Original Article

Educational video as a healthcare education resource for people with colostomy and their families

Vídeo educativo como recurso para educação em saúde a pessoas com colostomia e familiares

Video educativo como un recurso para la educación salud a las personas con colostomia y familiares

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ABSTRACT

Objective: To know the perceptions of participants in a support group for people with colostomy on the use of video as a resource for health education.

Method: Qualitative research with 16 participants in a support group for people with colostomy in Santa Maria, Rio Grande do Sul, Brazil. Data were collected in April and May of 2016, through a focus group, and subjected to the thematic analysis proposed by Minayo.

Results: The results led to three categories: care and self-care are learned alone: the lived reality; health education and learning through educational video: perceived opportunities; the singularities of the educational video from the viewpoint of people with colostomy and their families.

Conclusion: The scarcity of guidelines retards independence and hinders autonomy in care and self-care. The audio-visual technology applied in this study complements the educational guidelines, and can enable changes and the opportunity to rethink pedagogical nursing practices.

Keywords: Health education. Colostomy. Nursing. Educational technology.

RESUMO

Objetivo: Conhecer as percepções de participantes de um grupo de apoio para pessoas com colostomia sobre a utilização de um vídeo educativo como recurso para atividade de educação em saúde.

Método: Pesquisa qualitativa com 16 participantes em um grupo de apoio a pessoas colostomizadas de Santa Maria, Rio Grande do Sul, Brasil. Os dados foram coletados em abril e maio de 2016, por meio de grupo focal, submetidos à análise temática proposta por Minayo.

Resultados: Emergiram três categorias: O cuidar e o cuidar-se aprendido sozinho: a realidade vivida; Educação em saúde e aprendizagem por meio do vídeo educativo: possibilidades percebidas; As singularidades do vídeo educativo na ótica de pessoas colostomizadas e seus familiares.

Conclusão: A exiguidade de orientações posterga a independência e dificulta a autonomia para o cuidado e o autocuidado. A aplicabilidade da tecnologia audiovisual desenvolvida complementa as orientações educativas, possibilitando transformar e repensar as práticas pedagógicas na enfermagem.

Palavras-chave: Educação em saúde. Colostomia. Enfermagem. Tecnologia educacional.

RESUMEN

Objetivo: Conocer las percepciones de los participantes de un grupo de apoyo para personas con colostomia acerca de la utilización de un video educativo como recurso para la actividad de educación para la salud.

Método: Estudio cualitativo con 16 participantes de un grupo de apoyo a las personas colostomizada, de Santa Maria, Rio Grande do Sul, Brasil. La recogida de datos ocurrió en abril y mayo de 2016 y se hizo por medio de un grupo focal, que se sometió a análisis tematico propuesto por Minayo.

Resultados: Emergieron tres categorías: El cuidar y el cuidarse aprendido por sí mismo: la realidad vivida; Educación para la salud y aprendizaje por medio del video educativo: posibilidades percibidas; Las singularidades del video educativo en la óptica de las personas colostomizadas y sus familiares.

Conclusión: La escasez de orientaciones retrasa la independencia y autonomía para el cuidado y autocuidado. La aplicabilidad de la tecnología audiovisual desarrollada complementa las orientaciones educativas, posibilitando transformar y repensar las prácticas pedagógicas en enfermería.

Palabras clave: Educación en la salud. Colostomía. Enfermería. Tecnología educacional.

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INTRODUCTION

Cancer is an important public health problem given its epidemiological, social, and economic magnitude. It is also responsible for altering and sickness profile of the population, especially in developing countries. It is estimated that in the next few decades the impact of the disease on the population will account for 80% of the more than 20 million new cases by 2025. In Brazil, the National Cancer Institute ("INCA") estimates an incidence of 600 thousand of new cases of cancer in the country in 2016-2017[1].

The projection indicates that the incidence of cancer will continue increasing in the developing countries and will grow even more in developed countries. In this perspective, the epidemiological profile reveals that non-melanoma type skin cancer will have the greatest incidence, with about 180,000 new cases, followed by tumours of the prostate, female breast, colon and rectum, lung, stomach, and cervix[1].

According to the INCA, colorectal neoplasm includes tumours that affect one segment of the large intestine (colon) and rectum, and is the main pathology of the gastrointestinal system. In this case, the most widely used therapy is surgical resection, associated with chemotherapy or not, taking into consideration the size, location and extent of the tumour[1].

The surgical procedure involves removing the site affected by the tumour and extracting the affected portion of the intestine, which often entails performing a colostomy. In this case, the colostomy refers to the extraction of a portion of the intestine and the making of an external orifice, or stoma, to bypass intestinal transit and ensure the survival of the person affected by colon and rectal neoplasm[2].

The adjustment and acceptance of the individual to this surgical procedure is a complex process given the physiological changes to which the patient is exposed. Consequently, patients experience a range of feelings when faced with the new reality, and are forced to cope with difficulties and limitations until then unknown, as well as changes to their body image[3].

The context that surrounds an ostomy does not merely alter biological aspects, it can often results in psychological morbidity and has emotional effects that negatively impact the patients' quality of life. From this perspective, the adverse effects of an ostomy reflect on family and social relationships, employment, and the sexual activity of patients[4].

These negative feelings can be reinforced by socioeconomic and cultural factors in which the ostomy patient is inserted, and possibly cause social isolation and the feeling of mutilation[5]. Nurses play a critical role in ostomy care and have the potential to guide patients and their families to cope with the new life experience because of their relationship and contact with the patients[6].

Professional nurses are responsible for providing guidance and answering any questions that can help patients during the process of adaptation, and health education activities are an important part of this work in the nursing routine. The role of nurses in the lives of ostomy patients and their family members includes the provision of guidelines and instruments for home care, and encouraging self-care and the consequent independence and autonomy of patients, reflecting directly on their quality of life[7].

In the process of health education, nurse can use information resources and specific material to facilitate communication and the understanding of patients. Nursing and health technologies represent a clear advancement in care and directly improve the assistance offered to patients and their families. Therefore, these resources may also be useful to help patients understand certain events and promote a quicker adaptation to the changes patients experience[8].

Health education strategies include several technological resources, such as tools that enable collaborative practices and autonomous learning, presented through information and communication technologies[9]. Among these resources, the educational video is a didactic and technological instrument that provides knowledge and favours critical awareness and the promotion of health[6].

Educational videos have been used in a range of pedagogical experiences, which shows the relevance of their applicability in learning and teaching, and they combine several elements, such as images, text and sound in a single knowledge promotion object[9].

In the context of ostomy patients and their families, and to provide the knowledge and encouragement they need to cope with the current experience, we prepared a research project to develop, validate, implement, and assess an educational activity for this population. Thus, in 2015, an educational video was created especially for this population[10]. This technology was evaluated and validated by expert judges and representatives of the target public, who confirmed its efficacy as a resource that disseminates knowledge for ostomy care, and strengthens

and encourages the families to accept the new condition of the family member[10].

Subsequently, we sought to evaluate the impact of the use of educational videos as a health education resource for the families of colostomy patients in the immediate postoperative period, and the analysis of the results showed that nursing interventions with this audio-visual technology reflected positively on families, and proved valid to illustrate and supplement the educational guidelines[11].

Considering the need to continue evaluating the suitability of the produced video and its applicability for the population of interest, we identified the need to expand the use of this innovative feature in healthcare and present it to patients who underwent a colostomy due to cancer. The confluence of results obtained in the research mentioned above, associated with this study, reveals that the created and evaluated material can be incorporated into the nursing practices in the form of educational videos to construct the knowledge of patients, their families, and health professionals.

Based on the observations above, the guiding question of this study was the following: "What are the perceptions of the participants of a support group for people with ostomy on the use of educational videos as a resource for healthcare education activities?" Thus, the objective of this study is to know how the participants of a support group for people who underwent a colostomy perceived the use of an educational video resource for health education.

METHOD

This is a descriptive, qualitative study. Qualitative research focuses on the motives, aspirations, beliefs, values, and attitudes that result from human action. It aims to unravel social processes and works with the universe of meanings, experiences, and the explanation of people who experience a given phenomenon[12].

The study scenario was a support group of colostomy patients of the municipality of Santa Maria/RS, who met every month with the coordination and planning of an ostomy nurse in an area provided by the municipal government. The main objective of the support group is to provide information and the opportunity to talk about stoma care to improve the quality of life of colostomy patients. The group dynamics are based on a participatory methodology, in which the members actively and effectively participate in the construction of collective knowledge, enhancing the experience of each individual.

Sixteen patients participated in the research. Of these participants, eight were colostomy patients due to cancer and eight were family members who participated in patient care and voluntarily accepted the invitation in one of the meetings to participate in the study. The criteria for inclusion were members of the colostomy support group (patient and family member), regardless of the time of participation, aged 18 or older to ensure they could legally participate in the study, and members with the physical and cognitive conditions required to communicate. In the case of the patients, they underwent a colostomy due to cancer of the cervix or rectum, regardless of the post-operative time. The criterion for exclusion was participants of the support group with a colostomy that did not result from neoplasia.

The data were collected from April to May 2016, and obtained after the participants signed an informed consent statement, representing one of the ethical stages of research. The data collection procedure began with a form containing socioeconomic and demographic questions to characterise the participants, followed by the production of data using the focal group technique. It should be noted that this meeting was scheduled exclusively for the study, in a especially reserved location for this purpose, in the building of the Universidade Federal de Santa Maria, unrelated to the support group meetings or other types of complementary information.

The focus group (FG) is a research technique that involves group interaction through debates and dialogue for the researcher to collect data according to the manifestations of the group participants, who expose their views, their perceptions, and narrate experiences about a given topic of collective interest. In nursing, the FG allows the exploration of issues that require effective interaction with the studied population. Moreover, it helps the researcher to interpret the reality experienced by certain social groups and understand everyday practices, actions and reactions for a certain event[13].

The participants were divided into two groups of eight people, consisting of four patients and four family members. The meetings occurred on two different days, in opposite shifts, according to the availability of the participants, and sought to establish consensus among all the participants. Each meeting lasted one hour and thirty minutes, approximately. The number of meetings was sufficient to answer the research question and the objective of this study.

The room for the meetings was prepared to provide a welcoming environment that facilitated approximation between the participants. The chairs were arranged in a circle to encourage eye contact among the members. Furthermore, ambient music and a welcome message were used in the reception of the study participants.

The FG was divided into three stages: the first stage consisted of an introduction dynamic to break the ice and bring the participants together. In the second stage, we used discussion triggers to encourage the participants to talk about their experiences related to the care and self-care of the stoma and the cancer, resulting in a group dialogue that simulated the participation of all the FG members. After this stage, the participants were invited to watch the educational video.

The video, with audio and visual resources, shows situations staged by actors that simulate real events of the people and their families who live with an ostomy for cancer. It lasts 8 minutes and 35 seconds and consists of an introduction about the experience of undergoing a colostomy, followed by management of the stoma and collection bag with an encouraging statement of a family member about cancer and the new way of living, and a final message. As regards the management of the stoma and collection bag, the video provided information on the cleaning products and methods.

The third step of the FG was the final and closing part of the meeting. In this period, the participants were invited to drink tea to complete the data collection process in a friendly and fraternal environment.

The collected data, namely the discussions generated in the FG, were recorded and transcribed in full. The statements of the participants were subjected to thematic content analysis, consisting of two operating levels[12]. The first level consisted of exploring the material to understand the social context of the subjects. The second level comprised the interpretation, ordering, and sorting of the data. Once the transcribed material was read exhaustively, the data were separated into themes and categories, to join the similar and converging parts. The material was subjected to a final analysis, during which the data were discussed according to the collating framework.

The identity of each participant was protected with alphanumeric identification codes (P1, P2, F1, F2, and so on). The letter "P" refers to the patient and the letter "F" to the family member. After institutional approval, the research project was accepted by the ethics committee with opinion #1.461.655 of 22 March 2016[22].

RESULTS AND DISCUSSION

Of the 16 participants of the study, eight were people with an ostomy for cancer; five women and three men. The other eight participants were family members involved with the care of these patients; six women and two men. The participants were between 34 and 84 years of age, and they were mostly the spouses, daughter and sisters of the colostomy patients. The ostomy time of the patients who underwent a colostomy varied between six months and 34 years.

After data analysis, the common themes were grouped into three categories, which will be presented and discussed below. For the study participants, exposing their thoughts in relation to the educational video for colostomy patients and their family members meant that they would have to relive their own experiences and, consequently, look at the video. Thus, the categories describe the process undertaken by the participants of the FG to address the theme.

Care and self-care are learned alone: the lived reality

The learning process for care and self-care starts at the time of hospital discharge, when the nurse provides educational guidelines for stoma care, and cleaning and changing the collection bag. This process is important for the patients and their families to acquire the skill and confidence to care for this new condition.

During hospitalisation, the participants stated that the lack of systematic care and guidelines for hospital discharge was one of the negative aspects of nursing care. Furthermore, they perceived that the lack of specific knowledge of the health workers regarding the assistance and care of intestinal stomas hinders the learning process and delays their adaptation to the new reality.

> *I believe that doctors need to give us more guidelines when we are still in the hospital, before and after surgery. (F7)*

> *There was no one to teach us, there was no nurse at the end of surgery or a doctor to come in and say something to help. Let's do this or let's do that. We didn't have this guidance. (F2)*

> *No guidance. We had no guidance about where to get the bags, where they donated them, nothing. When we left the*

hospital, we bought them. I went from pharmacy to pharmacy searching for them. (F8)

Since ostomy care requires specific skills and knowledge, during the hospitalisation period, the nurses should provide the first guidelines to meet the demands of patients and their families, and ensure they are prepared for home care. Moreover, they must exploit the available resources to help patients become independent at home, which is where the family and/or patients assume the continuity of care[14].

Today, however, the trend is to reduce the hospital stay, which limits the time available to prepare guidelines for the patients and their families. Consequently, the return home can be a challenge permeated by difficulties regarding stoma care and adaptation to the new daily activities[15].

Despite this reality, care and guidance is part of nursing work and considered a way of promoting independence and self-care. For the study participants, the lack of guidelines extended the learning process, and they were forced to seek ways to meet the demands of the ostomy.

We had no idea, but we did the best we could. We learned by doing. We learned to put the bag after reading the manual, which was written more or less, and do this and do that. (F2)

I had to figure it out, I wanted to help and I did it [...] She didn't know, so, at home, I had to learn on my own. (F1)

I went on the internet looking, see what it was, these stoma patients. I don't know, because we didn't know. In fact, I had no knowledge, no one that I know was in that sort of situation, so I looked it up. (F3)

The need to learn to care for and take care of oneself did not only emerged from the lack of information, but also as a means of promoting autonomy to perform care. The families use the resources readily available to them to meet the demands that arise and find answers to their own questions. In other words, the colostomy patient and their family members resort to the internet, the manual of the bag, and people who have gone through similar experiences to acquire the new skills and potentialities they need. The search for autonomy helps them make decisions regarding their therapeutic conduct and stoma care and handling[16].

The need to perform stoma care and change the colostomy bag in situations in which the family member responsible for care was unable to provide this care was referred to as a factor that motivated the patients to pursue autonomy and independence to take care of themselves.

I learned because I thought it was too much to call my sister at night. Because actually, I had to do it, but she was changing it and helped in the bath. It made me sick, but then I learned and now I know how to do it. But I learned on my own, I needed to! (P2)

At first I believed that there would always be someone to change the bag for me, I was scared. I'm very anxious, I couldn't stand waiting to clean it, so I learned. (P1)

The statements reveal that in an adverse context, faced with the need for some kind of care, the patients can become aware of their capacity to act as active subjects of the process of self-care, overcome difficulties, reconstruct themselves, and acquire new knowledge. In this sense, it is necessary to respect the uniqueness of each individual, and the time required for learning based on internal variables, resulting in the re-significance of their losses and acceptance of their disease[16].

However, for the patients and their families to become independent and protagonists in the process of living with a colostomy, the nurses must be committed and able to provide guidance on hygiene, stoma care, peristomal skin, provide collector bags, and support care. Post-discharge monitoring is essential for the adaptation of colostomy patients and their family members.

Health education and learning through educational video: perceived opportunities

Nurses must assume the role of mediators and facilitators of care to ensure the required care skills, answer questions, and listen to the fears and desires of the patients and their families. Thus, effective communication through sensitive listening allows the exchange between professionals and users, establishes bonds, and helps overcome the difficulties arising from the colostomy.

The process of health education occurs through the pedagogical practice of nursing work, and can be facilitated by the use of didactic and technological resources that promote learning and self-confidence, and prepare people for care. However, the adopted teaching resources must be assessed to sustain and substantiate their educational effectiveness[11]. The audio-visual technology presented to

the participants of the study was considered valid for the health education of colostomy patients and their family members, as shown in the following statements:

If they had shown this video to the person who did the colostomy, at the hospital, she would have come out stronger. It is effective, absolutely. (P5)

The video had all the basic and fundamental information. (F5)

It is one of the best explanations I've seen to date. Because in the video they show you, and most people just tell you how to do it. (P2)

The possibility of viewing the stoma, the material, and how to handle these materials in the video brings people of an unknown and frightening context together, and allows them to see themselves in the situation and think about the strategies they need.

The technological resources are essential for the teaching and learning process because they represent an active teaching methodology that promotes knowledge and skills[17]. The information shared by the nurses through educational actions are a catalyst for care practices and the exercise of independence and autonomy of the colostomy patient and their families[18].

With respect to the information contained in the educational video, it was perceived by the participants of the study as easy to understand, and the pictures, sound and time considered appropriate, enabling the effective applicability of the video as a pedagogical resource.

It was good, very good. It had a few technical terms, more normal everyday words. I managed to understand the message. I saw a synthesis of what really matters. If it were longer it would get pretty tiresome. (F4)

Now I really learned, I learned a lot with the video. (F6)

The video really showed what it is all about. For those who don't know, I think it is very useful. (P4)

Much better than doing the demonstration in a doll. The video is enough. I don't think it needed the audio, just the visuals would be enough. Perfect! (P3)

The approach of objective, clear, and easily applicable guidelines that target real situations is presented in the form of images to support the understanding, appropriation, and empowerment of patients and their families, and reflect the way they will cope with the demands of care.

Nurses as healthcare educators can use creativity to create materials that facilitate teaching and learning, as it is through health education that they clarify the queries of colostomy patients, to improve their quality of life[14]. There are other ways of attending to the needs of colostomy patients, strengthening nursing practices, and complementing the verbal education process, with the possibility of expanding this education.

In relation to encouraging the family unity shown in the video, the study participants stressed the importance of this approach because they believe the family should be involved in the care of people with colostomy.

This video is not only for those who use the colostomy. For those who do not use it, it is even better, such as family members. (P8)

It is interesting to show to the family, too. Show the patient and family members, not to be scared. (F2)

I think that the family is the main thing. If the family does not accept the colostomy patient, it's only going to get worse. The family has to accept! The video, for family, helps a lot. (P7)

Considering these observations, it is perceived that the video content can be useful for the family because it presents a brief background of the reality experienced in the family circle when there is a member with cancer and the colostomy. From the perspective of care, considering the family as the first source of support, it should be involved in the therapeutic process since the stimulus offered by significant people creates optimism, provides support, and enables the adaptation and acceptance of the new condition[15].

The joint participation of the family in the educational video as part of the acceptance, adaptation, and care process is important in the lives of patients, and referred to a reassuring by the participants, as shown in the following statements:

I think this video reassures people. Not only the person with the stoma, but the family as well. It pushes us act more naturally. It's not something out of the ordinary. This tranquillity that the video gives the family. And when the family

can't accept it very well, it gets easier. The video definitely helps a lot. (F5)

For those who watch the video, the patient and the family, it helps, yes. It makes us see it in a natural way, because at first I was afraid to leave the house. I felt that everyone was looking at me [...] The video shows that this is part of the process and it is something I have to go through. (P6)

The effectiveness of audio-visual technology as social support for family caregivers of people with chronic illnesses was investigated in study in Colombia. The results identified that caregivers were satisfied with the video because they considered it innovative, respected the information they received, and because it motivates, empowers, and helps them understand and learn about the topics. It concluded that audio-visual technology supports greater clarity and understanding of the themes identified as a need for educational care[19].

The video, used in this study as a potential technology for health education, proved to be an effective resource to facilitate and support learning in relation to care and living with a colostomy. Moreover, it helps viewers identify with some everyday situations and familiarise themselves with the care required in this new condition.

The singularities of the educational video from the viewpoint of people with colostomy and their families

Nursing work involves the search and production of technological resources that support healthcare education. These resources can help them become the subjects of their actions, and use the content provided by technology according to their personal demands and pace of learning.

Audio-visual technology allows the construction of multidimensional knowledge because it complements the actions performed by the nurses in their relationship with the patients and their families, according to the individuality and specificity of each individual. The following statements reveal how the participants perceive the general singularities of the care process shown in the video.

I think the point of the material, the way to do the cleaning and the changing of the bag, I think it's really a question of each individual. One person can prefer one kind of bag and another person might prefer another. (P3)

I, for one, don't like the bag they showed in the video. I think it's terrible. That bag is rubbish. (P7)

The video is relative. It shows a stoma, only one type of stoma. There are several. Some are more outward and larger. It shows a good stoma, but it does not show the others. (F3)

Even though the video is considered an effective health education tool, it has some features that are considered limitations of the approach and highlight the uniqueness of each person and care, such as the different types of stomas, their alterations, collecting bags, and cleaning products. This evidence refers to the need to involve the use of technology with verbal guidance and illustrations of the listed aspects.

The educational technology of nurses, considered a part of the nursing practice, consists of interconnected knowledge and instruments, which are built, but can and should be rebuilt over time by people according to their individual needs[20]. In addition, the video is a contributory instrument for learning about care, and it should be associated with the individual understanding capacity, and, subsequently, with the replication of learned information to foster reflections and instrumentalise care.

The educational video as a health education activity helps to strengthen family unity and the autonomy and preferences of ostomy patients. Based on the understanding of the information received, the patients and their families take control over and build a unique form of care, according to their beliefs, values, and affinities, and the socioeconomic and cultural environment in which they live.

FINAL CONSIDERATIONS

This study provided valuable insight into the context in which people with colostomy bags and their families learn, develop, and organise care. It also allowed us to identify the perceptions of the members of a support group for colostomy patients regarding a health education activity with an educational video produced for this care specialty.

In the reality experienced by the participants of the study, the scarcity of educational guidelines hindered and postponed the independence and autonomy required for the care and self-care of people who underwent a colostomy and their families. In order to meet

the demands of ostomy patients and in light of the lack of information, the participants found their own way of learning how to care for these patients, which also reveals that they were not prepared for the return home after hospitalisation.

However, and corroborating the search for autonomy in care, it was perceived that the educational video as a healthcare education resource for people with colostomy and their families can instrumentalise pedagogical nursing practices and contribute to the construction of care and self-care. It can also be used to approach the subject, stimulate discussion, and, through images and testimonials, build confidence in relation to the future, reassurance, as well as self-confidence and tranquillity for people with colostomy bags and their families.

The health education resource used in this study was perceived as an effective strategy since it was able to enhance the habitual nursing practice and support and guide ostomy care, including cleaning and changing of the collection bag. The approach of encouraging the family in the educational video was perceived as relevant because it supported the process of acceptance, adaptation, and care of people who undergo a colostomy, and positively transformed the health/sickness context they were experiencing.

Although it was considered a guiding resource for colostomy-related care, the educational video has limitations in its scope and in its thematic approach. However, since the video explores basic care, addresses the practical everyday issues of people with a colostomy bag, and encourages family participation in care and adaptation process, it can serve as a reference for people who are facing this situation, and is mostly indicated for the pre-surgery and post-surgery period and during preparation for discharge. Considering the favourable results obtained here, the video is available for use at the Hospital Universitário de Santa Maria, in ostomy sector of the Secretaria Municipal de Saúde and the website of the Associação Gaúcha de Estomizados.

A limitation of this study is the fact that the focus group consisted of patients with colostomy for cancer, so the feasibility of the video could not be considered for people with a colostomy bag for other causes. Moreover, the scarcity of studies related to the development and use of educational technologies in the area of stomatherapy intended for this specific population somehow restricted the resources to analyse comparatively the methods and obtained results.

The study contributes to teaching/research/assistance regarding the applicability of audio-visual technology in the planning and development of nursing educational guidelines, which enables the transformation and substantiation of pedagogical practices. Thus, it can support the use of specific healthcare education actions for people who undergo a colostomy and their families, and stimulate the production and validation of educational technologies geared towards the needs of people, in order to facilitate learning and promote quality of life.

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