoma is a complex process in anyone's life. Adjusting to a new way of life can be complicated, stressful and challenging for patients. With continued education from professional caregivers, the patient and/or family can avoid or mitigate adverse events and improve the quality of life of stoma carriers. The aim of this study was to investigate the quality of life of stoma patients and their relationship with health education in hospital in a qualitative way. The present study included 15 patients of both sexes older than 18 years and living with a stoma for at least one year after surgery. Patients were interviewed using a semi-structured interview, which was recorded. Transcripts were made and analyzed after the interview. A total of 6 women and 9 men aged between 40 and 86 years took part in the study. The results show that patients were very satisfied with health education they received in hospital, but their subjective experience of the quality of life was not satisfactory in all areas analyzed, such as travel and social life. Stoma has an impact on the participants' quality of life. High quality health education of patients by professionals, as well as family and social support play an important role in the lives of stoma patients. These are protective factors that improve the participants' quality of life.

Key words: *Health education; Surgical stoma; Quality of life*

Introduction

The prevalence of people undergoing ostomy is 0.12% worldwide[1]. According to recently published data, the estimated number is about 750,000 people in the United States living with some form of stoma, whereas in Europe their number is 700,000[2]. In the Republic of Croatia, there are approximately 7,500 people living with a stoma (0.2%)[3]. According to the Croatian National Cancer Registry, which was established in 1959 with the aim to collect, manage and analyze cancer incidence data, colorectal cancer was the third most frequent cancer by incidence in men (15%) and second in women (13%) in 2019[4], and represents a huge problem within the Croatian health care system[5]. Worldwide, colorectal cancer was estimated to be the third most common cancer and second leading cause of cancer death in 2018[6].

Ostomy is usually performed during the treatment of inflammatory bowel diseases, traumas, acute diverticulitis, but most commonly in colorectal cancer[7]. Although the national screening for colorectal cancer exists in the Republic of Croatia since 2007, the response rate is still low, approximately 20%[8,9].

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The life with stoma has a lot of challenges which impact everyday life. By the World Health Organization definition, quality of life (QoL) is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"[10]. According to the aforementioned definition, QoL represents the multidimensional concept which is related to physical and mental health of an individual, independence, social interactions, personal beliefs and relation with the environment.

Results of a systematic review by Vonk-Klaassen *et al.*, which included studies that used validated instruments to measure QoL in stoma patients, have shown that living with stoma negatively affects QoL[11]. People with stoma are more prone to develop anxiety and depression due to body image appearance and physical functioning[12]. Interdisciplinary care is needed to improve overall health and QoL, with nurses playing a central role in the successful management of health in this population[13,14]. Besides nursing professionals that help the patients overcome mental, physical, social, and emotional hurdles, community support is also an important factor. In Croatia, such support is provided by the Croatian Association of Disabled Societies (ILCO)[15]. The Association is organized in 15 branches throughout Croatia and its mission is to support the patients with information regarding social and health care rights, as well as to provide psychological support before and after ostomy. In addition, ILCO is actively involved in raising awareness and removing the stigma associated with having a stoma.

The aim of this study was to qualitatively analyze QoL in stoma patients and to gain an insight into patient experiences in different QoL areas, as well as to determine patient satisfaction with health education provided by hospital nurses.

Subjects and Methods

Participants

This study involved 15 participants aged between 40 and 86 years. Of these 15 participants, 6 were women. Inclusion criteria were age 18+ and presence of stoma of more than one year. Exclusion criteria were terminal illness, patients with cognitive impairment, and patients who did not speak the Croatian language. All participants signed an informed consent form before participating in the study. This study was approved by the Ethics Committee of the Faculty of Health Studies, University of Rijeka.

Methods

Participants were purposively selected using the chain sampling method. The study was conducted using a semistructured interview. All interviews were conducted by telephone due to the COVID-19 pandemic. Interviews were recorded, transcribed, and analyzed by three independent researchers, after which a consensus was reached (Table 1). Thematic analysis was conducted[16,17].

Table 1. List of topics and questions for the participants

Topic	Subtopic
Sociodemographic data	Age, gender, marital status, ostomy implant
Satisfaction with health education in hospital provided by nurse professional	How satisfied were you with the education about stoma care you received during your stay in the hospital?
Inclusion of family members in stoma hygiene education in the hospital setting	Who of your family members has been involved in stoma hygiene education?
Knowledge about health and social care rights	How would you describe the availability of information on health and social rights?
ILCO membership	Are you a member of ILCO?
Psychological functioning-adaptation and acceptance of life with a stoma	Have you had challenges in accepting your life with stoma?
Physical functioning	How does stoma affect your physical functioning in everyday life?
Social support	How would you describe your social life?
Economic domain	Are there any additional costs incurred by your condition?

ILCO = Croatian Association of Disabled Societies

Results

Sociodemographic data

The sample consisted of 6 women and 9 men who participated in the study. Their age ranged from 40 to 86 years. The mean years of life with stoma was 7.7 (range 1-27) years. Thirteen participants were married, while one was divorced, and one widowed. With the exception of one participant who worked part-time, all others were on sick leave (n=4) or received disability pension (n=10).

Satisfaction with health education on stoma hygiene at hospital and inclusion of family members in education

Most participants were very satisfied with health education on stoma hygiene provided by the hospital nurse professionals, while some felt that the education could be improved, and one participant was unable to attend the education session at the hospital due to a serious health condition. Most participants involved family members in the education, some chose not to involve family members, and one did not have the opportunity to involve family members. In addition to the education in the hospital, most participants had positive experiences with community nurses.
Quotes:

"I don`t know, when you come back home and you have an incident like diarrhea, you don't know how to behave in such specific occasion".

"There are ways to improve education. Only one time is not enough".

Knowledge about health and social care rights

All participants were aware of health-related services and accessories needed for routine stoma care. The lack of knowledge and rights were related to social care services. The results showed that participants who were members of ILCO had better insight into health and social care rights. On the other hand, those who were not members of ILCO were less familiar with social care rights.
Quotes:

"There is no place for patients where you can ask questions about rights and other relevant documentation. I found out everything from other patients. None of the information was available at the hospital".

Inclusion of informal caregivers in stoma hygiene education in the hospital setting

Most participants included family members in health education on stoma hygiene. Some of the informal caregivers were overwhelmed with stoma care despite their best will. Those who did not involve informal caregivers said that it was their own problem.
Quotes:

"I was alone. They also insisted, but I wanted to be alone".

"The wife was there, but only the second or third time when the nurse came".

Adaptation and acceptance of life with surgical stoma

For those who had already suffered from severe health problems before, adaptation and acceptance were faster because the stoma was a relief for them. On average, five to six months were sufficient to accept life with the stoma. The most frequently mentioned motives for acceptance were family, personal strengths, religion, and healthcare providers. From the participants' perspective, challenges in adjustment were digestive problems, fears related to stoma bag leakage in public, body self-perception, and significant psychological challenges such as depression, anxiety and fears in the first 6 months to a year.
Quotes:

"I cut down trees and prepare the wood for winter. I do everything. So, I don't mind stoma at all".

"The hardest part was accepting that I am not the same old me anymore".

"... I was really sad. It takes some time to plan the trip and other things. The biggest fear was that stoma bag would wear off. That's a horrible feeling".

"The worst thing is that you cannot go anywhere because you have to empty the stoma bag".

Physical functioning

Participants are able to perform most daily activities, but with limitations such as bending and lifting weights. The most commonly mentioned challenges related to participants' physical functioning were digestive problems and handling stoma bags during their stay outside the household. Fourteen participants did not participate in any type of exercise program. Clothing adjustments were required for normal physical functioning.

Quotes:

"When you have diarrhea, there are a lot of problems".

"I cannot do all the activities. If I want to mop the floor, I cannot. The shoes have to be without laces".

"If I just had regular bowel movements, I would not feel the stoma. So, I have to plan my days according to the bowel movement schedule".

Social inclusion, family life and travel

Twelve participants reported having a fulfilling social life, with the rest limiting themselves to family as their social environment. Some of the participants experienced negative reactions from the acquaintances such as pity and indignation, but most of them had positive experiences and reactions to their condition. Half of them had discomfort related to the emission of gases in social environment (noise and smell). Fourteen participants stated that stoma did not affect their family life so far, but they experienced some challenges at the beginning. Seven participants stated that when they travelled, they limited themselves to their own vehicle, which they found to be the most suitable means of transport. Most of the participants were affected by COVID-19 pandemic so they missed social life.

Quotes:

"It affects family life a bit when grandchildren see the stoma bag. I have to be careful, so they don't see it".

"People can think that I am disabled, but if I think I might be dead, this is a better solution".

"It becomes uncomfortable when uncontrolled emission of gasses happens, people don't have to listen to that".

"...sometimes it affects family life, if I turn onto my left side in my sleep, and the base plate eases up and leaks, I have to change all bedsheets".

Nutrition adaptation

All participants stated that they ate the same food as before the ostomy surgery or with minor adjustments due to gas emission.

Quotes:

"I eat normal, and have normal body weight".

"I start to eat normally relatively soon after the operation".

"Everything as before the stoma, light food".

Economic impact due to stoma

Eight participants stated that they did not have additional costs due to stoma hygiene and supplies. The others had additional costs mainly for anti-odor sprays, nutritional supplements, hygiene supplies (specialized cleaning products), and medications.

Quote:

"At least HRK 250 up to HRK 400 *per* month. I am afraid of odors".

Discussion

The aim of this study was to obtain information from participants about health education after ostomy in the hospital setting and perceptions of QoL domains. Satisfaction with health education on stoma management provided in the hospital was found to be very satisfactory. The importance of lifelong learning for nurses in stoma care is necessary as they are a link between the patient and the multidisciplinary team[18,19]. Enterostomal therapy is a specialized education for nurses caring for people with stoma, wound, or continence needs[20]. The first enterostomal therapists in the Republic of Croatia were educated in 2017 through a lifelong learning program according to the guidelines of the World Council of Enterostomal Therapists[21]. The results of this study showed that patients had confidence in the hospital nurse professionals that provided health education. Those who were familiar with their health care rights were more satisfied with health care services received inside and outside the hospital by community nurses. Most participants involved informal caregivers (family members) in the process of health education, which was found to be important for various aspects of social and health systems[22,23]. In addition to reducing costs in the health and social system, family caregivers play an important role in supporting patients to meet their needs during the adjustment and acceptance process[24]. One of the most important findings in this study was that participants who were not members of ILCO were not sufficiently informed about their social care rights. ILCO provides support to stoma patients in meeting their specific needs[15]. The results of this research show that hospital and out-of-hospital nurse professionals should provide education and resources not only in the health care system but also in social care system[25-27].

High levels of self-efficacy can improve the patient's QoL, adjustment to illness, mental health, and health literacy of the patient[28].

Studies show that women, unlike men, have greater challenges in accepting life with stoma[29]. Acceptance of living with stoma leads to a higher QoL[27]. The results of this study show that patients need about five to seven months to overcome the physical, mental, and psychological barriers. Other studies have also confirmed that the barriers in adapting to stoma are due to the psychological effects (odor, noise, leakage, body image) and physical functioning which affect social activities[12,26,29-31]. According to Verweij *et al*., the adaptation is more complex and difficult in younger patients than in older ones, although older patients have more difficulties with physical functioning. The explanation for this finding may lie in differences in coping and body image between these two groups[31]. The results of the study by Anaraki *et al*. showed that about 70% of stoma patients suffered from depression during the process of adaptation[32]. Supporting the needs of stoma patients is an ongoing process and should therefore be ensured even after discharge from the hospital, as another study has shown[12]. Social activities of the participants in this study were fulfilled but limited to the company of family and friends who were familiar with their condition (gas discharge, noises). Other studies report on reduction in social activities among participants[12,29,31]. Half of the participants in this study reported difficulty with transport and travel due to fecal excretions, noise, and exhaust fumes, and therefore only travelled by their own car. Other studies did not find significant results in this domain of QoL[33].

Fear of leakage, gas emission and noises were perceived as the biggest obstacles to social activities and travel, but still none of the participants adjusted their diet. Digestive problems were common among most participants. These problems lead to limitations in social activities (due to fear of fecal leakage, noises, and gases) and also in traveling. Nutrition is essential not only during recovery but also for normal functioning at long term, as it prevents electrolyte imbalance and malnutrition[34,35]. While most patient information suggests return to a normal diet, the literature and this study show that ostomates should adapt their diet to their individual needs[36]. This finding indicates that health education and literacy in ostomates should be improved not only in the hospital but also in the out-of-hospital setting, with an additional focus on individual nutritional needs to improve QoL.

Living with a stoma did not incur additional costs for half of the participants, others faced significant costs as their income came mainly from disability pension or sick leave. LeBlanc *et al*. also pointed at the financial burden that was impacted by stoma[37]. The savings in the health care system, but also in ostomates can be achieved through continuous education of patients by nurse professionals in the hospital, in the home environment, and through the ILCO[38].

Conclusion

This qualitative research provided an insight to the QoL of stoma patients and determined patient satisfaction with health education provided by hospital nurses. Although the study included a small number of respondents, this kind of QoL research is not that often in Croatia and provides an overview of patient experiences and contributes to patient trust in the health care system.

The results of this study can be used as a guide for further education of nurses and also for further research on the patient QoL.

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Sažetak

KVALITETA ŽIVOTA OSOBA SA STOMOM – KVALITATIVNO ISTRAŽIVANJE

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Suočavanje sa zloćudnom bolešću i kirurškim zahvatima te postavljanje stome predstavlja složen proces u životu svakog pojedinca. Prilagodba na nov način života može biti komplicirana, iscrpljujuća i izazovna za bolesnika. Uza stalnu poduku koju pružaju medicinske sestre bolesnik sa stomom i/ili njegova obitelj mogu izbjeći ili ublažiti neželjene događaje te poboljšati kvalitetu života. Cilj ovog istraživanja bio je kvalitativno ispitati kvalitetu života bolesnika sa stomom i povezanost sa zdravstvenom podukom koja se provodi u bolnici. Predmetno istraživanje je uključilo bolesnike obaju spolova starije od 18 godina koji imaju stomu najmanje godinu dana nakon kirurškog zahvata. Ispitanici su intervjuirani polustrukturiranim intervjuom koji je snimljen. Nakon provedbe intervjua izrađeni su transkripti koji su analizirani. U istraživanju je sudjelovalo ukupno 6 žena i 9 muškaraca u dobi od 40 do 86 godina. Rezultati pokazuju da su bolesnici zadovoljni zdravstvenom podukom koja se provodi u bolnici, no njihovo subjektivno iskustvo nije zadovoljavajuće u svim ispitivanim domenama kvalitete života. Stoma ima utjecaj na kvalitetu života ispitanika. Kvalitetna zdravstvena poduka bolesnika uz potporu obitelji i prijatelja ima važnu ulogu u životu osoba sa stomom. To su zaštitni čimbenici koji unaprjeđuju kvalitetu života ispitanika.

Ključne riječi: *Kvaliteta života; Stoma; Zdravstvena poduka*