Key elements of an educational intervention in nursing for the promotion of cancer survivor adaptation

Elementos-chave de uma intervenção educacional em enfermagem promotora da adaptação dos sobreviventes de cancro

Abstract

Background: There is less investment in the cancer survival phase worldwide, and in Portugal, there is no known intervention program focused on cancer survivor adaptation.

Objective: To explore the key elements in the development of an educational intervention in nursing that promotes cancer survivor adaptation.

Methodology: Qualitative exploratory study using a focus group with 9 experts for data collection.

Results: Knowledge about the disease, self-management of symptoms, self-control of emotions, knowledge about coping strategies, and involvement of family members should integrate the content of the intervention to be developed. Educational strategies should be articulated with motivational and relational strategies. Cancer survivors must be involved in the learning process. The care plan must be individualized and include a health contract.

Conclusion: This study allowed identifying a minimum set of characteristics that should integrate an educational intervention in nursing.

Keywords: nursing; neoplasms; survival; adaptation, psychological; patient education as topic; health education

Resumo

Enquadramento: Em todo o mundo assiste-se a um menor investimento na fase de sobrevivência ao cancro e em Portugal desconhece-se a existência de qualquer programa de intervenção centrada na adaptação dos sobreviventes de cancro.

Objetivo: Explorar os elementos-chave a considerar no desenvolvimento de uma intervenção educacional em enfermagem promotora da adaptação dos sobreviventes de cancro.

Metodologia: Estudo exploratório qualitativo com recurso à técnica do grupo focal com 9 peritos para a colheita dos dados.

Resultados: O conhecimento sobre a doença, a autogestão dos sintomas, o autocontrole das emoções, o conhecimento sobre estratégias de coping e o envolvimento dos familiares devem integrar o conteúdo da intervenção a desenvolver. Estratégias do tipo educacional devem ser articuladas com estratégias motivacionais e relacionais. É fulcral que os sobreviventes estejam implicados no processo de aprendizagem. O plano de cuidados deve ser individualizado e contemplar um contrato de saúde.

Conclusão: Este estudo permitiu identificar um conjunto mínimo de características que deve integrar uma intervenção educacional em enfermagem.

Palavras-chave: enfermagem; neoplasias; sobrevivência; adaptação psicológica; educação de pacientes como assunto; educação em saúde

Resumen

Marco contextual: En todo el mundo se invierte menos en la fase de supervivencia del cáncer y en Portugal se desconoce la existencia de un programa de intervención centrada en la adaptación de los supervivientes de cáncer.

Objetivo: Explorar los elementos clave que se deben considerar en el desarrollo de una intervención educativa en enfermería que promueva la adaptación de los supervivientes de cáncer.

Metodología: Estudio exploratorio cualitativo, para el cual se utilizó la técnica del grupo focal con 9 expertos para recoger los datos.

Resultados: El conocimiento de la enfermedad, el autocontrol de los síntomas, el autocontrol de las emociones, el conocimiento de las estrategias de afrontamiento y la participación de los miembros de la familia deben integrar el contenido de la intervención que se desarrolle. Las estrategias educativas deben articularse con las estrategias motivacionales y relacionales. Es fundamental que los supervivientes se impliquen en el proceso de aprendizaje. El plan de atención debe ser individualizado e incluir un contrato de salud.

Conclusión: Este estudio se identificó un conjunto mínimo de características que debe incluir una intervención educativa en enfermería.

Palabras clave: enfermería; neoplasias; supervivencia; adaptación psicológica; educación del paciente como asunto; educación en salud

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Introduction

Surviving cancer has become an increasingly common experience. It is estimated that about 43.8 million people worldwide remain alive five years after diagnosis (International Agency for Research on Cancer, 2018). Causes of this phenomenon are population aging, scientific research, early diagnosis, effectiveness of health systems in treatments, as well as investment in health professionals. Although they differ in treatments and prognoses, cancer diseases have common characteristics, such as the huge physical, psychological, social, economic, sexual, functional, and spiritual/existential impact (Rowland, 2016). Cancer research has focused predominantly on prevention and the treatment and end-of-life phases. However, there is less investment in the survival phase, which is characterized by feelings of ambiguity and uncertainty, that is, despite the satisfaction for being alive, at the same time, the fear of recurrence can be an obstacle for achieving a healthy life journey (Rowland, 2016). Nevertheless, there are often feelings of abandonment and insecurity due to the interruption of treatments and, above all, the termination of regular contact with health professionals. All these feelings can interfere with the survivor’s ability to develop effective strategies to deal with the problems occurring daily, which can trigger anxiety and hinder cancer survivors’ entire adaptation process to their new status (Naus et al., 2009). An exploration of the literature published in the last ten years found that there is no intervention program focused on cancer survivor adaptation in Portugal. Therefore, integrated into a research whose general objective is to develop an educational intervention in nursing to promote cancer survivor adaptation, this study aims to explore the key elements to be considered in the development of this intervention.

Background

Multiple definitions of cancer survivor have been found in the literature over the past few decades, with Feuerstein’s (2007) being the most consensual. According to this author, the cancer survivor is the person diagnosed with cancer who has completed the active phase of treatments. After treatments, survivors need to find a meaning of the disease in their own life, deal with the effects of the disease and treatments, recover role performance, restore personal relationships, and deal with the threat of relapse and/or death. The transition to the survival phase requires the incorporation of new knowledge, behavioral changes, modification of meanings attributed to critical events, and, consequently, self-redefinition (Meleis, 2010). Although this is not a conventional health-disease transition, nurses should assume a supportive role in periods of instability triggered by change, considering that a transition implies adaptation to change, rather than the return to the pre-existing state (Meleis, 2010). Adaptation to the disease is a dynamic process that translates into a reaction marked by the ability to reorganize, reintegrate, and reorient, which is influenced by the characteristics of the disease, the individual characteristics of the person, and the sociocultural characteristics (Roy, 2009). This process is not exclusively limited to the diagnostic phase, extending beyond the end of treatments (Naus et al., 2009). According to the same authors, the adaptation of the cancer survivor is a process resulting from a self-assessment of possible threats to the self, how each one deals with meaningful life experiences, and one’s beliefs.

One inevitable aspect of cancer survivor adaptation is the importance of coping in the adaptive process, which is fundamental to deal with the problems that arise throughout this phase. Coping consists of a set of cognitive and behavioral efforts that the person develops to solve, reduce, tolerate, or minimize the internal or external demands that emerge from a stressful situation, understood as a burden or as something that exceeds their personal resources (Lazarus & Folkman, 1984). In the context of oncologic disease, coping is related to the acceptance of health status, role performance, adaptation to physical disability, satisfaction with health status, hope, body image, family and social support, self-control of anxiety, fear of recurrence, self-esteem, self-management of the disease, sexual performance, motivation, among others (Lazarus & Folkman, 1984). Still in this context, coping is essential to solve problems related to the disease realistically, reduce feelings of threat, preserve physical integrity, help maintain social relationships and role performance, promote positive self-control, create a personal concept of value and social acceptance, increase self-esteem and, above all, improve quality of life. Some people adapt appropriately to the survival phase, but others experience feelings of negativity related to fear of cancer, post-traumatic stress, depression, and, especially, anxiety, which significantly affects adaptation, return to everyday life activities, and quality of life (Stark & House, 2000). Thus, anxiety is described in the literature as feeling nervous or worried, and most of the time, it manifests itself as a normal response to a threat. However, when it interferes with daily life and personal relationships, it is considered a disorder that does not disappear over time and may persist for years and interfere with the adaptation process.

Research Question

What are the key elements to be considered in the development of an educational intervention in nursing to promote cancer survivor adaptation?

Methodology

A qualitative exploratory study was designed using a focus group technique for data collection, according to the methodological guidelines provided by Krueger and Casey (2015). The focus group, also known as the discussion group, is a research technique aimed at data collection, through the interaction of a group of experts with similar characteristics, on a particular topic presented by the researcher and moderator of the discussion.
This technique, consisting of five phases, allows acquiring information and understanding a particular topic of interest, as well as knowing the limitations or difficulties of a given program or service, understanding different perspectives, generating new research hypotheses, and stimulating new creative ideas and concepts (Morgan, 1998; Krueger & Casey, 2015). In the first phase (planning), the participants were selected using a non-probabilistic purposive sampling, and the inclusion criteria were defined. All experts must be holders of the title of specialist nurse and present at least two of the following criteria: a) have a master’s or doctoral degree; b) to be the head nurse of a service that cares for cancer patients for at least five years; c) to carry out their professional activity with cancer patients for at least ten years; d) to be a lecturer in the context of adaptation to the disease and/or disease management for at least five years; e) to have carried out at least three research studies in the area of adaptation to the disease and/or oncologic disease management. A moderately structured approach was chosen, and the funnel format was used, which means that as the discussion develops, the questions become more and more specific (Morgan, 1998). Also at this stage, the script for the focus group was defined, as well as the role of each researcher. The second phase (preparation) consisted of the recruitment of participants and the logistical organization of the discussion. The recruitment of the participants occurred in three moments. In the first moment (invitation), which took place 4 weeks before the meeting, the participants were invited to participate in the study via email. Once the invitation was accepted, information was made available to the participants on the essential aspects of research and the issues discussed. The second moment (confirmation) occurred 2 weeks before the focus group meeting, in which participants were asked to confirm their presence. Finally, the third moment (validation) occurred on the day before the meeting, in which the participants received a phone call to validate their presence. Of the 14 invitations made, nine participants accepted and were present until the end of the meeting. The meeting took place at the Escola Superior de Enfermagem do Porto and consisted of a single session of 180 minutes, using a round table. Before the discussion began, a guide was given to all participants. In this guide, the nine questions presented were organized according to three topics: content of the educational intervention in nursing (questions 1-4), inclusion and exclusion criteria of patients (question 5), and operationalization of the educational intervention in nursing (questions 6-9). Table 1 shows the questions presented at the meeting, which were previously tested using an element external to the investigation and with the same characteristics of the experts.

Table 1

Questions presented to the experts at the focus group meeting

<table>
<thead>
<tr>
<th>(1) Which areas related to the promotion of adaptation should be considered in the development of an educational intervention in nursing in cancer survivors?</th>
<th>(5) What characteristics should be taken into account for the inclusion of participants?</th>
</tr>
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<tr>
<td>(2) What nursing interventions related to the promotion of adaptation should be considered in the development of an educational intervention in nursing in cancer survivors?</td>
<td>(6) Who seems to be in a better condition for the implementation of an educational intervention in nursing in cancer survivors?</td>
</tr>
<tr>
<td>(3) What strategies can be used in the development of an educational intervention in nursing in cancer survivors?</td>
<td>(7) What will be the most appropriate time for the implementation of an educational intervention in nursing in cancer survivors?</td>
</tr>
<tr>
<td>(4) What objectives do you define for an educational intervention in nursing in cancer survivors?</td>
<td>(8) What approach will be the most appropriate for the implementation of an educational intervention in nursing in cancer survivors?</td>
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<tr>
<td>(9) How can nurses who implement an educational intervention in nursing in cancer survivors be prepared/trained?</td>
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In the next phase (moderation), the principal investigator conducted the discussion, with the support of two other research team members who monitored and provided logistical support (audio recording, recording, and observation of group dynamics). At the beginning of the session, the principal investigator reiterated the ethical and legal aspects, contextualized the research, explained the overall objectives of the study, and encouraged participation. With regard to the fourth phase (data analysis), first, the audio recorded content was fully transcribed, as well as the collected notes, in order to build the basis of this process. Subsequently, this content was divided into categories for reflection on the topics present in the script or on new topics (coding/indexing). Each participant was assigned an identification code (P1 to P9). The text extracts pertaining to each category (a priori categorization based on the script questions) were compiled for analysis (storage/retrieval). This process was carried out manually, and no specific program was used. Finally, a systematic analysis of the collected data was performed to allow their interpretation (interpretation). With only one meeting with a group of nine participants, theoretical saturation
was not expectable. However, as Morgan (1998) points out, this option is not wrong and applies to cases where it is difficult to reconvene the experts’ group. Thus, to minimize the impact of this limitation, a heterogeneous group of experts was selected, objective questions were answered, the duration of the meeting was increased, and triangulation was used in order to compare the consistency of the data obtained in the discussion with the information obtained from other sources. For the last phase (dissemination of results), a report was prepared and sent via email to all participants prior to the publication of the results. Regarding ethical and legal considerations, all participants consented to participate in the study and voluntarily signed an informed consent form for this purpose. It should be noted that confidentiality was guaranteed to the participants. This study was approved by the Joint Ethics Committee of the University Hospital Center of Porto and the Abel Salazar Institute of Biomedical Sciences, with reference no. 2020/CE/P008 (P320/CETI/ICBAS).

Results

Figure 1 illustrates the characteristics of the experts’ group that participated in the research.

![Figure 1](image-url)
able to deal with them and knowing what they can expect from the future is extremely important, because it reduces unpredictability” (P2)). Self-surveillance of health status refers to another area of great importance — self-management of symptoms — which includes the need for the survivor to develop the ability to make decisions in the face of symptoms, such as fatigue, pain, insomnia, gastrointestinal changes, sexual disorders, among others. The experts understand these two areas mentioned above as key areas in the development of the intervention since they are the factors that most relate to anxiety. In this way, there is another area that deserves great attention—the self-control of emotions. In this particular area, one of the experts highlighted the management of uncertainty regarding the disease, stating that “it is common to find high levels of anxiety associated with complementary diagnostic tests in the survival phase” (P1), and another alluded to the fear of recurrence/death, mentioning that “the unpredictability of cancer is one of the factors that cause the most anxiety in cancer survivors and they need to be prepared to deal with it” (P3). The identification and self-knowledge of the signs and symptoms of anxiety (such as feelings of threat, recognition of danger, anguish, restlessness, tachycardia, palpitations, among others) are important for the survivor to be able to deal with them. In the face of these negative feelings, the experts reiterate that cancer survivors should be encouraged to develop anxiety self-control skills, redefine their personal goals, resume their normal life, set limits to avoid stressful/threatening factors, engage with work and/or hobbies and, not least, connect with activities that provide them with pleasure and relaxation, such as arts, humor, or nature. If in some cases it is beneficial to encourage the expression of emotions, in other cases, it is important to teach relaxation techniques, which are effective both to “reduce the level of daily anxiety” (P1) and deal with “acute stress situations” (P1). Some of the experts also stressed the need to promote knowledge about adaptive coping strategies for problem-solving because “we know that, at this or other stages of the disease, people that use escape/avoidance as a coping strategy have more difficulty dealing with problems and making healthy choices… this may lead to a greater risk for them” (P2), and “people must learn strategies to deal with their problems and feelings” (P3). Adaptive coping strategies, according to the shared opinions, play a key role in dealing with the disease and reducing anxiety, either by modulating reality-based assessments (“helps to make realistic assessments of problems and possible solutions” [P1]), or through the search for information, obtaining instrumental, emotional, or spiritual support, improving communication, increasing encouragement and motivation for behavioral change and reintegration of self-concept. Both knowledge and self-management of disease-related aspects are fundamental for the entire adaptation process. However, it is important to highlight the importance of a family support network. Family involvement is one of the areas to be considered in the development of an educational intervention. According to the experts’ group, “survival is not an individual process, the involvement of significant family members, especially the spouse, is usually recommended by the literature and, in my experience in clinical practice, I have encountered several successful examples when there is such involvement” (P6). However, it was unanimous among experts that the decision to involve the family member should be made by the survivor themselves because “there are people who need their space… I remember a cancer survivor eight years ago who told me that it was the first time they were having this conversation” (P5), and also because some family members assume the role of superprotectionism, which can limit the success of the intervention. From the experts’ perspective, educational strategies alone may not be as effective as desired and, therefore, motivational and relational strategies should also be considered in the approach to adaptation to oncologic disease. Consequently, teaching, informing, instructing, engaging, encouraging, and stimulating interventions, articulated with an educational intervention plan, should be implemented. In this way, “it is essential, in addition to education, to consider motivation and involvement as key elements of the process” (P2), and it is important “to develop a therapeutic relationship that can keep the survivor involved in the learning process” (P5). The experts also stressed that there should be a standard educational plan, and interventions need to be individualized and adjustable to each patient because “there are different pathological processes and clinical options, as well as individual preferences and particularities” (P1). According to one of the experts, the strategies should focus on the decision-making/autonomy of the survivor in order to “allow them to choose one of several options... this ends up holding them accountable for the options taken and allows for greater involvement in the learning process” (P3), for example, “through negotiation and contractualization, using a health contract, the survivor must select the areas that make up his intervention plan” (P3). This partnership strategy would allow for greater proximity, more commitment, and greater accountability. Strategies that consider phone calls were also mentioned, with the understanding that keeping the survivor connected is essential for a successful intervention and that “phone calls (or other similar technologies) can be beneficial for monitoring and follow-up” (P8). In general, the experts consider that the main objectives of the intervention are to raise awareness and involve survivors in adapting to the disease/new health condition, stimulate personal development and self-knowledge, develop knowledge about anxiety self-control, increase knowledge about the adaptive coping strategies, and promote/motivate/encourage adaptation to the disease/new health condition.

Inclusion and exclusion criteria for participants
In general, the experts considered it interesting to include participants with various types of oncological pathology because, despite the particularities associated with each oncological pathology, “it is possible to develop an educational intervention in this area that has a common basis but can be adjusted to each participant” (P5). As regards the exclusion criteria of the participants, the opinions of the experts did not differ, since all agreed on the need to
consider both cognitive capacity, which allows the person to “understand the information transmitted to them” (P6), an physical capacity, which allows the person to “engage in the activities of the intervention” (P6), such as going to the hospital or performing relaxation techniques.

Operationalization of the intervention
Throughout the discussion, it was also noted that it is important that the intervention begins in the hospital environment and before the end of treatments. This was the idea with the greatest approval rate among the experts because “survival must be understood as a process” (P3), and it is necessary to “initiate first contacts when the end of treatments is near” (P7) in order to capitalize on “the motivation inherent in the end of treatments” (P4) and “intensify intervention in the survival phase… because this is when we (nurses) reduce contact with survivors” (P3). Most experts mentioned the importance of “incorporating anticipatory survival care into the routines of professionals working in day hospitals” (P8), enhancing the survivor’s involvement and strengthening the professional-patient partnership. Individual intervention and/or group intervention was also a subject of reflection. The general opinion was that both can meet the needs of survivors in the context of adaptation. One of the experts said that “it is common to take these two types of approach, but from the experience I have, patients are more receptive to group interventions” (P7). However, the selection of the approach should consider “the preferences of the participants, as well as the objectives that are meant to be achieved” (P5). In this particular case, although group intervention allows “the sharing of experiences that helps to understand how others deal with similar problems” (P5), “it is essential to have individual contact in order to personalize the intervention and provide a moment for sharing more personal matters” (P5). Regarding the preparation of professionals, there needs to be a training program that provides all the information (content and form) about the intervention to be implemented. The experts stressed the importance of effective articulation between professionals performing the intervention and researchers, as well as a standardization of information transmitted to cancer survivors (“professionals must be in tune with each other… there must be consistency, both in the content and in the way of implementing the intervention” [P3]).

Discussion
It should be noted that, according to the experts, the development of an educational intervention in nursing that promotes the adaptation of cancer survivors is useful. Garrett et al. (2013) believe it is necessary to develop interventions that integrate an educational component in the transition to survival. Mullan (1985), who was the first author to introduce the concept of cancer survivors, proposes that educational interventions be developed and used systematically to help integrate cancer into the life path, alleviate the most negative aspects of the cancer experience, encourage more optimistic visions, improve adaptation to the new condition, teach how to develop coping strategies to deal with disease-related problems, enhance knowledge/training for anxiety self-control, and promote the physical and mental well-being of the survivor. The educational component of an intervention can be effective in providing informative support and, in this sense, Helgeson et al. (1999) reported that cancer survivors who enjoyed an educational support program had better emotional, functional, and social/family well-being than survivors who made up the control group. Information resources are important determinants of the psychological health of a cancer survivor, that is, access to accurate and understandable information about health status, side effects of treatment, prognosis, and support services available in the community is a valuable resource. It is known that a higher education level is related to better psychological health since more educated individuals can obtain and seek more information, as well as better understand the information provided to them so that they can adjust expectations to reality. Another idea that emerges from the results is that, in addition to knowledge about the disease, the educational intervention should consider self-management of symptoms, self-control of emotions, knowledge about coping strategies, and family involvement. Coolbrandt et al. (2014) claim that educational interventions significantly impact the ability to self-manage symptoms, such as fatigue, sleep disorders, dyspnea, and pain. The development of educational strategies to inform survivors and encourage their active participation allows for better health surveillance and management of side effects (O’Malley et al., 2016). Regarding the impact of educational interventions on the self-control of emotions, the literature is not consensual. Akechi et al. (2015) state that anxiety self-control can be one of the main components in improving the quality of life of cancer survivors, but question the impact of information transmission as a useful strategy for reducing anxiety, arguing that only psychological support is effective. On the other hand, Yi and Syrjälä (2017) report that anxiety can be one of the main problems in adaptation after cancer, so learning self-control strategies effectively reduces anxiety. Stark & House (2000), who report anxiety as the most frequent symptom in the cancer patient population, argue that it is crucial to explore the meanings that survivors attribute to events, as these are the basis of the threat and may differ from patient to patient. These authors also state that education and information are essential to reduce anxiety levels since fears are generally based on incorrect information. Smith et al. (2015) developed a program that teaches and trains coping skills to cancer survivors and concluded that participation in the program was associated with statistically and clinically significant improvements, both for the reduction of anxiety, depression, stress, and fatigue and for the increase in well-being. Towsley et al. (2007) also explored the coping experiences during the transition to cancer survival and developed a model called Learning to live with it, demonstrating how survivors use various strategies, attitudes, and previous life experiences to integrate cancer disease into their lives. Also, according to
these authors, the learning of coping strategies is essential for the individual to adapt to the disease and the condition of survival. Although the adaptation process is influenced by physical, social, informative, and financial factors, according to the same study, cancer survivors develop coping strategies to obtain a new balance. These include, mostly, modification of activities, replacing them with pleasant and pleasurable activities, use of social support and internal and external relativism, reflexive acceptance, overcoming of expectations, spirituality/religiosity, maintenance of usual routines, and obtaining information. Finally, the experts stressed that it is essential that survivors are involved in the whole learning process and, therefore, negotiation and contractualization should be used to ensure that they have the opportunity to decide on the aspects of the intervention. In this sense, the Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, Board on Health Care Services, and Institute of Medicine (2013) support this idea by advocating that the patient should be at the center of the structure, and the most important goal is to meet the patient’s needs. Thus, health systems should support all patients and family members in informed decision-making about care, always considering their needs, values, and preferences. The results of this study should be analyzed, taking into account their limitations. Thus, the authors of this study recognize that one of the weaknesses of the adopted method is related to the fact that data collection results from the interaction between the experts and the moderator, which questions the impact of the role of the latter, both in the generation and analysis of the data, as well as in the participation of the members of the group. The results may also have been influenced by the sample size and the number of meetings held. Nevertheless, this method is useful for the development of the intended intervention and in the context where it is applied.

Conclusion

Specialist nurses shared ideas about the key elements to be considered in the development of an educational intervention in nursing. Although, in Portugal, there are still few studies on cancer survival and almost none that address educational interventions in the processes of adaptation throughout the disease, the relevance of the study in this current context seems to be consensual. Based on the data collected, it can be concluded that an educational intervention in nursing that promotes cancer survivor adaptation should essentially address knowledge about the disease, self-management of symptoms, self-control of emotions, knowledge about coping strategies, and should also promote the involvement of family members. Educational strategies should be articulated with motivational and relational strategies to enhance the results of the intervention. Cancer survivors must be involved in the learning process and, for this purpose, the care plan must be individualized and contemplate a health contract with the survivor, which allows them to make decisions according to their needs, values, and preferences. Regardless of clinical and sociodemographic characteristics, the experts consider it possible to develop an individualized intervention, which may start before the end of treatments and be implemented in the hospital environment. Thus, this intervention should be carried out by professionals who have had prior training. The findings of this study may be considered relevant for nursing because it is the first step towards the development of an intervention program focused on cancer survivor adaptation, which does not yet exist in Portugal. It is also important because it provides suggestions on how nursing interventions should be used to enhance the capacity of survivors to deal with the problems that occur throughout the survival phase and to minimize the damage that anxiety can cause in this context. These data may be even more relevant because they have been collected from experienced professionals with current scientific knowledge. Further studies should be conducted to identify and validate the primary foci and the set of interventions that should integrate this type of program. Research should also focus on nursing interventions that promote adaptation, valuing the role that nurses can play in this area. This study also informs decision-makers about the importance of encouraging nurses to broaden their practices, especially when responding to patients’ needs.

Author contributions

Conceptualization: Peixoto, T. A., Peixoto, N. M.
Data curation: Peixoto, T. A., Peixoto, N. M.
Formal Analysis: Peixoto, T. A., Peixoto, N. M.
Investigation: Peixoto, T. A., Peixoto, N. M., Pinto, C. A., Santos, C. S.
Methodology: Peixoto, T. A., Peixoto, N. M., Pinto, C. A., Santos, C. S.
Project administration: Peixoto, T. A.
Supervision: Pinto, C. A., Santos, C. S.
Validation: Pinto, C. A., Santos, C. S.
Writing – original draft: Peixoto, T. A.
Writing – review & editing: Pinto, C. A., Santos, C. S.

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