

# Oncology Nurses' Experiences With Patients Who Choose to Discontinue Cancer Chemotherapy

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**Purpose/Objectives:** To describe the experiences of oncology nurses whose patients prematurely discontinue cancer chemotherapy.

**Research Approach:** Qualitative, in-depth interviews.

**Setting:** Large oncology practice in South Carolina.

**Participants:** Seven oncology nurses.

**Methodologic Approach:** A general interview guide was used to obtain descriptions about nurses' experiences with patients who chose to discontinue chemotherapy. Interviews were analyzed using van Manen's approach to hermeneutic phenomenology.

**Findings:** Nurses experienced mixed emotions and struggled to balance their feelings with their respect for patient autonomy. Participants perceived that treatment side effects and inconvenience, advanced age, pessimistic attitude, and lack of social support influenced patients' decisions to discontinue treatment.

**Conclusions:** Findings indicate that nurses experience distress when patients prematurely discontinue treatment, and participants identified opportunities to support patients in continuing treatment.

**Interpretation:** Oncology nurses respect patients' rationales for discontinuing therapy and support their right to independent decision making. Nurses also struggle to cope with their reactions to patients' decisions. This tug of war somewhat parallels patients' struggles to balance quality of life with longevity.

Premature treatment discontinuation of IV cancer chemotherapy is associated with high rates of relapse and death, but descriptions of providers' experiences with patient decisions to stop treatments have not been well documented. Some studies have linked older age, depression, and lack of social support with IV chemotherapy discontinuation (Hu, Wu, Jiang, Zhang, & Xu, 2011; Irwin, 2013; Kissane, 2009; Kubicek et al., 2011; Navari, Brenner, & Wilson, 2008). However, the body of literature on patients discontinuing IV chemotherapy is lacking when compared to that of patients declining to initiate IV chemotherapy or discontinuing oral chemotherapy.

Although some studies have examined the experiences of physicians whose patients refused cancer treatment, to the authors' knowledge, the experiences of other oncology professionals who encounter the phenomenon have not been described (Madjar, Kacen, Ariad, & Denham, 2007; van Kleffens, van Baarsen, & van Leeuwen, 2004; van Kleffens & van Leeuwen, 2005). As important members of the healthcare team who spend more time with patients than physicians do, oncology nurses are likely to yield important insights into patients' decisions (Peter & Liaschenko, 2004). Their strong relationships with patients may provide extensive

understanding of patients' treatment decisions, which likely differ from that of physicians.

In addition, because of their closeness with patients, nurses are emotionally affected by decisions patients make and work in a setting lacking in resources to help them cope with job-related stress (Boyle, 2015). This emotional burden could affect how nurses intervene and their ability to affect treatment adherence. Although studies have been done of nurse-led treatment adherence interventions, whether these interventions were based on nursing experiences with treatment discontinuation is unknown; they would likely be stronger if nurses' experiences were included during intervention development (Ell et al., 2009; Rosenzweig et al., 2011). Currently, the lack of nursing perspectives on chemotherapy discontinuation is a major gap in research on treatment adherence. Therefore, the purpose of this study was to describe the lived experience of oncology nurses who care for patients with cancer who choose to discontinue IV chemotherapy when a likelihood exists of curing their disease, improving their quality of life, or increasing their lifespan.

## Research Procedures

The authors used phenomenology to guide their research, particularly van Manen's approach to hermeneutic phenomenology (Morse & Field, 1995; Munhall, 1994; van Manen, 1990).

Nurses were recruited from a large oncology clinic in South Carolina until data saturation was reached (Munhall, 1994). Participants volunteered because of their experience with patients who chose to discontinue therapy and their willingness to discuss the topic openly.

The authors identified seven female oncology nurses who were interested in participating in this study. Their average age was 51 years (range = 36–63 years), and they had a mean of 20 years (range = 10–35 years) of experience in oncology practice.

## Data Collection and Preparation

An interview schedule was developed for this study based on literature review and was critiqued by team members. It was designed to encourage in-depth description by nurses who cared for patients who chose to discontinue IV chemotherapy against the advice of their oncologists. The main interview question was, "What is your experience with patients who have chosen to discontinue chemotherapy? Can you describe what the experience was like?" Nurses were instructed to think about patients who stopped chemotherapy when a likelihood existed of curing their disease, improving their quality of life, or

increasing their lifespan. The authors were not interested in patients who stopped therapy when they had no chance for a cure or improvement. Prompts such as "Can you give me an example of that?" and "Do you remember how that made you feel?" were used when necessary to encourage more detailed descriptions.

Audio-recorded telephone interviews were conducted by the first author at a time and location of each participant's choosing. All participants chose to complete their interviews at the oncology practice during clinic hours. Interviews lasted an average of 19.5 minutes (range = 11.5–32 minutes). The study was approved by the University of South Carolina Institutional Review Board.

Interviews were transcribed verbatim by a professional transcription service. After transcription, the first author compared each transcript to the audio recording to check for accuracy. Each interview was saved as a separate Microsoft Word® data file.

## Methodologic Approach

Van Manen's approach to hermeneutic phenomenology includes identifying a subject that one finds interesting, exploring experience as it is lived versus how it is conceived, considering the central themes that define a phenomenon, and describing the phenomenon through writing (Munhall, 1994; van Manen, 1990).

## Data Analysis

Van Manen's steps to conducting thematic analysis include (a) discovering themes in descriptions, (b) identifying statements related to the themes, (c) writing about the themes, and (d) using artistic sources, such as music, art, or literature, to describe themes. Finally, essential themes are determined (Munhall, 1994; van Manen, 1990).

Transcripts were analyzed and interpreted by the first author using van Manen's method. Specifically, after data preparation, each transcript was read to get a first impression. Then, transcripts were reread multiple times to identify themes related to the phenomenon using the selective approach (van Manen, 1990). Essential statements were first underlined in each data file, and recurring themes in the data were identified. Specific colors in Microsoft Word were used to highlight statements with similar meanings. During subsequent readings, additional themes were identified, and all related statements in the transcripts were highlighted.

Linguistic transformation occurred by reflecting on and writing about the themes discovered in the transcripts. All statements with similar meanings, and therefore highlighted with the same color, were grouped into a theme and copied and pasted into a

new file in which the theme was described and interpreted to represent the entire study group. Themes were descriptively titled using literary metaphors, allusions, and participant quotes. Essential themes were then identified and interpreted by writing descriptions and explanations of the themes (van Manen, 1990).

## Rigor

An audit trail was created to ensure the validity of the study. Prior to performing interviews, the first author bracketed her thoughts by identifying preconceived biases about the phenomenon and its interpretations and noted and dated those in a journal (Chan, Fung, & Chien, 2013). Following each interview, the first author documented observations about the interviews, and she kept a journal throughout the study to document and reflect on her biases and perceptions. All highlighting and description of themes were performed in dated Microsoft Word files. A member check was performed in which participants were mailed a summary of the findings and invited to respond anonymously to confirm whether interpretations were accurate. Those who responded agreed with the interpretations.

## Findings

Two major findings emerged from the data: (a) the experience for the nurses when patients chose to discontinue IV chemotherapy treatment and (b) the nurses' understanding of patients' rationale for discontinuing chemotherapy treatment. Essential themes that emerged relating to nurses' experiences when patients chose to stop chemotherapy included (a) "it just affects ya" and (b) "tug of war." Essential themes that were discovered regarding nurses' understanding of patients' rationale included (a) "life, interrupted," (b) "I've lived a good life," and (c) the "Eeyore effect." These themes were illustrated with participants' statements, and, for the sake of readability, repetitive figures of speech have been omitted (e.g., "you know"). Because patients were not direct participants, patient demographics were not always available but were included if described by the nurses.

### Finding 1: Nurses' Experiences When Patients Chose to Stop Chemotherapy

**Theme 1.1:** The theme of "it just affects ya" referred to the strong emotions that nurses experienced when patients chose to prematurely discontinue chemotherapy. "It's very frustrating" was a common sentiment. As described by one participant,

You see people that you love, and you just want to shake 'em. It's just like your family members . . . making bad choices; it hurts because you care about 'em, but ultimately sometimes there's just nothing you can do about it.

Many participants expressed sadness over a patient's "disheartening" decision to stop therapy. For example, "I cried with [the 42-year-old patient]. . . . I tried very hard to talk her out of her decision." The nurses developed attachments to the patients and wanted the best outcomes for them, which they believed would be achieved by completing chemotherapy treatment. One nurse stated, "It breaks my heart when people have curable diseases that choose to stop [treatment]." In describing an older adult patient with prostate cancer, another nurse recalled, "It was horrible because I knew that we could . . . keep his symptoms controlled, and he would have been fine. But he did not want [to continue treatment]."

In extreme cases, participants' feelings verged on anger or resentment. As described by one nurse, "Your initial feeling is some anger and some frustration. . . . [Then you think,] 'You don't care about yourself, then why should we?'" Regarding a patient who stopped treatment because of marital problems, one participant stated, "I was so angry. I could understand her point. . . . But I was very angry."

Disbelief was another feeling nurses experienced when patients chose to stop treatment. Watching patients make what nurses thought were bad choices and knowing they couldn't do anything about it was difficult. For example, "That's really hard to understand when you have somebody that has a disease that can be cured and they choose not to do that." Another participant said, "I can't believe [the young patient with breast cancer] would risk her life because she didn't wanna lose her hair."

**Theme 1.2:** The theme of "tug of war" pertained to the nurses' struggles with balancing the responsibility they felt for their patients' care with the respect they had for patients' individual decisions. This back-and-forth tension of an ideal (nurses' beliefs and values) versus the real (patients' rights to decision making) reminded the authors of Paul McCartney's song "Tug of War," hence the use of the song's title as the theme name.

Nurses agonized over "patients making decisions that really aren't as sound as they should be but knowing that a patient has the right to choose." The participants had to accept that, "You can prepare and equip them, but you're not responsible for the results." One nurse described how this acceptance had to be learned with experience: "When I was a new

nurse in oncology, I'd go home and cry, and I'd be so upset and worry to death on these patients. . . . So I had to learn that healthy boundary for myself."

Although the balancing act was often distressing, in some instances, nurses were also able to identify positive emotions during those experiences. For example,

[When a long-term patient discontinues treatment, it's] bittersweet because you get very attached to the patients. . . . We're glad that they're getting a chance to enjoy life . . . [but] we know that the chemotherapy is their chance at extending their life. . . . So I have mixed emotions on it.

The theme of tug of war was divided into two subthemes: (a) "all you can do is equip them" and (b) "I have to respect that."

**Subtheme 1.2.1:** The subtheme of "all you can do is equip them" referred to the responsibility nurses felt to fully educate patients on their treatment options and the likely outcomes if they chose to discontinue chemotherapy. One participant noted, "You have to educate 'em and give them the information they [need] to make the decisions but realize that, ultimately, it's up to them." Participants also felt a responsibility to remove all barriers to completing therapy by helping to control treatment side effects, exploring financial options, and offering counseling. For example, "I wanted to make sure she wasn't stopping for the [wrong] reasons. . . . We want to [understand] . . . why they're stopping because a lot of times the reasons they want to stop are things that we can help."

When patients did choose to stop chemotherapy, some nurses felt personal responsibility for the decision. It resulted in soul searching to determine where they went wrong and how they could improve in future situations. One nurse stated, "You feel like you may have failed them. . . . So you look into yourself to see what you may have done . . . to cause the patient to discontinue IV chemo treatment."

**Subtheme 1.2.2:** The subtheme of "I have to respect that" described the regard for patient autonomy that was evident among the nurses. Even when nurses were frustrated with patients' decisions to discontinue chemotherapy, they respected their rights to make their own healthcare decisions. One participant noted, "I wouldn't want [someone to] come in, taking full control over me, and telling me that, 'Hey, you have got to do this, you have no choice.'" Nurses recognized that other circumstances besides the disease factored into the decision-making process and that patients' priorities may not always align with providers' priorities. For example, "We need to really be open-minded . . . and talk to our patients. . . . We may have no idea what's going on personally, financially."

## Finding 2: Nurses' Understanding of Patients' Rationale

**Theme 2.1:** The theme of "life, interrupted" referred to the profound effect that undergoing cancer treatment had on a patient's life, as if normal life were put on hold while his or her entire being was consumed with receiving treatments and fighting the disease. One nurse described a middle-aged Caucasian patient who was "sick and tired of being sick and tired . . . not feeling like she could be part of family outings and stuff." Participants perceived that dealing with the grueling chemotherapy side effects, the inconvenience of coming to the clinic for weekly treatments, and the resulting diminished quality of life were important factors in patients' decisions to discontinue chemotherapy. They described patients who came to the clinic almost weekly, only had "one or two days of finally feeling somewhat human, and then they'd just come back in to get knocked down again with the next treatment."

The most common side effect believed to be associated with stopping treatment was debilitating fatigue that prevented patients from participating in and enjoying their normal lives. Patients who were undergoing long-term chemotherapy treatment were considered particularly susceptible to requiring a break from the constant fatigue. One nurse related, "[Patients] feel like, 'I'm just so beat up. I [can] hardly put one foot in front of the other, and I just can't enjoy life.'" Another participant stated, "[The fatigue is] all-consuming where a good night's sleep's not gonna help it, and they feel like they just can't go on."

In addition, nausea, neuropathy, and hair loss were thought to contribute to patients choosing to stop treatment. The nurses described some patients who felt that dying would be a preferable alternative to dealing with the side effects of chemotherapy. One participant reported, "[Patients have said], 'I'd rather die than take this stuff.' So they stopped treatment." Nurses also recognized that most patients felt better prior to receiving chemotherapy and that some patients felt "like symptoms are outweighing the benefit." One nurse stated,

[Patients] go through a cycle or two of treatment where [chemotherapy] doesn't make them feel well, and their feeling was, "I really wasn't that sick to start with," and so they rationalize, "I've had surgery; they took the cancer out."

The inconvenience of attending weekly treatments was considered to be another factor in some patients' decisions to stop treatment, particularly among patients who were on long-term chemotherapy. As one nurse noted, "The chemo treatments just consume

everything; they're not really living, they're just coming for treatments."

**Theme 2.2:** The theme of "I've lived a good life" described the acceptance of the end of life that older adult patients tended to exhibit. Nurses perceived that, among older adult patients, the small amount of added lifespan potentially gained through chemotherapy was often outweighed by the overwhelming side effects. Participants identified differing priorities between older and younger patients. Older adult patients were thought to place a higher priority on quality of life, and younger patients focused more on quantity of life. Participants noted that older adult patients often felt that "continuing onto treatment is not gonna prolong their life . . . a noticeable amount of time, but if they did stop the treatment, they would possibly have some good days before they moved on." One participant recalled, "[The 82-year-old patient with prostate cancer] told us straight out that he had lived his life, and this is not the way he wanted to do this."

Some participants perceived older adults to be weaker prior to treatment and less able to tolerate the side effects of chemotherapy. For example, one nurse noted, "[Chemotherapy is] just more overwhelming to them than the younger population. [They] just don't have the stamina to start with." Older adults were also considered to have more obstacles to completing treatment. As described by one participant, "[The older patients] can't figure out transportation, everything else, and they think it's just gonna put a burden on their family."

**Theme 2.3:** The theme of "the Eeyore effect" referred to the pessimistic attitudes or lack of support described by some of the participants that reminded the researcher of the gloomy donkey in the Winnie the Pooh children's stories. Nurses expressed that attitude was very important in the treatment process and that "over and over again, you'll see that so much of . . . the process is mental."

The participants felt that some patients who discontinued treatment had a difficult time accepting their diagnoses and were angry or anxious about going through treatment and searching for reasons to avoid the experience. As reported by one nurse,

[The patient] had a lot of issues . . . and was angry that she was having to go through chemo. . . . [Such patients have] difficulty accepting their diagnosis. . . . They just don't really want to be going through this treatment, and so they look for any way they can to get out of it.

Family problems and lack of support also were perceived to be important factors in treatment discontinuation. One participant noted, "If you have

somebody who's alone . . . and there's nobody there cheering 'em on . . . they're gonna give up easier." Some participants identified patients who discontinued chemotherapy out of fear of their families learning they had cancer. One nurse recalled, "[An African American patient] hadn't told her family she had cancer. . . . She was afraid that the side effects would . . . lead to her being asked more questions as to what was going on." Another nurse noted, "[A 20-something patient with lymphoma] never told anybody in his family that he was going through treatment. . . . [He said], 'I don't want my kids to be devastated.'"

Some nurses relayed stories in which the process of dealing with a cancer diagnosis put a strain on patients' marriage, and patients chose to discontinue treatment to concentrate on repairing the relationship or to deal with a divorce. For instance, "[The patient's] husband left her while she was in the hospital. She quit therapy because she was more interested in her marriage." In addition, patients were identified who chose to discontinue chemotherapy to prioritize other family members over their own health. For example, "[The] husband [of a patient with long-term gynecologic cancer] was ill, too, so she stopped treatment to take care of him and put herself on the back burner."

## Discussion

Among this sample of oncology nurses, the phenomenon of patients prematurely discontinuing IV chemotherapy treatment against the advice of their oncologists was an event that remained a prominent memory and evoked great emotions. Nurses were able to recall specific occurrences with detail—even those that happened more than a decade ago—because those cases stood out in their minds. The nurses came from a variety of oncology specialties, and the patients they referred to did not appear to overlap. Generally, participants could recall only one or two specific patients who chose to discontinue chemotherapy, even when multiple prompts were used, and this sometimes resulted in short interviews. Although the sample size was small, data saturation was believed to be reached, which is the goal in phenomenology (Munhall, 1994).

Nurses experienced complicated emotions when confronted with patients who chose to prematurely discontinue chemotherapy, and these findings underscore the need for counseling and other resources to help nurses cope with job-related stress (Boyle, 2015). Nurses cared for and were invested in their patients and desired to help them achieve the best outcomes. Feelings varied with each situation and often resulted in an internal struggle for the participants as

they balanced their emotions with the respect they had for patient autonomy. They also grappled with feelings of frustration, responsibility, and helplessness. The nurses often acknowledged that a myriad of factors influenced patients' treatment-related decisions and that other considerations beyond a cure or prolongation of life may have been a patient's priority. In some instances, the participants understood the reasoning behind the patient's decision to stop treatment, but, in others, they could not understand why the patient made the decision. However, they accepted that the patients had the right to choose and still supported them in their journey.

A comparison between the current findings and those from a similar study among oncologists is enlightening (Madjar et al., 2007). Although participants in both studies felt helpless when patients chose to act against medical advice, contrary to the current study, the oncologists in the Madjar et al. (2007) study wished to feel in charge and appreciated as oncology experts. Therefore, a rejection of recommended treatment was considered a challenge to their authority and a blemish to their reputations. The oncologists appeared to be more focused on treatment goals and failed to acknowledge that patients may have differing priorities that affect their treatment decisions, and the participants in the current study were empathetic and displayed some understanding about the choices patients made.

The nurses described patients whose lives had to be put on hold while undergoing treatments. They thought overwhelming fatigue, other side effects, and regular treatment appointments prevented patients from participating in their normal activities and that, sometimes, stopping treatment was the only way for patients to get relief and participate in the lives they wanted to live.

Older adult patients were thought to prioritize quality of life by discontinuing treatment to avoid the side effects. Some quantitative studies have also shown that older age is associated with chemotherapy discontinuation (Hu et al., 2011; Kubicek et al., 2011). Other factors that were believed to influence discontinuation included having a pessimistic attitude and lacking family support. These findings are in line with other studies that have found that depression and social support are related to nonadherence to chemotherapy (Irwin, 2013; Kissane, 2009; Navari et al., 2008).

## Limitations

Because of the small sample size and nature of the current study, the authors were unable to fully explore the reasons behind premature treatment discontinuation and its effect on nurses. The themes

## Knowledge Translation

- Honoring patients' decisions about treatment discontinuation while continuing to care for other patients may be emotionally taxing for nurses.
- Proactive identification of symptoms and solutions may be an important strategy to assist patients in continuing treatment.
- Patients may need help connecting with support systems and should be encouraged to talk to their families about their experiences if they are contemplating treatment discontinuation.

presented in this article arose from interviews with seven nurses from a single oncology practice. The inclusion of additional nurses or those from another practice may have uncovered different themes.

## Implications for Nursing

The nurses in the current study became emotionally involved with their patients and struggled to balance their own desires with the patients' wishes, which resulted in emotional turmoil. Nurses should recognize that patients' decisions to discontinue treatment can be distressing. Providing access to counseling and other support in the workplace could help nurses manage this distress.

Because side effects were thought to strongly influence patients' decisions to discontinue chemotherapy, oncology professionals should be proactive in providing symptom management. Because lack of social support was considered a contributing factor, nurses should strive to connect patients with support systems and help them talk to their families about their experiences to provide patients with more support for completing treatment.

## Conclusion

Nurses working with patients with cancer who chose to discontinue chemotherapy experienced a wide variety of emotions, including frustration, sadness, anger, and disbelief. They struggled to balance their feelings with their respect for patients' decisions. Side effects, inconvenience, older age, pessimism, and lack of support were believed to influence patients' decisions about discontinuing chemotherapy. The identification of these factors presents opportunities for additional research to understand why patients discontinue treatment and to guide interventions designed to encourage completion of chemotherapy.

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## Question Guide for a Journal Club

Journal clubs can help to increase your ability to evaluate literature and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. What coping mechanisms did these nurses use to deal with the emotions they experienced when patients stopped treatment?
2. These nurses did not talk about eliciting help from other colleagues to help deal with their distress. Who could be helpful in these instances, and how could they help?
3. What would you do in a similar situation?
4. The distress that these nurses experienced could be considered a form of moral distress. Of what other kinds of moral distress are you aware, and how are they similar or different?

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