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Humanistic nursing tailored to the needs of young men with cancer

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ABSTRACT

The goal of this study is to describe and understand humanistic nursing that is tailored to the needs of young men (18–39 years) with cancer. Eight young men with cancer (n = 8, average age = 28 years) were interviewed individually. Two themes emerged from the interviews: (1) trust between nurse and patient is paramount; and (2) this patient population has needs that are not currently being met through the humanistic nursing approach. The results of the iterative qualitative analysis of the data suggest that humanistic nursing tailored to young men with cancer should address their need to express their feelings, to be active and to receive psychological support.

Keywords: nursing care, patient experience, young adults, men, cancer, humanistic, qualitative research, Canada

INTRODUCTION

More than 7,500 adolescents and young adults between the ages of 15 and 39 will be diagnosed with cancer in Canada in 2022 (Statistics Canada, 2021). The most common cancers in young men are thyroid cancer, testicular cancer, Hodgkin's lymphoma, melanoma, non-Hodgkin's lymphoma, colorectal cancer and leukemia (Statistics Canada, 2021). The challenges and issues faced by patients in this age group are distinct from those faced by patients in other stages of life (Bradford et al., 2017). For example, compared to older men, young men appear to be more concerned about the loss of physical abilities (e.g., endurance, strength, speed) than changes to their physical appearance (e.g., hair, height, weight) (Campbell-Enns & Woodgate, 2013; Cecil et al., 2010). Moreover, young men tend to have many more questions and concerns about their fertility (e.g., loss of fertility, impotence) (Perez et al., 2018; Taylor & Ott, 2016; Wide et al., 2020).

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Young men with cancer may also experience significant changes to their social lives. For example, following a cancer diagnosis and treatment, they may disregard prescribed medical restrictions (e.g., reduced alcohol consumption and fewer high-energy activities) in order to prevent their friendships from being impacted (Campbell-Enns & Woodgate, 2013). In addition, as these patients become busy with treatment and care, they tend to interact much less frequently with their peers (Mesquita et al., 2011; Love et al., 2014).

Humanistic nursing care is crucial following a cancer diagnosis. Humanistic nursing involves listening actively, fostering engagement and helping patients to recognize their strengths (Cara et al., 2016). The aim of humanistic nursing is to help guide patients toward the resources and environment they need to thrive (Cara et al., 2016). According to the literature (Liddon et al., 2018; Love et al., 2014), however, young men with cancer are not used to seeking help from nurses. In fact, a majority of young men do not openly express their emotions or feelings to nurses, stating that they perceive nurses as being overworked and, therefore, try to avoid bothering them (Taylor et al., 2018).

Researchers have reported that some concerns specific to young male cancer patients (e.g., personal identity, romantic and sexual relationships, work) are rarely addressed by nurses (Belpame et al., 2016; Bibby et al., 2017; Galan et al., 2017; Kim et al., 2016). Additionally, some healthcare professionals appear to have preconceived notions about men, particularly with regard to their ability to express emotions (Handberg et al., 2018; Martopullo et al., 2019; O'Neill et al., 2016), which may influence how nurses provide care and support to young men with cancer.

Young men with cancer have unique patient experiences, and their personal circumstances (e.g., work, school, social lives) are highly variable (Alexis et al., 2020; Love et al., 2014), suggesting that these patients require a humanistic nursing approach that is tailored to their individual trajectories and needs. To the best of our knowledge, there is little documentation on humanistic nursing for this patient population. The purpose of this study is, therefore, to describe and understand humanistic nursing care for young men (18–39 years) with cancer. The research question guiding this study was: How do young men with cancer experience humanistic nursing care?

To describe and understand humanistic nursing for this patient population, we used the Humanistic Model of Nursing Care – UdeM (Cara et al., 2015; Cara et al., 2016) as a reference. This model is appropriate for our study, as it addresses aspects of humanistic nursing (e.g., listening actively, fostering engagement and helping patients to recognize their strengths) that promote a caring relationship between nurse and patient (Cara et al., 2015; Cara et al., 2016). Under this

model, humanistic nursing involves supporting people not only as individuals, but also as members of a family and a community. Indeed, the families of young men with cancer are especially impacted by their illness and worry about the changes that it may bring about (Mesquita et al., 2011).

METHODOLOGY

A qualitative descriptive approach was selected, as it allows participants to provide rich, detailed descriptions of given phenomena from their own perspective (Thorne, 2016). This approach is unique in that the description of each phenomenon serves to inform professionals of a potential need (Thorne, 2016). This inductive approach enriches research by providing practical, specific solutions to problems identified by the targeted group (Teodoro et al., 2018). The study was approved by the research ethics board of an integrated university health and social services centre (CIUSSS) in the province of Quebec (certificate #2022-2423). All participants signed a consent form.

Sampling and recruitment

The study was conducted in a French-speaking teaching hospital in Quebec, Canada, that offers cancer care. The convenience sampling method (Denzin & Lincoln, 2017) was used to select study participants. Participants were recruited with the help of oncology nurse navigators as well as through a post on social media (e.g., Facebook, LinkedIn) that was shared by community cancer care organizations. Participants were eligible if: (1) they were between the ages of 18 and 39; (2) they were male; (3) they had been diagnosed with cancer and had finished active treatment; and (4) they were able to speak and understand French or English. The study targeted participants who had completed treatment so that they would have had some time to reflect on their experience. A total of eight participants were recruited, which, according to Guest et al. (2006), is sufficient to gain a broader understanding of a specified phenomenon.

Data collection

Eight semi-structured interviews, averaging 60 minutes in length, were conducted by videoconference ($n = 8$). The questions were inspired by the Humanist Model of Nursing Care – UdeM and related to how humanistic nursing was tailored to the needs of young men with cancer. For example, one of the questions was: “How did the nurses support you as part of your cancer care?” The participants also completed a sociodemographic questionnaire.

Data analysis

Iterative qualitative data analysis was performed using Miles et al.’s (2014) approach, which involves condensing and displaying the data, and drawing and verifying conclusions. The written transcriptions of the interviews were reread and compared to the audio recordings, and then imported into QDA Miner v. 5.0.19 (Provalis Research, 2020). During analysis, codes were assigned inductively to segments of text with meaning for the phenomenon of interest. The data were displayed in graphic and table form. The transcripts, codes and tables were analyzed iteratively. The Humanist Model of Nursing Care – UdeM influenced the final cycles of coding

as it helped identify themes and subthemes. This model and the questions asked also influenced which units of meaning were selected. Coding and conclusions were discussed and validated by the authors (AE, KB) in order to increase the credibility, reliability and transferability (Miles et al., 2014) of the results. To further ensure the credibility of the study, an expert in oncology and qualitative research (KB) validated the analysis and interpretation of the results. Additionally, the reliability of the conclusions drawn was confirmed by consulting the logbook containing methodological notes that comprehensively document the data collection process (Miles et al., 2014).

FINDINGS

Eight participants between the ages of 20 and 33 (average age of 28) were recruited. All participants were from the province of Quebec, Canada, and had been hospitalized at least once following their cancer diagnosis. All participants had undergone surgery and chemotherapy. Four of the participants in the sample were single, three were married fathers and one was in a relationship without children. Four participants had testicular cancer, three had sarcoma and one had lymphoblastic lymphoma. Almost a third of the participants were students.

Two themes emerged from the analysis of the data: (1) trust between nurse and patient is paramount; and (2) this patient population has needs that are not currently being met through the humanistic nursing approach. These themes and their subthemes are described in the following paragraphs.

1) Trust between nurse and cancer patient is paramount

The first theme is the importance of trust between nurse and cancer patient. In order to build trust, the nurse must create an environment that promotes patient health (Cara et al., 2016). This theme has four subthemes: (1) being present for the patient; (2) establishing a partnership of care between the patient and the nurse; (3) being available to the patient; and (4) taking an interest in the patient’s feelings and emotions.

Being present for the patient. The participants mentioned that they were able to develop a good relationship with their nurses when the nurses took the time to have a conversation with them. According to Cara et al. (2016), being present requires seeing the patient as an individual who is empowered in their own care. Participants noted that good conversations took place when nurses sat with them, looked them in the eye and asked about their interests. The participants appreciated that the nurses answered their questions at these times. The participants mentioned, however, that they felt that the nurses were rushed and said that they shared less openly when this was the case. One participant said, “*We could tell that she was in a bit of a hurry when she came to see us, which I didn’t like so much. She didn’t take her time with us. You could feel the stress. It wasn’t her fault.*” (Participant #7).

All participants said that they found the presence of nurses comforting while they were hospitalized in oncology. Many participants felt alone during this period of their lives. Even when they did not require continual nursing care in their room, they appreciated that a nurse was present at all times.

One participant said, “Trying to build trust, knowing you’re not alone. I needed to be in my own bubble, but knowing that if I needed help, someone was there for me while I was hospitalized.” (Participant #5).

Establishing a partnership of care between the patient and the nurse. Despite the many challenges of a cancer diagnosis, the majority of participants said that it was important for nurses to include them in their care by taking their decisions into account. They felt it was essential for nurses to ask their opinion and to assess what was most important to them. For example, when discussing the impact of chemotherapy on fertility, nurses should include patients in the decision-making process by giving them the knowledge they need to make an informed choice. According to the participants, when medication (e.g., chemotherapy) was being administered, nurses clearly explained the expected effects and side effects. As a result, the participants felt they were able to start piecing together information and asking questions, and thus participating actively in their care. The analysis also showed that participants did not want to feel alone in their fight against the disease. They mentioned that nurses should include them more, as they want to be involved in their own care. One patient said:

It’s about trying to find the absurd (humorous) in the situation or trying to turn things around, so you don’t feel alone [...] in fighting your illness, but it’s also about trying to make you feel like you’re part of a team. You’re told what’s going on, what you can do. That gives you some power at that time. I’m not powerless; there are things I can do to improve my situation. That really helped me make sense of things in my head so that I could participate in my treatments. (Participant #6).

Being available to the patient. Participants reported that scheduling follow-up visits with nurses after completing their cancer treatment was very important. More than half of the participants said that they also appreciated when the nurses put them in touch with other young men who had gone through a similar experience. The majority of participants indicated that they were grateful to receive contact information for oncology nurse navigators (e.g., email address and phone number for the clinic) to get in touch if needed (e.g., to request information, ask questions or discuss worries). They said they could use this information to communicate with nurse navigators if any questions or health concerns arose. When participants didn’t have follow-up visits with nurses, they said they felt worried, but they did not mention their worries to their friends or loved ones. Half of the participants complained that their follow-up visits were not scheduled at the outset; they indicated that they would have felt more reassured if they had had an appointment set up in advance, as well as the opportunity to meet with the nurse navigator as needed. One participant explained:

I would have liked this to be structured and more accessible. Even with my appointments now, there are still gaps. In the beginning, my appointments were every six months. Now they’re every 12 months. But it still feels like there are gaps. It’s like the healthcare system hasn’t quite caught up with the times [...]. (Participant #3).

However, the other half of the participants mentioned that nurses helped them schedule follow-up appointments (e.g., for check-ups or bloodwork, or to see doctors). One participant said:

Yes, it’s difficult to call the hospital with all the numbers there are to make an appointment. The nurse would say to me, “I’ll do that for you, and we can meet on that day.” The nurse gave me all the information. (Participant #8).

It seems that the appointments with nurses give the young men a chance to ask questions, receive information and participate actively in their care.

Take an interest in the patient’s feelings and emotions. Feelings and emotions are an expression of what people are going through at a given moment. Participants said that they often felt down during their cancer journey. Half of the participants mentioned that they faced these moments of sadness alone since they found it difficult to express their emotions and ask for help. One participant said:

What’s important to understand is that, when I was in the hospital, I was in a sterile room. When anyone did come in, it was really just to see me. So, if I had a problem, I had to call someone in. It wasn’t my style to call, but I really was all alone all the time. I didn’t have anyone to talk to. (Participant #1).

Participants said that nurses should go further in their care of young men with cancer by showing an interest in knowing and understanding how they feel. More than half of participants agreed that nurses should encourage patients to express their emotions while being sensitive to when and how patients wish to do so. For these patients, physical activity can be a means of expression. One participant described this need as follows: “I would say, understanding the way we express our emotions. And understanding that moving, for us, is a need to move, but there are also other ways to blow off steam.” (Participant #6).

2) This patient population has needs that are not currently being met through the humanistic nursing approach

The second theme describes the needs of young men with cancer that are not currently being met through the humanistic nursing approach. To further personalize their care, young men with cancer would like to receive resources that would create a better patient experience. This theme can be divided into five subthemes that represent unmet needs: (1) care adapted to the patient’s reality; (2) connection with other young men with cancer; (3) specific information; (4) being active; and (5) psychological support tailored to young men.

Care adapted to the patient’s reality. More than half the participants said that they did not notice any difference between the nursing care provided to young men as compared to older men. In fact, they said that nurses asked the same types of questions to all patients. The participants would have liked to be asked questions or talk about topics more relevant to their lives as young men (e.g., personal identity, work or school). All participants stated that nurses have a heavy workload and that they have to work quickly in order to care for their patients.

This is one of the reasons that participants might feel that a nurse's manner is the same for all patients, regardless of age. One participant said:

It didn't seem like being younger or older made any kind of a difference. I think that even if I were 50 or 60, it wouldn't have changed anything. I feel like we were all the same. (Participant #1).

Connection with other young men with cancer. All participants said that it was important to spend time with other young men with cancer. The participants felt alone during their treatment because there were rarely other male patients of the same age around. The majority of participants appreciated it when nurses invited them to meet other young men so that they could discuss their shared experiences and interests. With other young men, they were able to talk about working, getting their energy back and being able to play sports again. They were also able to talk about topics such as the side effects of treatments and protocol phases. The participants said that, in general, young men open up more when they are with people of the same age. In the words of one participant:

It was nice to talk to someone who's going through something similar. The treatment was four hours long and we talked for four hours. We never used our phones. We talked and it was great. Everything else just fell into place. (Participant #4).

Specific information. The participants expressed that they would have liked to receive clearer and more specific information from the nurses. In some cases, they did not receive any information on their particular type of cancer. The transcripts show that having a better idea of what to expect was one of the things they would have hoped for. They said that they felt unsettled without this information, as though they were the only ones with their type of cancer. All participants brought up the need to adapt the information to the reality of young men. In some cases, the participants received basic information, but they indicated that they would have liked to discuss certain subjects (e.g., the impact of cancer on young adults) in greater depth. For example, one participant said:

I would have liked to receive more written information, more materials relevant to me and my type of cancer. There are lots of different types of cancer. A one-size-fits-all approach doesn't work. The information I got about the operation and the chemo was very general, about testicular cancer and prostate cancer together. I'd love to see something like a pamphlet. It sounds simple, but I'd just want to be told what to expect. (Participant #3).

Being active. The participants stated that, even with a cancer diagnosis, it was difficult to be cooped up in their hospital rooms. All participants said that they knew that the hospital was not a recreational space, but they would have liked to move around, participate in activities and socialize. One participant stated:

It's hard as a young person to be shut up in your room and not be able to socialize with the outside world. That was hard for me. The nurses tried to make up for that.

It's not always easy. We can talk about this and that, but there are no activities, there's nothing going on. There are a lot of things [improvements] to think about on that front. (Participant #2).

More than half of participants said that, despite their illness, they wanted to be active and feel useful. They were determined to do everything they could to get through the treatments, as this participant stated:

I think that most people my age, I think we see it from this point of view. Our heads are screwed on right. We just have to stay cool and have this "I'm ready" attitude. It doesn't make things any more enjoyable, but at least we're doing something. (Participant #4).

Psychological support tailored to young men. Participants stated that they experienced significant anxiety, which they did not mention to their loved ones or healthcare professionals. They said that it was difficult enough to be diagnosed with cancer, but that the anxiety and stress that gradually set in made things worse. The participants stated that, unfortunately, they did not receive psychological support from the nurses in this regard. They said that they would have liked for the nurses to talk about mental health and the psychological impact of a cancer diagnosis. As one participant stated:

In terms of how I feel, I didn't have any psychological support. I had less support in that area. They were more focused on the side effects of the treatments. From a psychological point of view, I didn't get anything at all. It was more questions about the physical aspect, but much less about the psychological aspect. (Participant #3).

Participants stated that they received psychological support at the end of their cancer treatment; however, they would have liked for the nurses to have been able to evaluate them and refer them to the relevant resources as soon as they were diagnosed. One patient said:

On my last day of chemo, I happened to find out there was actually psychological support available. There was a psychologist at the hospital in the oncology department. Maybe I would have used it earlier [...]. I used it after the chemo, maybe I would have used it halfway through. I wouldn't have gone every week, that would've been too much. But just to help deal with the cancer and find out how to cope. It's useful information that I would have liked to have had. I didn't even know psychological support was available. (Participant #5).

DISCUSSION

In this qualitative study, we have described and sought to understand humanistic nursing care tailored to the needs of young men with cancer. Our findings suggest that humanistic nursing care should involve building a relationship of trust and addressing the unique needs of this patient population.

Establishing trust between nurse and cancer patient appears to be fundamental (Guzik et al., 2021; Smith et al.,

2020; Tay et al., 2018). Our findings highlight the need for nurses to be a reassuring presence for these patients. Our findings also indicate that young men are interested in being more actively involved in their cancer care journey (e.g., teaching, support groups). Our study suggests that, if nurses do not take the time to get to know young men with cancer as individuals and involve them in their own care, these young men may not have the desire to open up to nurses. This is consistent with findings from other studies that show that, in general, young adults want nurses to spend time really getting to know them as people (Guzik et al., 2021; Smith et al., 2020; Tay et al., 2018).

The young men with cancer interviewed for this study saw scheduling followup visits with nurses as essential. This scheduling not only makes patients feel more secure after completing their treatments, but it also allows them to contact nurses to ask questions and discuss concerns if new symptoms appear. These findings are consistent with those of other studies that show that followup visits with healthcare professionals allow young adults to feel safe and part of a community throughout their care journey (Guzik et al., 2021; Lea et al., 2021). Unfortunately, however, although participants described follow-up visits as being important, they also mentioned that there were many problems with arranging them.

Our findings suggest that young men with cancer have difficulty expressing their emotions when experiencing sadness during their cancer journey. The participants explained that they did not want to worry their friends or healthcare professionals with their grief and preferred to keep their feelings to themselves. These findings are similar to those of Sharp et al. (2022) and Handberg et al. (2018), except that those two studies examined the difficulty that men in general have in expressing their emotions and do not specifically address young men with cancer. Our findings clarify that this issue also affects young men.

The second theme of our findings shows that young men with cancer have needs that are not currently being met through the humanistic nursing approach; these include the need to connect with other young men with cancer and the need for care adapted to their reality. Firstly, our results show that the young men with cancer did not find that the nursing care they received was any different from that provided to other cancer patients in terms of presence, questions asked, information received and other aspects. This is consistent with other studies showing that young adults generally like to be recognized as being individuals with needs, preferences and worries that are different from those of older people (Belpame et al., 2016; Cameron et al., 2021). Additionally, according to our findings, young men with cancer seem to want to discuss and share information with other young men with cancer, as they may have experienced the same challenges and issues (e.g., difficulty in expressing their emotions, loss of physical abilities, changes in appearance, fertility questions) during their cancer journey. To be able to do so, they need nurses to put them in contact with other young men with cancer. This finding does not appear to have emerged in other studies.

Our findings show that young men with cancer are unique in their need to feel active. Prior to their diagnosis, participants were involved in a wide range of activities (e.g., dancing, soccer, bowling) with their friends. Our study indicates that the lack of any such activities during hospitalization can lead young men with cancer to feel isolated. This corroborates the findings of studies by d'Avutu et al. (2022) and Bilodeau et al. (2022), which show that young adults describe their patient experience as one of feeling lonely and dependent on others. Other studies have proposed the creation of social spaces specifically for young adults in order to facilitate interaction with other patients of their own age as well as with nurses (Holland et al., 2021; Phillips et al., 2017).

This study reveals that many participants did not receive psychological support from nurses when they needed it. Additionally, our findings show that participants would have liked to receive psychological support as soon they were diagnosed with cancer. According to Holland et al. (2021), young adults with cancer may need just as much psychological support during the cancer journey as afterwards. Mental health is a widely stigmatized topic, and other studies show that men may perceive that healthcare professionals, including nurses, do not take their worries seriously (Lea et al., 2021; Sharp et al., 2022). Our study highlights the importance of having nurses evaluate young men's support needs and referring them to the appropriate psychosocial resources.

Many of these findings apply to men in general. However, the findings relating to establishing trust with nurses and the need to be active are unique to young men with cancer.

Strengths and limitations

With regard to limitations, the participants in our sample had different diagnoses and were of varied ages (ranging from 20 to 33 years). Given the diversity of participants in this study, it is possible that the experience described differs from those of other men in their twenties or thirties or who have a different diagnosis. Additionally, our results describe humanistic nursing care tailored to the needs of young men with cancer living in Quebec, Canada, and the results should therefore be interpreted in this context. As for strengths, this study is innovative in that it provides insights into the unmet needs of young men with cancer, a little-studied patient population. Although only eight individuals took part in the study, data saturation was observed around the sixth interview.

Implications for nurses

Our findings suggest that training for oncology nurses and nursing students could include topics such as discussing feelings and emotions with young men, scheduling follow-up visits, identifying needs that are unique to young men, recognizing the importance of psychological support and facilitating connection with peers. We also suggest that additional services (e.g., nurse navigators, support groups for young adults and information adapted to the reality of young men) be implemented to improve the provision of humanistic nursing care to young men.

CONCLUSION

This study has allowed for a better understanding of humanistic nursing care tailored to the needs of young men with cancer. Our findings suggest that oncology nurses should pay particular attention to patients' needs for psychological support, to be active and to express their feelings and emotions.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest in connection with the writing or publication of this article.

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