

## RESEARCH ARTICLE

# Lived experiences and caring needs in young adults diagnosed with cancer

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## Abstract

**Aims and Objectives:** To explore the lived experience of young adults diagnosed with cancer and to increase our understanding of how to help them with their caring needs.

**Background:** Being diagnosed with cancer is normally related with an existential crisis. This indicates that the individual cannot avoid thoughts of death, loneliness, guilt, and meaninglessness. In person-centered care, the caretaker should have a holistic view of the person. Professionals must meet the patient's different needs to strengthen health and well-being for the diagnosed. This approach encourages the traditionally passive patient to become an active consumer who works in partnership with the healthcare provider.

**Design:** For this study, a content analysis of narratives was conducted, targeting age groups of 20–29 to take part of young adults' experiences.

**Methods:** Qualitative analysis of narratives and followed checklist (e.g., COREQ).

**Results:** During the analyzing phase, two main themes emerged: Interactions with Professionals and Cancer Voyager. In the results, both positive and negative feelings regarding encounters and support received from the professionals were described, this affected the young adults' well-being and their ability to participate during treatments. The young adults felt as being on a journey with no control over which direction the road may take.

**Conclusion:** Outcome of the result shows the importance of making the young adult, one in a team. When working in a person-centered way, patients gain control by owning their own responsibility during treatments.

**Implications for Nursing Practice:** There is a need in nursing education to address existential matters, to make nursing students ready to be approach but such questions in their professional work. Also, we believe that the experienced nurse must be given means to feel confident to handle questions about existential matters. By developing skills in the area of e-Health, collaboration through support groups,

and last but not least switching to patient-centered care, we can offer effective and evidence-based care tailored for this population.

**KEYWORDS**

cancer, hope, interaction, lived experience

## 1 | INTRODUCTION

Each year in Sweden, about 800 people between the ages of 15 and 29 are diagnosed with cancer. Worldwide, this is a large and important healthcare consumer group with unique long-term support needs.<sup>1</sup> The immense progress in cancer treatments over the past 2 decades has increased the population of young cancer survivors,<sup>2</sup> with a corresponding increase in demands on healthcare organizations and society.<sup>3</sup> Living with a life-threatening disease at a young age can have a significant impact on the existential dimensions of life. Between ages 15 and 29, psychological development is closely related to the growing adolescent body. Adolescence involves a transition from searching for one's identity to finding out who one truly is or wishes to be.<sup>4</sup> This critical transition can affect psychological fundamentals, impacting normal young adult development.<sup>5,6</sup> The Internet and social media are now part of everyday life and the use of blogs is commonplace. Previous research has highlighted the role of blogs as a form of self-therapy,<sup>7</sup> and the Young Cancer (Platform) provides encouragement and information about blogs for young people with cancer.

## 2 | BACKGROUND

Adolescent and young adult oncology (for those aged 15–39 years) is a relatively new field of clinical practice and research. The number of new young adults diagnosed with cancer each year is an estimated one million worldwide. About 82% of these will be cancer survivors who are at risk of late treatment-related complications; cardiotoxicity, second primary cancers, cognitive shortfalls, fertility issues, changes in sex life, and psychological issues.<sup>8,9</sup> These complications may result in poor health, stigmatization, and fewer opportunities to become established in the labor market.<sup>10</sup>

According to Sand and Strang,<sup>11</sup> cancer diagnosis is commonly associated with an existential crisis, where the individual has persistent thoughts of death, loneliness, guilt, and meaninglessness. Often referred to as border situations, these important life events can have both positive and negative consequences for the individual. With every individual, however, the affected person must adjust their approach to life, altering them in ways that are both intense and indefinable.<sup>11–13</sup> In the long run, border situations can support personal growth by prompting a re-evaluation of the meaning of one's life.<sup>11–14</sup> These existential challenges are driven by the human search for meaning and purpose. Young adults with cancer are likely to experience the suffering caused by helplessness and an inability to

affect the course of the illness.<sup>15</sup> The concept of suffering relates to experiences of pain and the darker existential focus often associated with disease.<sup>16</sup> According to Eriksson,<sup>17</sup> difficulties in the search for fellowship with others, including family members, friends, or people who share the same experiences, may also cause suffering.

To help to alleviate suffering, the healthcare provider must respect and acknowledge the patient's dignity<sup>17</sup> by taking into account the uniqueness of each individual's understanding and experience of their disease.<sup>15</sup> In person-centered care, the caretaker must adopt a holistic view of the patient to ensure that their needs are met in strengthening health and well-being. This approach encourages the traditionally passive patient to become an active consumer, working in partnership with the healthcare provider<sup>18</sup>; in other words, person-centered care is grounded in the patient's own life story. To meet the individual's unique needs, staff must address the physical, psychosocial, and relational dimensions of care within the healthcare environment.<sup>19</sup> The presence of a nurse during treatment is a key factor in facilitating the partnership approach that patients need.<sup>20,21</sup> This issue has not yet been investigated in the population of young adults diagnosed with cancer, because there is, as of yet, no adequate ethical and practical platform for a person-centered approach.<sup>22</sup>

In this study, researchers use the phenomenological term lived experience. Lived experience is used to describe a phenomenon that exists in a person's everyday life.<sup>23</sup> To describe this phenomenon researchers have to use an insider's view, which means that the data is built from a self-referent perspective. To understand this perspective, researchers have to take details of participants' lived experiences in a specified time period in their lives.<sup>24</sup> Lived experience is considered a favorable method in describing the connection between everyday experiences told by a selected group of participants at a specific time in their lives, with the aim to address issues such as existential, physical, and psychological experiences.<sup>25</sup> According to Yardley,<sup>26</sup> research works in the biomedical and healthcare fields are often criticized for measuring the quantitative impact of the illness versus qualitative ones such as existential, psychological impacts. By focusing on subject's individual life, including lived experience, existential and emotional values, the researchers can find essential meaning in the result. The outcome of the research can be more meaningful, satisfactory, and veracious when focusing on the subject's existential and emotional encounters which is the direct result of their own lived experiences. This term demonstrates its relevance by providing an acceptable framework to help in understanding the complexity of a person's social and personal dimensions.<sup>27</sup>

3 | AIM

To explore the lived experience of young adults diagnosed with cancer and to increase our understanding of how to help them with their caring needs.

4 | METHOD

4.1 | Design

The present study captures young adults' lived experiences of cancer and healthcare support through a qualitative narrative analysis of relevant blogs. According to Skott,<sup>28</sup> this form of analysis supports reliable retelling of stories through an interpreter. The method is widely used to explore “soft” data related to individual experiences and feelings. To do this successfully, the researcher must approach the analysis with an open mind and an awareness of their own assumptions. By studying their narratives, the researcher can explicate how each individual constructs meaning in everyday life, thereby gaining a deeper understanding of their story.<sup>28</sup>

4.2 | Data collection

The material was found at a national support group for cancer. When reading the narratives, the study aim was used as a guideline, and relevant words were marked in the text. The participants were not asked to participate but had agreed to share their stories on an official platform with no restrictions on data sharing. The process of the study was followed through using a checklist (e.g., consolidated criteria for reporting qualitative research (COREQ): a 32- item checklist for interviews and focus groups) (see File S1).

4.3 | Participants

The participants were eight young females (aged 20–29 years) who had been diagnosed with cancer and shared their thoughts on everyday life through blogs (in Swedish). The duration of blogging at the time of the study ranged from 6 months to 5 years. The content of the selected blogs aligned with the study aims. All participants were members of an Internet platform for young people.<sup>29</sup>

4.4 | Data analysis

To begin, the authors read through all the material (268 pages), marking the text in different colors according to its relevance. This generated a number of small groups in different colors that could all be linked to the study's aim. When this process was complete, the data were further condensed while retaining their meaning, reducing the number of groups (see example in Table 1). This process

TABLE 1 Example of a unit of analysis

Meaning unit	Condensed meaning unit description close to the text	Condensed meaning unit Interpretation of the underlying meaning	Subtheme	Theme
"Feels like I am always pinching or rubbing my body—searching, sometimes I am scared to scratch an itch because of the possibility of finding a new bump. I am terrified of living in this body—the same body that I once cherished so highly." (Blog 3)	"Fear of own body that I once loved and trusted; fear of trusting my body; fear of finding bumps when I touch my body and a strong sense of being terrified of the future."	"Fear of what the future might hold"	Ongoing fear	Cancer Voyager

**TABLE 2** Findings

Theme	Subthemes
Interactions with Healthcare Personnel	<ul style="list-style-type: none"> <li>• Perception of information received from healthcare personnel</li> <li>• Alienating versus supporting encounters</li> </ul>
Cancer Voyager	<ul style="list-style-type: none"> <li>• Physical and mental changes due to cancer treatment</li> <li>• Life in limbo and finding hope</li> <li>• Ongoing fear</li> </ul>

continued until sentences could not be further condensed without loss of meaning. The numerous subthemes were then assembled as a mind map, providing a helicopter view of the larger themes to which the subthemes seemed to belong. The final outcome was two themes and five sub-themes (see Table 2). To protect the identity of the participants, all data were anonymized and stored; each participant was assigned a unique number (from 1 to 8).<sup>28</sup> In addition to trying to protect the identity of the participant, the original quotations were translated into English, not word for word, but rather to convey the meaning of the original quote made by the participant.

The analysis followed Skott<sup>28</sup> procedure for interpreting text without losing track of the story's meaning, informed by the study aim to maintain relevance. Based on Skott's<sup>28</sup> account of how to read a text as either plot or theme, the authors adopted a thematic approach, as the stories felt more like abstract data.

## 4.5 | Ethical considerations

When using shared blog data for research purposes, certain ethical considerations must be respected. When an individual logs on to a blog platform to share their stories with other users, they agree that the information may be used by others.<sup>30,31</sup> For the purposes of this study, all participants were asked to share their lived experiences through blogs accepted by the platform for young cancer patients. They were informed by the platform that others could access their thoughts and feelings, and they fully accepted this, as they wanted others to learn from their life stories. Participants were free to shut their blogs down and deny access at any time during the process. Their identities are protected here by the use of paraphrasing rather than direct quotations.<sup>32,33</sup> As this study was conducted as part of an advanced educational program, ethical approval is not required under Swedish law.<sup>34,35</sup>

## 5 | RESULTS

The results are presented under two main themes, *Interactions with Healthcare Personnel* and *Cancer Voyager*, which are further illuminated by subthemes (see Table 2).

## 6 | INTERACTIONS WITH HEALTHCARE PERSONNEL

The participants described both positive and negative feelings about their interactions with healthcare personnel. Differing individual perceptions of these encounters may have affected the treatment received, as identified in the subthemes.

### 6.1 | Perceptions of information received from healthcare personnel

In their first encounters with healthcare, the participants inevitably have certain expectations and fears. In general, these thoughts were reported as initially positive, as the participants hoped to be cared for and helped to understand what had happened to them. Further along on their journey through the healthcare system, these thoughts began to sound more negative regarding both healthcare and healthcare providers. This negativity reflects the young adults vulnerable situation. Participants felt this might have been prevented if their treatment and interactions had been more structured and planned. The key issues highlighted by the participants included lack of trust, incorrect information, too little information, and difficulty in understanding the information provided. All of these factors contributed to the participants' loss of trust in the professionals.

The findings indicate that the participants felt they were not properly informed about upcoming tests and treatments, and that they were regarded as "people with cancer" rather than as individuals. Participants found that on trying to confirm the information given, the answers they received tended to differ from earlier information. In their fragile state of mind, this was seen to amplify their own worries and stress, as inconsistent information from professionals compelled young adults to search for reliable information about their condition. Another aspect of this information problem was that those who contacted them rarely had any connection with them as a patient, and they were referred to someone else when asking follow-up questions. As a result, the participants had to spend hours searching for the right person to answer questions arising from the inconsistent information they received.

To get any information about what was going to happen to me, I had to spend days calling KS (hospital), without getting any answers. All they could say was that they didn't know which ward was going to contact me. After some time, I got a letter back home [saying that] a long list of tests needed to be done, and an appointment with a name that had no relevance to me. The letter offered no description of the kind of appointment. Not a single answer to my thousand questions, which were increasing in number every day. (Blog 6)

The participants also described their meetings with healthcare personnel as positive and an essential part of their extended treatment process. They felt that those who spoke to them treated them with respect, and that structure, planning, and execution were good. The participants also felt that they could comprehend the information provided in these meetings; the fact that all of the relevant professionals were in the same room meant that the participants and their relatives could ask any questions they needed to.

## 6.2 | Alienating versus supporting encounters

For the participants who were struggling to cope with the side effects of their treatment, having to deal with caregivers who seemed stressed, disinterested, ignorant, or oblivious to patient care was experienced as diminishing, hurtful, and weakening. Thoughts such as “Don't they understand how sick I really am?” led the participants to question their own opinions about their health and care needs—an effect described as all-consuming and undermining in their already fragile state. This engendered feelings of apathy toward upcoming treatments and tests, as the participants began to stop caring about what might happen to them and just went through the process feeling numb. Having to question one's own level of sickness and whether one was worthy of being cared for left participants feeling alienated.

The participants cited lived experiences of caregivers' disinterest in the person behind cancer and ignorance of their real needs as their reason for not questioning the care they received. They failed to take an interest in the many treatments they had to endure, even when the execution of that treatment differed from what had previously been agreed upon. They expressed feelings of just wanting to get off the “cancer train” and to deal with the consequences later. All of the participants felt numb in relation to their care and providers and felt they never wanted to set foot in a hospital again once their treatment was complete. They had developed negative feelings about hospitals and care, including panic, worry, nausea, and anxiety attacks. These feelings persisted after they had finished treatment and resurfaced whenever they got a letter or phone call related to the hospital.

No more blood pressure control, no EKG, no measurements of my pulse or saturation. I am left all alone to ask ‘am I worse or better?’ They left me alone, with death hanging around my neck. All that I feared to feel in order to survive this is like dark shadows around my head. Did I really survive? Am I still alive? Or is this all just a sick joke and will everything be taken from me again? (Blog 7)

In encounters they described as supportive, the participants felt that their questions were answered; professionals took their time and were interested and present. These caregivers were described as kind, very patient, and not afraid to show their own emotions. The

participants characterized these professionals as a great source of support in helping them to deal with negative feelings, alleviating their worry and anxiety. This support during their treatment gave them increased hope for the future, restoring their energy for undergoing treatment and helping them to feel happier despite the severity of the disease. Feeling respected and included as “the person behind cancer” was described as a motivating factor, enabling them to endure with hope. These caregivers were seen as allies whose expert knowledge provided a light in the darkness. These caregivers gave the participants the confidence to ask questions and to seek help when life felt difficult because it felt that someone was sharing their burden

I was transferred to this very primitive oncology ward that looked more like a nursing home than a hospital. But my god, the staff here is wonderful, not at all like this primitive place where they work. (Blog 2)

## 7 | CANCER VOYAGER

Feeling powerless was the most consistently reported emotion associated with a cancer diagnosis, as if on a voyage with no control over its direction.

### 7.1 | Physical and mental changes due to cancer treatment

The experience of pain, both physical and psychological, was an essential feature of treatment as described by the participants. While various individual side effects were experienced as shameful—incontinence and loss of bowel control, having to ask for help with showering, and going to the bathroom—physical pain was generally considered the hardest to endure. Other physical changes such as loss of hair, muscle tone, and body parts were also hard to adapt to. Participants felt they had to develop a new identity to come to terms with their treatment, which forced them to adopt a new persona to acknowledge the reality of being seriously ill. Their sickness could no longer be hidden or denied, which adversely affected their mental health, as being stared at in public left them feeling naked to the gaze of others. Those lived experiences were expressed in terms of not knowing what to expect in the future and having doubts about their ability to cope with the burden of their illness and the mandatory treatments. Unrecognized symptoms such as exhaustion imposed great physical and psychological strain during treatment and in their everyday life. The loss of power over one's own life persisted throughout the illness and afterward, and participants made decisions, however small, to restore some of that power—for example, instead of waiting for their hair to fall out, they would shave it off, restoring some sense of control over one side effect of treatment.

I am exhausted; my body and mind went into this with full force to heal me, and now they are like an old cellphone. I can only manage to play one turn of Snake before the battery light goes red and says 'low battery, please charge'. (Blog 2)

## 7.2 | Life in limbo and finding hope

Facing the new persona created by having to endure arduous treatment and the possibility of death, the participants felt they were left in a kind of limbo. Following treatment, loss of the much-needed support that had been central to their everyday life for a long time led to feelings of depression and devastation. Those assigned to another unit expressed both happiness for not being abandoned and frustration because they were not fully free of the hospital. These double-edged emotions were seen to interfere with their progress towards a new future. The participants described this period as a continuing suspension of real life because, although cancer-free, they still lacked the energy to move on.

The participants referred repeatedly to the difficulty of feeling alone in a crowd while undergoing cancer treatment, as nobody close to them could understand what they were going through or feel exactly what they were feeling. These thoughts left them feeling isolated, alone, and weakened: "It's me and cancer, and others are on the outside looking in." The feeling was so intense that the participants often had to stop what they were doing and withdraw until they could bring these feelings under control, causing them to feel even more isolated.

I hate all your stupid comments, said in all friendliness—sure, I am going to be well and free of cancer, but everything is taken from me, and I will never get it back. I will never be able to have kids [because] I am without a uterus or ovaries—nothing left that made me a woman. They took it all away and made me well and healthy again, but what is healthy? Your kind words feel like slaps across my face. (Blog 1)

The participants identified hope as their main source of energy in everyday life in coping with all the negative feelings associated with cancer and its treatment. They created that hope from the positive things they experienced during treatment, such as feeling stronger, being able to cope on one's own, getting leave from hospital following successful treatment, and needing less help in everyday life. Coping successfully with aggressive treatment and surgery boosted the participants' energy levels, leading to positive energy cycles. Family members also helped in this regard by helping them to return to more normal life and a sense of self-sufficiency, inspiring hope and the possibility of a future. Sharing feelings about death, dying, and being sick with others who had come through the same situation also gave them the

willpower to push through tough treatments in the hope of being well in the future.

## 7.3 | Ongoing fear

During treatment, having to accept that their life was on hold created fear of an involuntary journey with no end. Life became a long wait: to conquer cancer or to be conquered by it. The fear of this struggle for survival was experienced as ongoing, with no possibility of a break. The participants commonly described thoughts such as giving up, taking matters into their own hands, and ending their life.

Diagnosis also introduced another fear: losing the ability to have biological children as a consequence of their treatment or surgery. Having to make decisions about fertility while undergoing treatment or necessary surgery was considered to be one of the toughest decisions of their life. Most of these young people had never previously thought about having children; now, they had to face the risk of becoming infertile. Confronted with decisions about saving eggs or adopting and how this might affect their relationship with their spouse, feelings of stress, anxiety, and worry were an exhausting feature of this phase of the "cancer voyage." They described the prospect of possible infertility as worse than the cancer diagnosis itself in light of the effect on their persona and their future life. Hope itself was cited as the primary reason for fighting on and enduring backlashes, failed treatments, and other difficulties. For those who had to face the reality of infertility, adoption was the way forward.

"I will never be able to bear a kid in my stomach//I hope they change the law so I can have my own kids if not I guess I have to adopt... One thing is for sure kids I do want. This was the biggest blow to my face of all that I gone through. The panic of not being able to have kids of my own will probably soon hit me but for right now I don't dare to stop and feel" (Blog 1)

Toward the end of treatment, the participants expressed fears about what they might be without cancer, and how they would re-adjust to an ordinary life. Fear of relapse and how they would deal with it was common at this stage, as well as concern that doctors might not give straight answers in this regard. Thoughts about dying, which were always present, also intensified toward the end of treatment, and the participants described these as negative and depressing. Those feelings were expressed in terms of an increased need to control their health, examining bumps on their body. Normal colds and fever were no longer taken lightly and had to be checked by a doctor as soon as possible. To be able to resume a normal life, the participants said they had to learn how to live with thoughts of death and dying as a difficult but necessary part of moving forward. This was harder for some, who reported that such thoughts undermined their will to live, requiring them to struggle each day to live a normal life. To that end, the participants developed survival strategies such as living one day at a time, blocking negative thoughts



through mental training, and appreciating the life they were about to regain.

One year back home, one year with grief, one year of having to feel better and force a smile. One year of sorrow, fear, anxiety and panic about what happened and what I have to live with from now on. I feel I am not allowed to feel the way I want to feel; I feel I have to keep it inside, and it's killing me, but I keep forcing a smile, forcing an answer—I am fine, and so on. I am just saying—one whole year of this. (Blog 5)

## 8 | DISCUSSION

The present findings strengthen existing knowledge of young cancer victims' sense of vulnerability. One possible source of this vulnerability is that the various existing patient associations are too heterogeneous. Research comparing heterogeneous and homogeneous groups suggests that certain subgroups manage to avoid the stigmatization associated with more advanced cancer or as in this case in a young otherwise healthy population.<sup>36</sup>

In relation to *Interactions with Healthcare Personnel*, it became clear that participants' lived experiences of self were deeply impacted by the feeling of being alienated by the professionals, prompting a sense of numbness regarding their own treatment. In contrast, some of the participants described positive experiences of professionals who were interested, present, and trustworthy, all of which contributed to feeling supported and finding an ally. The differing lived experiences within this relatively small group indicate that the healthcare system must face this challenge by moving increasingly toward person-centered care.

The participants' negative feelings related mainly to lack of trust and information that was inadequate, incorrect, or difficult to understand, all of which undermined trust in the professionals. These findings align with evidence from an earlier qualitative study in Norway in which 20 young cancer survivors were interviewed about their preparedness for a return to everyday life after cancer treatment. The informants reported that they were unprepared and experienced a discrepancy between their expectations and reality, especially regarding the holistic impact of late effects. As in the present study, their return to everyday life was hindered by a lack of understanding among their networks and the professionals responsible for follow-ups.<sup>3</sup> This made the transition much harder than expected, leaving them isolated and feeling neither healthy nor ill, confirming Muntlin Athlin et al.<sup>37</sup>

According to Carlsson et al.,<sup>38</sup> making it possible for nurses to take part in a reflective group with coworkers made it easier for them to handle ethical issues that might arise during work. Also, they could establish that after 5 years, the participants still had positive effects from being part of the group. None of the participants could remember anything negative about taking part in the reflective

group and most of them acknowledged that the experience had developed the way they carried out their work.<sup>38</sup>

Our findings confirm the importance of a person-centered approach to ensure that the participants automatically become part of the team and take responsibility for themselves, and that different professionals do not tell them different things.<sup>18</sup> This is completely in line with Sweden's national cancer strategy, which remains to be fully implemented. It appears likely that young people themselves will be the ones to effect change through their active involvement in society, including online platforms. This is the promise of e-Health at its best; it is unfortunate that those of us who work in healthcare have not yet been able to achieve this consistently.

Regarding the theme of *Cancer Voyager*, participants described how life was interrupted in a way that caused suffering, and how unjust it seemed that their future plans had been disrupted. The findings also highlight the sense of powerlessness when the cancer diagnosis became real. According to Yalom,<sup>13</sup> all humans face the same dread: the wound of death. The only possible way of dying without regrets is to realize one's personal potential and live life to the fullest. Instead, participants reported a sense of being in limbo, forced to take on a responsibility that they did not feel ready for. Along with the ongoing physical and mental pain, this heavy burden of responsibility caused them to feel vulnerable, prompting existential questions and fear in relation to infertility and the future. In the same context, Odh et al.<sup>15</sup> reported challenges that included thoughts of death, changed future plans, uncertainty, desire for a normal life, and a search for the meaning of life. Grinyer<sup>39</sup> and Zebrack et al.<sup>40</sup> also found that cancer in young adults diminished quality of life and interrupted the life course, echoing the present findings regarding individual suffering and the importance of appropriate nursing care for this patient group. In her study of stigmatization of young cancer survivors, including teenagers, Olsson<sup>41</sup> detected a concern about their body and sexual health. Scarring influences one's subjective sense of attractiveness, and this group of cancer survivors had a poorer body image and sense of sexual health than a healthy control group. It also became clear that young people appreciate questions about their mood and existential issues, which will require greater knowledge and courage among healthcare professionals in the future.

The present findings also confirm that participants were afraid they would be unable to bear biological children in the future. This causes grief for those rendered infertile by their cancer and changes their future plans, leading to great existential suffering. According to Carter et al.,<sup>42</sup> some women felt that their future made no sense if they could not have biological children, leading to depression, anxiety, and sadness.<sup>42,43</sup> To alleviate the experience of grief and to help cancer patients to rebuild their quality of life, it is important to ensure access to social support during the course of the disease.<sup>44</sup> Nurses should listen to patient concerns about fertility problems associated with cancer diagnosis and should encourage conversation about this issue. In addressing the patient's sense of loneliness in this context, supportive information and guidance is crucial; the nurse should listen to the patient's experiences and should be able to

answer questions to provide psychosocial support.<sup>45</sup> To support young adults with cancer, the nurse must be able to capture their individual existential experiences.<sup>46</sup> According to Muntlin Athlin et al.,<sup>37</sup> what the patient undergoing cancer treatment and rehabilitation really needs is some way of recovering their self-sufficiency and dignity. They found that patients ranked their relationships with physiotherapists and physicians higher than those with nurses because the former groups empowered them to cope in an acceptable way. Muntlin Athlin et al.<sup>37</sup> called for more research in this area, emphasizing that a tailored personal relationship, effective communication, and trust building through direct contact with a nurse should be central to cancer treatment and care. The present results confirm that individuals affected by cancer at a young age found their situation unfair and difficult to cope with because most people of their age had a healthy lifestyle. As illustrated in the subtheme, *ongoing fear*, constant fear of relapse, and death create feelings of uncertainty that affect the patient's whole existence. Mortality, which was not previously a concern, became a reality only when they received their diagnosis. Odh et al.<sup>15</sup> also reported that a cancer diagnosis raises this issue for young adults, causing feelings of anxiety, fear, and uncertainty about the future. Axelsson et al.<sup>47</sup> argued that patients may find it hard to burden relatives with existential thoughts, which therefore remain unvoiced. Ramondetta et al.<sup>46</sup> noted that nurses can play an important role in providing supportive care by encouraging patients to talk about these issues.

Participants in the present study felt that none of their relatives could understand what they were forced to go through, and this led to feelings of loneliness. Deckx et al.<sup>48</sup> found that the loneliness experienced by cancer patients can be alleviated by social support from others who have had the same experience. Young Cancer (an online platform for young people in Sweden) introduced the concept of "cancerous hangover" to describe the physical, psychological, and social aftermath of a cancer diagnosis. The objective is to stimulate hope for the future by ensuring that no cancer patient will have to fight alone, even after treatment.<sup>29</sup> Similarly, Eriksson<sup>17</sup> discussed the phenomenon of the "life suffering" that sickness creates, and how this can cripple the patient psychologically for life. According to Eriksson, life suffering can be prevented if it is acknowledged at an early stage by encouraging patients to talk about feelings that make no sense to them but account for their suffering. As described here, such thoughts might include feeling scared after being pronounced healthy or not feeling healthy even though one's cancer is gone.

Sweden is currently in the process of switching to person-centered care and e-Health support and apps are in development. Although healthcare provisions for cancer rehabilitation are governed by national guidelines and policy,<sup>1,49</sup> only two out of three cancer patients are currently offered a contact nurse,<sup>50</sup> and this is a crucial issue in providing further support for this group. While nursing research confirms the importance of a holistic perspective, there are major financial concerns in maintaining the level of experienced nurses. This is an acute problem in Sweden, where many professionals will retire in the coming decade, and it may prove difficult to recruit and retain new nurses.

As Chenail<sup>51</sup> noted, blogs are an attractive setting for qualitative research because data are easy to access and collect—that is, researchers can use blogs both as a source of data and as a means of obtaining information or sharing progress with others. In particular, blogs are useful because of their often personal nature. Interviews with the bloggers to get their opinion and to be able to ask following questions, would have been preferable. Since this study is based on a set frame from a nursing program's final essay, this was not possible to achieve. The authors' review of the findings showed that the results of this study were enough to go forward with the article. This is confirmed by the present findings, many of which are novel and conflict with expectations. To ensure the study's validity, it was discussed and viewed by a number of objective third parties. The study was conducted over a longer time span to ensure the quality of the data, remaining as open and rigorous as possible throughout in relation to the informants' narratives to further assure that validity.<sup>52</sup>

## 9 | CONCLUSION

Along with the ongoing physical and mental pain, this heavy burden of responsibility caused this young group of people to feel vulnerable, prompting existential questions and fear in relation to infertility and the future. Also, participants expressed that healthcare personnel seemed unwilling to talk about existential matters with them, leaving them with anxiety and sadness. They ranked their relationships with physiotherapists and physicians higher than those with nurses because the former groups empowered them to cope in an acceptable way. Participants in the present study felt that none of their relatives could understand what they were forced to go through, and this led to feelings of loneliness. They found it nearly impossible to share existential thoughts with relatives, which left their concerns unvoiced. Earlier studies in this context found that the loneliness experienced by cancer patients can be alleviated by social support from others who have had the same experience.

### 9.1 | Implications for nursing practice

For this group of young people with cancer, it is essential to offer tailored, personal relationships, effective communication, and trust building through direct contact with a nurse. There is a need in nursing education to address existential matters, to make nursing students ready to be approached by such questions in their professional work. Also, we believe that the experienced nurse must be given means to feel confident to handle questions about existential matters. The nurse has to have the courage to meet and challenge the vulnerability in this group of cancer patients. This can only be possible if the nurse has the opportunity of regular, critical reflection with a supervisor. Collaboration in teams and with support groups will make nursing care more comprehensive in the future. Being presented with the possibility of a regular group session both within



the same profession but also with other professions can be positive for the participants in the group sessions. Getting advice and support, not only from coworkers, but also from other professionals were found to enhance the experience of clinical supervision according to Hyrkäs et al.<sup>53</sup> Developing e-Health with digital tools is desirable for a successful transition to person-centered care. More effective evidence-based care can be tailored for this population, allowing the patient to take responsibility for their own knowledge, needs, and support. With this understanding, healthcare personnel will be able assist young adults with cancer in their care and treatment to make their journey less difficult.

## DATA AVAILABILITY STATEMENT

Data are openly available in a public repository that issues datasets with DOIs.

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