

The Impact of Interlink Community Cancer Nurses on the Experience of Living With Cancer

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Purpose/Objectives: To describe the impact of expert oncology nursing support provided by an independent nursing service, Interlink Community Cancer Nurses, on patients' experience of living with cancer.

Design: Qualitative research design guided by hermeneutic phenomenology using a broad data-generating statement.

Setting: Homes of participants in a metropolitan city.

Sample: Purposive sampling was used to select participants for the study. Eighteen women and two men with a variety of cancer diagnoses and living circumstances participated in the study. Accrual was stopped when data saturation occurred.

Main Research Variables: Patients' perceptions of the experience of receiving care in the home setting from expert oncology nurses.

Findings: Seven core themes described the participants' perceptions of and the impact of expert oncology nursing care on their experience of living with cancer.

Conclusions: Expert oncology nursing support in the community is perceived by people living with cancer as having a significant impact on their experience and influencing their well-being and survival. The knowledge and experience of oncology nurses and the way in which care is delivered are critical elements. Further research should continue to explore the relationship between expert community oncology nursing support and healthcare outcomes for people with cancer.

Implications for Nursing: Community nursing agencies need to examine their ability to ensure access to knowledgeable and experienced oncology nurses who can support and address the needs of people with cancer across the cancer trajectory.

“Cancer changes everything” is a statement frequently used by people diagnosed with cancer to describe the profound impact that cancer has on their lives (Eick-Swigart, 1995). The cancer experience creates a sense of uncertainty, apprehension, fear, and anxiety and can disrupt every aspect of life for patients and their families, challenging their psychological, social, spiritual, and financial resources (Fitch, 1996). Individuals try to make sense of what is happening to them and struggle to integrate the demands of cancer treatment, making small and massive adjustments to their everyday lives in the face of the disruption the disease brings (Corner, 1997). These adjustments may include changing the way they view themselves, their lives, and their relationships; reexamining values; and addressing fears and concerns.

Key Points . . .

- A diagnosis of cancer is a life-changing experience, and patients need support in making the day-to-day adjustments necessary in living with cancer.
- The knowledge and experience of expert oncology nurses provide patients with a sense of security and stability in dealing with cancer.
- The way that nurses deliver oncology nursing support may make patients with cancer feel that their nurses are more a part of their cancer experience.
- Access to oncology nurses is an important element in supportive care and the quality of care of patients with cancer and their families.

Nurses play a significant role in facilitating patients' ability to make the adjustments required to meet the challenges of cancer and its treatment. The nature of the interaction between nurses and their patients may have a profound influence on shaping the cancer experience. The therapeutic nature of nursing, in which nurses are able to acknowledge patients' distress, accept it, and make it more tolerable, may have a significant impact on patients' cancer experience (Corner, 1997).

The structure and delivery of community nursing services emphasize the technologic, instrumental aspects of nursing care with eligibility for access to care and payment based on medical care needs. Therapeutic elements of nursing care, which support patients in making the necessary adjustments to a diagnosis of cancer and facilitate recovery and adaptation, may receive less emphasis in the allocation of community nursing support. Community nurses are expected to provide care to patients with many differing diagnoses and may have varying levels of expertise in the care of patients with cancer. In many provinces throughout Canada, nursing care services are brokered through a government-funded homecare program with strict eligibility

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criteria based particularly on physical care requirements. Patients early in the diagnostic and treatment period, when supportive care needs for information, education, coaching, and counseling support are greatest, seldom are eligible for homecare services.

Interlink Community Cancer Nurses (ICCN), a nonprofit, community-based oncology nursing program, was founded in 1988 to provide patients with cancer and their families access to oncology nurse expertise and information, education, and psychosocial support in meeting the challenges of cancer and its treatment as early as possible in the cancer continuum. Interlink caregivers are expert oncology nurses who focus their attention on assisting patients and their families in dealing with the physical effects of the disease and its treatment as well as its social, psychological, and emotional impact along the cancer trajectory (Howell & Jackson, 1998).

The ICCN program was modeled after the Macmillan Nurse Program in the United Kingdom (Webber, 1994). Macmillan nurses act as clinical nurse specialists, providing advice and support to other healthcare professionals caring for patients with cancer in the community. ICCN is funded partially through the provincial cancer organization but functions independently of the government-funded homecare program. Interlink nurses work collaboratively and in partnership with community services and the government-funded homecare program in the provision of services and work complementary to primary care and peer support services available to patients with cancer. Interlink nurses provide service to adult patients and families in a large metropolitan city, whereas pediatric Interlink nurses provide service to children and their families on a province-wide basis. A defining characteristic of the program is the specialized oncology nurses who draw upon a great deal of expertise in a defined area of practice. Referrals to ICCN come from a number of sources, such as social workers and nurses in ambulatory cancer treatment centers, oncologists, and case managers in the government-funded homecare program. About 25% of the patients are self-referred. About one-third of patients are newly diagnosed and in the treatment phase of illness; other patients are referred at the time of recurrence or during the palliative phase of illness. ICCN nurses see patients as soon after diagnosis as possible to provide information and education and facilitate the patient/family adjustment and adaptation to cancer and its treatment. Patients and families usually are not eligible for government-funded home care at this stage of the cancer continuum. About 60% of the operating dollars for ICCN are raised through private donations. Patients are not charged for the service.

Interlink nurses offer consultative expertise to healthcare professionals in the community and provide direct supportive care to patients with cancer. They are experienced oncology nurses who provide supportive care to patients and their families from early diagnosis through cure or through palliation through a home visiting program. These nurses do not provide traditional "hands-on" care but bring in-depth expertise in oncology nursing to bear on the practical and human needs of people experiencing cancer. Their use of time in patient care is influenced by the needs of patients and not through government regulation. In contrast, primary care nurses who provide technical care, such as IV infusion, treatment administration in the home, and pain and

symptom regulation as part of their overall nursing role, are contracted through the government-funded homecare program. A case manager coordinates the care, brokers the services, and determines the hours of service to be provided according to guidelines developed by the government. The Interlink nurses' ability to respond to individuals' personal experience with cancer may be particularly effective in helping them to meet the demands of cancer treatment and address the challenges that cancer brings to their lives.

A need to understand the individual's experience of receiving expert oncology nursing support in the community exists, as does a need for nurses' understanding of the experience of receiving oncology nursing support. These needs only can be met through methods that seek to uncover the perceptions of individual patients. The impact of individualized oncology nursing support in the home from the patients' point of view has not been examined.

This study is part of a larger phenomenological study that explored the individuals' experience of living with cancer and their perceptions of the impact of oncology nursing care on that experience. The purpose of this article is to describe patients' experience of oncology nursing support provided by ICCN and its impact on patients' experience of living with cancer.

Methods

This study was guided by hermeneutic phenomenology to gain understanding and insight into the participants' perceptions of their experience of receiving in-home oncology nursing support provided by ICCN. The goal of phenomenology is to describe lived experience by capturing the richest and fullest descriptions of the phenomenon (Streubert & Carpenter, 1995). The goal of the interviews was to obtain the most detailed description possible of the experience and to ensure that participants, not the interviewer, determined the content discussed. A broad, data-generating statement was posed: "I am interested in your experiences of receiving care from ICCN. In particular, I want you to describe how you believe the nursing you receive affects you. Please tell me what your experience of living with cancer has been like since the Interlink nurse came to see you here in your home. Tell me everything that you remember happening and everything that you thought and felt about it." Additional probes were used during the interview, such as "Please tell me more about that," "What did that mean to you," and verbal reflections of the informants' statements to encourage clarification and more in-depth descriptions.

Sample

Purposive sampling was used to select participants for the study. Because phenomenology seeks to identify the commonalities of experience, even in light of diverse sample characteristics, no effort was made to control for the participants' illness or demographic variables. Eighteen women and two men participated in interviews conducted over a nine-month period. Participants ranged in age from 28–78 years and were from a variety of professions, socioeconomic situations, and lifestyles. Cancer diagnoses included lymphoma (3), prostate cancer (1), breast cancer (8), cervical cancer (1), ovarian cancer (3), astrocytoma (1), pancreatic cancer (1), and sarcoma (2). Six of the participants were in the terminal

stage of illness, whereas others had experienced recurrent episodes of cancer and cancer treatment. Participants had been dealing with cancer for a time ranging from eight months to four years. Participant accrual was stopped when data saturation occurred (i.e., no new themes emerged).

Procedure

After ethical review approval, an Interlink nurse gave potential participants a letter describing the study and the researcher obtained permission to contact subjects by phone to explain the study and determine their willingness to participate. Prior to participating in the interview, participants received further explanation of the study in their homes and signed a consent to participate. Participants were informed as part of the consent process that their responses would not be shared with their Interlink nurses or any other member of the Interlink team.

Participants also were advised that their care would not be affected now or in the future as a result of their participation in the study. The consent process assured participants that the interviews were not an evaluation of their Interlink nurses' performance. An experienced researcher conducted in-depth, audiotaped interviews lasting from 30–90 minutes in the participants' homes.

Data Analysis

The audio recordings of each interview were transcribed verbatim and verified for completeness and accuracy by comparing the text word-by-word with the audiotape. Each of the investigators read the transcripts to obtain a sense of the whole experience from the participants' viewpoint. To avoid bias, each researcher examined the total extent of the data, extracted significant statements from the transcripts, and linked these statements to each other to form separate themes that described the phenomena as a whole.

The primary investigator and one co-investigator analyzed the interview data using the constant comparative method described by Strauss and Corbin (1990). This form of analysis resulted in immersion in the data with repeated review of the transcripts. The investigators labeled, expanded, clarified, defined, and verified the emergent themes. Trustworthiness and credibility of the data were verified by having the two investigators independently analyze the findings and develop the theme categories. A third investigator, experienced in the use of phenomenology, validated the findings to ensure that the formulated meanings remained closely linked with the data.

Results

Qualitative analysis of the interview data revealed core themes that described the participants' perceptions of the experience of receiving care from Interlink nurses. These core themes were (a) sharing the journey, (b) unburdening, (c) taking time to address all needs, (d) understanding the illness, (e) providing a link to information and resources, (f) stabilizing, and (g) uncovering the strength to survive.

Sharing the Journey

From the moment Interlink nurses entered patients' homes, they became part of their cancer journey. This gave patients a feeling of "being held up" throughout the jour-

ney as they faced some of the most difficult aspects of living with cancer.

She's part of my cancer experience. I felt a great amount of support. . . . It was a fantasy of literally holding me up. Being able to face what I had to. I felt even that, you know, if the doctor had said, "Well, this isn't working. You're gonna die," that I could somehow find her. And she'd hold my hand and I'd be crying and somehow she would have the words to cover that situation.

The sustained presence of Interlink nurses, as participants faced treatment side effects, recurrence, and, in some situations, terminal illness, fostered the development of a strong relationship. Participants described feeling that their Interlink nurses always would be there for them throughout their cancer journey.

There is a very strong relationship between her and I. I think the connection started when she came in, introduced herself, sat down, and just listened. And then afterwards, whatever I needed, whether it be information or help getting through a feeling or an emotion, she was always there. She never denied me . . . she never ignored my calls . . . she was just always there. I would leave a message and she would just, you know, she'd get right back to me.

The relationship between Interlink nurses and participants became even more important as relationships with friends changed and, particularly, when illness progressed.

People don't come and see you anymore. And you know that this person will. And that's a very important factor in the life of somebody whose, you know, friends sort of fall away because you always seem to be dying and getting better and dying and getting better and dying. . . . People become, I think . . . afraid that maybe you really are [dying] this time. And throughout all that . . . Interlink has been there for me without fail, every two weeks.

Participants described Interlink nurses as their primary source of support and, in some situations, their only source of support in dealing with the realities of living with cancer.

You know, we need all the support. We need all the help. We have nobody here. Just a couple of friends. We need someone to help us, you know . . . and that's how we called Interlink. There's nobody you can turn to. It's the most devastating feeling when you're in that kind of situation. . . . At least this way there's this someone you can turn to . . . especially in a case like this. We have no family. Nobody.

Participants felt cared for and protected by their Interlink nurses. This support was important to them in coping with the cancer experience.

The Interlink nurse, she seemed to be right in there with me. Feeling everything, and she was very nice, helpful, pleasant, and she made me feel like I was taken care of. You know . . . like she was taking me under her wing.

Unburdening

Participants anticipated the Interlink nurses' home visits for the opportunity to unburden themselves of their thoughts,

feelings, and fears and to gain their insight about how to handle these challenges of illness.

Nothing went right for me. Thank God for Interlink. You know, she would come and we would sit and then we'd talk and get things off my chest. There were things I couldn't say to my husband and my kids. . . . They are going through this with me. They're just as scared as me. . . . How are we gonna get through this? Aren't we? Am I gonna be one of the statistics or am I gonna be one of the ones that die or whatever. I could say anything to her and tell her how I felt, and even if it was my darkest thoughts, you know, and how scared I was feeling, or if I just broke down and cried.

I started to feel unwell throughout my body. Throughout all this, Interlink had been coming every two weeks, and I tell you, I think I, I wept on her shoulder quite a few times about this.

The Interlink nurses' ability to listen compassionately to participants' perceptions of living with cancer and the disruptions it brought to their lives was important to the participants in sharing their emotions.

The Interlink nurse will come once a week and we could discuss in detail my fears, the past with my husband. And I just could not wait from one week to the next 'til she came because she was like something to hang on to. She understood everything I was saying. She didn't think I was crazy, which other doctors probably thought I was. And not only did she have the knowledge, she had the understanding and the compassion to go with everything. And I think that is just so important . . . to have somebody come under those circumstances that can still be compassionate.

Interlink nurses' ability to provide support in the participants' own homes provided a sense of intimacy and privacy that facilitated the open sharing of emotions.

The care is much more personal and specific to my situation. . . . And also it's in my house . . . it's also so intimate and private, and I think it's just an easier way to cope with what's happening. . . . My first meeting with her was two hours. I know, I know without a doubt that because I was not in a hospital setting I got so much more out of the visit.

Interlink nurses' ability to assess the needs of patients in the context of their living circumstances was seen as positive.

The visit at home made you feel comfortable speaking to you about anything. You didn't feel rushed. She just sort of saw the circumstances in your home. Was able to piece things together as to how things were going or how they weren't going.

Being able to unburden themselves of their emotions and gain the Interlink nurses' assistance in coping with these emotions gave participants a feeling of calmness and peace.

I think that in any of my situations, the nursing has provided me with a little bit of peace in my heart, you know. The Interlink person will come in. I will discuss

what's happened to me in the recent bits. I will sit and discuss that, and it sort of gives me a feeling of calm as we discuss the various points of how I'm going to cope with that. And I get tremendous advice, and that helps me to deal with it.

Taking Time to Address All Needs

The participants valued the Interlink nurses' ability to take the time necessary during the home visits to address all of their needs.

The nurse came here and she looked after all my needs. All the aspects of my needs. I could talk to her about everything. From constipation to not sleeping well to, you know, she was there for me. And I needed that. And obviously the Interlink nurse has long experience in this business and so she is able to make suggestions of either they are not aware of at the cancer hospital or they don't come up because of the brevity of the contacts I have there. So it's, it's very pleasant to have somebody here who is willing to take the time to look into all aspects of the situation.

Participants spoke of the Interlink nurses as having an overview of all of their needs and said the nurses were helpful in addressing both their physical and decision-making needs.

This is where the difference is, I think, for the Interlink nurse. They have an overview, I think. They could identify if my pulse was racing in some way or, you know, if I was flushed or something physically going on, but they also can back right up and address, should I sell my house? It just didn't seem to matter what you ask, they'll deal with it. Whereas the [homecare nurses] are in and out and much more specific.

The time the Interlink nurses were able to spend gave participants a feeling that they wanted to be there and had the time to address the patients' needs.

The homecare nurse is good, but she can't give you that feeling, you know, that she'll look after you. Because she has to move on to the next patient, next patient, next patient. Where with Interlink, you didn't ever feel that it's somebody waiting for them, you know what I mean. She has time for you. And she wants to come.

One participant poignantly captured the importance of the time provided by the Interlink nurse when coping with cancer became very difficult. The feeling that the Interlink nurse would remain present no matter how much time it took and how this made participants feel special was captured in the following statement.

Yes. I'll need somebody then to not only walk in and walk right out because when you're alone there come more kinds of thoughts in your mind and you have to talk it over a bit some time. Sometimes the visits have been extended because times have been very difficult for me. And there's been no looking at the watch or rushing around or anything like that. It's just, I feel that I'm special. I think that's how they make you feel, that you're special although there's lots more out there. Today is your day, and that makes you feel very special about yourself.

Understanding the Illness

Participants spoke about the importance of the Interlink nurses' knowledge of cancer and their experience in caring for other patients with cancer. This combination gave participants a feeling that the Interlink nurses understood their illness experience.

It wasn't until Interlink started coming to see me and that had quite an impact in my life. . . . She was like a Godsend to me, when she came in and talked to me it was like she went through the cancer experience herself. Like she seemed to know all the side effects of the chemotherapy . . . she was telling me what to expect from it and whatever. Everything that she told me I was feeling.

The Interlink nurses' expertise and knowledge of cancer helped participants understand the effects of the disease and its treatment and helped them to prepare for what might occur.

I just need to know how to be with this. . . . Once I got the information, I was fine. And I think that notion of being alone is another part of it. You just have to figure everything out yourself. So, to have folks around who are so knowledgeable and available is really helpful . . . without the knowledge or somebody to talk to it's hard to be the patient and the caregiver at the same time. But once the services started, they could tell me. I guess the knowledge helps me know if it's sort of an ordinary thing or if it's an emergency or if it's just something we'll watch. I don't have to guess.

Interlink nurses taught participants about their cancer and interpreted information in a way that promoted understanding of the changes in their bodies. This understanding, in turn, helped patients to deal with bodily changes from cancer or treatment.

It's marvelous because if I didn't have her my poor doctor would be hearing from me a lot more often. 'Cause I want to know these things and she's just very good about helping me to understand what's happening to my body. And that's important to me because it helps me deal with it.

She educated me on all about the cancer and the illness. What was it about . . . because I didn't understand it. I mean, you know, for a person that's never been sick and they get cancer like that and you're so devastated and you don't know what's happening to you.

The Interlink nurses' knowledge of cancer meant that they were able to interpret the medical language and put it into words that participants understood and could address all of the participants' questions, frequently anticipating them before they were asked.

I think it helps me myself, personally. I'm one of the people who like to know. And the thing is, I can't understand it all. Where the Interlink nurse could put it into words where I could understand it.

What's happened to me? Who, who do I turn to? Who do I talk to? . . . So many questions came to mind. And I was satisfied with all these questions through the Interlink nurse. I knew that she understood. . . . She was so knowledgeable 'cause I didn't even have to ask ques-

tions. She was already giving me the answers before you can ask them.

The Interlink nurses also were skilled in identifying the informational needs of participants and recognizing what information they could handle.

She was very supportive. Always lots of information. Only for information that I asked. Not a lot of extra stuff that I couldn't handle. 'Cause I'm one of those people that the least I know about things the better off I am. And she realized and picked up on that immediately. So I wasn't bombarded with anything. She was good. She was excellent.

Interlink nurses were perceived as being very skilled in their provision of care because they were knowledgeable and able to guide participants through the experience of living with cancer. The interpretation of knowledge was coupled with a supportive relationship and, in turn, contributed to the participants' feeling or sense of being in control and regaining power.

They have the competence to know how to support someone in my situation. I mean, they're so skilled at what they're doing. I've never seen it in another person.

She has the skill to help me focus when I feel like I'm going adrift. You know, it's emotional. It's psychological. It's physical. It's like you're drifting and you're sinking and that's how she has helped me to focus. She has a way, a very gentle, compassionate way helping me to see what my priorities are.

It was really important to me. . . . It was like talking to a friend but a knowledgeable friend. So when I must've asked maybe the same questions five different ways . . . I felt I wasn't talking in the wind. Was always a solid response. I felt was an honest response. So I had a little bit of an idea of what was gonna happen, which was important to me 'cause all my control was gone. I mean, I had no control in life anymore. I really looked forward to seeing her all the time. I really did. It was just, it was so important to me on many levels because she was knowledgeable and I wasn't.

Participants described the Interlink nurses' knowledge as comforting, which set their minds at ease.

She knows all the medication. What strength of medication and everything. Because they study about cancer. They study only about cancer. They know everything what's going on with cancer. They know all the pain, all the illness, they know everything. It helps me. It gives me comfort. It gives me support. It gives me strength to go ahead and to try a better way to take the medication.

Whereas the Interlink nurse, she has that specialty in that oncology field, which set my mind at ease. When she was telling me what to expect, I thought I was gonna die. Everything was going through me. Like I was, I was so bad. I never felt that bad in my life.

Providing a Link to Information and Resources

Interlink nurses' knowledge of cancer meant that they could provide participants with information about cancer

and resources to assist them in getting through the cancer and treatment. Of particular importance to participants was the link to information they had through the Interlink nurses. Even if the nurses did not have an answer, they still could be counted on to get one quickly.

And so all throughout this if I had a question, you know, about what was gonna happen, I could just call the Interlink nurse. Didn't matter if it was important or significant or a detail or even the wrong words, it was just addressed. And it really helped me.

She is just a miracle worker. . . . If she doesn't have the answer, she finds that answer for me. And she phones me right back and she tells me. She doesn't leave it to linger . . . she gets right back to you.

Participants also perceived the nurses' ability to provide practical information to manage a situation as being very helpful.

Interlink nurse gave just little hints. Different little things that you can do, I could do, or try, to make myself more comfortable . . . she'd have some suggestions. Things that probably nobody else could even think of.

The knowledge and experience of the Interlink nurses differentiated them from the community nurses. Participants perceived that the community nurses had specific tasks to perform, did not have in-depth knowledge of cancer, and had little time to address their informational needs in depth.

This time I had support from Interlink nurse. And that was one thing that I was really grateful for because the nurse that came from home care, she knew quite a bit about cancer. But she did not know the fine details like the Interlink nurse knows and she could not spend the time with me. Like, the Interlink nurse would come for an hour, hour and a half. And she could answer my calls . . . and she has a very extensive knowledge of cancer and she can explain it very well. She is very practical and that's what I really appreciate.

Participants described not knowing what resources were available to them and the difficulty of searching for resources when they were fatigued and unwell. Subsequently, Interlink nurses led participants to cancer resources and, if necessary, mobilized the resources for patients.

I would go from one place to another 'til I felt I had enough. But being sick as well and having that much energy, it's really more difficult to do that. It's a real comfort to know that if I heard something or got information today I could check it out with the Interlink nurse.

She did link me up with different places, and I think I was even trying to find transportation for radiation, and she told me different places that I could phone. Which I didn't know. She told me about things that nobody told me about.

She's the person I link to the most. So if I branch anywhere I go through her first. She got me counseling for my son . . . she's just a miracle worker for me. She just pulled strings or whatever she can. . . . There was never a refusal. Never nothing in that sorta way. If I needed it . . . she just got it.

Stabilizing

Participants described feeling lost and spoke of the Interlink nurses as a stabilizing force in their experience with cancer. The connection with the Interlink nurses made them feel safe and secure even if they had to face impending death.

I thought, like I was in the, I was in the forest. I didn't know which way was what 'til the Interlink came into my life.

And she was coming to visit me once in a while when she could or just call me and we talked over the phone. Actually I can't imagine how difficult and how lost I would have been without her.

What the Interlink did for me was, you know, four years I had her, I guess it was security. I think you need that security that you're not gonna have to be floundering at the end. I felt that if something happened she would come through. Like in finding maybe palliative care or if suddenly the pain got worse or something that she would find the pain doctor that I wouldn't have to worry. And so she would come and I just knew that she was in control of things. That gives you such a peace of mind when you have cancer.

Participants used the metaphor of an anchor to describe the Interlink nurses' stabilizing force during their experience.

I guess one of the words I like to use is stabilizing. It just seems to tack things down or help to, OK, this is where we are at. And then if anything else happens, well, I'm prepared to deal with it. But, I guess, kind of like an anchor or stability, too, and somebody who knows.

When you have cancer, you're like a speck of dirt blowing in the wind. The Interlink nurse is your anchor. The experience with Interlink was enlightening; the isolation was the toughest. I could not have gotten through otherwise, because I was on the edge of the pit and she anchored me.

Participants relied and depended on the Interlink nurses throughout their experience with cancer. Their availability and quick responses to calls was important and helped participants feel that no matter what they might face in the journey with cancer, the Interlink nurses would be able to help.

But anytime that I needed her for anything, I would call her and she would be at the door. Yeah, it was very fantastic the way Interlink works.

I really appreciate the dependability. The reliability and the way the service is provided in a very strong manner. But it feels very secure, you know. That this is a highly professional person. I don't know anyone else who does it as comprehensively.

Participants described the importance of having someone to count on and described how much easier their situations were made by knowing that Interlink nurses would be coming and that they could depend on that to get through.

Like she would always call before she was coming so you weren't always anxious. Like sometimes when you're waiting you get a little anxious, you know. And she was pretty well always on time. You know what I mean.

But I feel that in all the visits there's never been one that's been missed that was arranged. Always on time. That's important to someone who is just housebound like I am. That's really important. You sort of wait by a window, you know, and I've never had a problem and there's always a little phone call just to see if I'm well enough. And I think that's a really good, a really good thing to do. . . . I really want Interlink to come.

Uncovering the Strength to Survive

Participants attributed their ability to get through the experience of living with cancer, their survival, and their well-being as direct results of receiving care from the Interlink nurses.

I do not believe I would have lived as long if I did not have Interlink. I would have run into the sea or something. My survival was dependent on her.

She has been a real person. She's been here once or twice a week. And without that I don't think I'd be sitting here today as well as I am. That's really the bottom line.

Participants believed that Interlink nurses uncovered their own strength to survive and nurtured their hope and courage. Participants described this as a spiritual connection with Interlink nurses that helped them through their journey with cancer.

I know, without any doubt whatsoever, that I would not be as well as I am. The Interlink nurse is my primary connection, link to my own strength. . . . I'm inspired by her. . . . She is a source to motivate me. You know, like I'm too weak. I feel tired and I haven't slept all night and it's kind of a spiritual link that I feel with her. You know, it's the flicker of hope when I feel hopeless about stuff. She has given me the sense of compassion, the understanding, the hope to see the strength in myself to go to the next step.

The Interlink nurse looked after me spiritually if you like. Kind of fed that. . . . And she was checking my mind by talking about it and so what she gave to me helped support me. And I just knew that she was supportive. She became really, really important. 'Cause I firmly believe that your mind and your spirit affect how you are physically.

Interlink nurses inspired participants' hope, courage, and belief that they could get through the experience of living with cancer.

And of course after I was diagnosed I called her and I said, "[Nurse], I think I might as well die now." I mean I, I really felt like I wanted to die. I didn't want to live. And she talked to me for an hour and a half. Gave me courage.

It gives me hope and courage and strengthens me even if I'm weak and vulnerable on that particular day. It gives me hope that no matter how difficult the journey gets you know from thinking Interlink was gonna be a backup . . . it's been my primary source of support. And, you know, I'm so grateful and I appreciate what it's done for me up to this point.

Participants described the Interlink nurses as enabling them to think positively, which they felt was an important element in their survival.

She would give me positive things to see and you believe her. Yeah, 'cause she gave me information . . . she said would give me hope. I think that's what really helped me get through it; because I was feeling very, very negative, once the Interlink nurse started coming around I seen myself change. And I started feeling more positive and everything and I think that's how I made it through the cancer, because the way I was going, I just let myself go.

I certainly feel much more positive now since I've had the Interlink nurse here. I think it would have been a much sadder story and much more worry for me if I did not have her. That's a fact. I do rely on her quite a bit and she's very good. It has certainly improved my outlook towards positive. And that makes a big difference in cancer survival as you know.

Discussion

The purpose of this qualitative study was to examine the impact of individualized oncology nursing support, as delivered by ICCN, on individuals' experience of living with cancer. A number of study limitations should be considered in interpreting the findings. Participants were from a particular oncology nursing program and may have represented those who felt positive about their experience with ICCN; subjects were interviewed at only one point in time during their illness trajectory; and, because of the vulnerability of their conditions, participants were unable to be contacted to validate the investigators' interpretation of their responses. The research interviews were conducted by a nurse who was a consultant to the ICCN program, which may have influenced the study findings. However, during the consent process, participants were informed that their comments would not be shared with their Interlink nurses or any member of the Interlink program and that their participation would not affect the care they received then or in the future. Despite these limitations, the findings of this study suggest that expert oncology nursing support provided in the home environment is perceived by people with cancer as having a significant impact on their experience of living with cancer. The knowledge and experience of Interlink nurses and the way in which the ICCN service is delivered surfaced as critical elements in the participants' perception of the support provided.

The knowledge and experience of Interlink nurses were recognized by participants as essential to their ability to make sense of what was happening to them and interpret and understand the illness experience. Interlink nurses brought compassion, skill, and knowledge to the encounter, transforming the participants' experience from one of feeling lost, fearful, and alone to an experience of feeling that their journey with cancer was shared and they were protected, which inspired their hope and courage. As Corner (1997) described it, a patient's relationship with a skilled nurse companion is like someone is "holding" the disease for a while and "holding" his or her distress. Interlink nurses became skilled friends, ensuring access to information and resources and promoting participants' confidence so that they could get through

even the most difficult aspects of living with cancer. Campbell (1984) described nursing as a skilled companionship where the relationship is for a fixed period of time and involves sharing a particular journey. The companions share all aspects of the journey, including the sights, sounds, and other experiences, as they travel together. Skilled nurse companions are there with patients during the journey and bring skills to the encounter that elevate companionship and make its goals therapeutic and healing.

The understanding and presence of a knowledgeable companion during the cancer experience may have had a therapeutic effect on participants, influencing their well-being and, ultimately, contributing to their sense of being able to survive. Increasing evidence exists that high-quality nursing is therapeutic and can be regarded as therapy in its own right (Corner, 1997; Evans & Griffiths, 1994; McMahon & Pearson, 1991; Pearson, Borbasi, & Walsh, 1997; Wright, 1994). Meutzel (1988) offered a description of therapeutic nursing as a companionable relationship that encompasses continuity, respect, and reciprocity and is supplemented by knowledge and skill.

The ICCN program's independent practice model allows Interlink nurses to structure care so that they are available and accessible to patients throughout the illness experience. Interlink nurses shared the illness journey and appeared to have a significant influence on shaping participants' experience with cancer. The sustained presence of Interlink nurses over time provided participants with a feeling that their illness journey was shared, they were not alone, they were safe, and they even could face death if they had to. Being present with the patients throughout their experience with cancer and its treatment allows nurses to develop deep and long-lasting relationships with their patients. Halldorsdottir and Hamrin (1996) described supporting a person with cancer as involving sensitive listening or providing sympathetic emotional attunement to the person on the often tumultuous journey through a cancer experience. Sharing the illness journey has been described as a therapeutic nursing act that is dependent upon the nurse-patient relationship and promotes understanding and healing (Benner, 1984). The therapeutic nature of nursing, as practiced by Interlink nurses, is a combination of skilled listening, coaching, guidance, compassion, and sensitivity to patients' experience balanced with knowledge, time, and the skill to address participants' needs as they surface. Euswas (1992) described the balance of knowledge, time, and the situated context of the environment as important elements in caring encounters between nurses and patients.

Participants perceived their relationships with Interlink nurses, coupled with what the nurses' knowledge and skill brought to bear on their experience with cancer, as contributing to their well-being and ability to survive. As Wallace and Appleton (1995) noted, patients describe nurse-client relationships as the link or lifeline to their potential well-being and believe that the nurses' presence helps them through periods of transition. Because of the extraordinary connection, patients feel hopeful about the future. Botoroff (1991) poignantly captured the value and importance of nurses in facing life-threatening illness. She stated

When a nurse is with us, in the sense of being present, we feel the security of her protective gaze, we feel valued as a person, the focus of her attention. We sense the nurse is

close enough to feel with us, sharing the loss that accompanies the disease we are experiencing in a sensitive, intimate way. She understands. When a nurse is truly present, seeing and feeling all these things, we sense a kind of hopefulness. For a moment we are not alone. (pp. 244–245)

Implications for Nursing Practice and Research

This study contributed to the researchers' understanding of the impact of specialized oncology nurses, particularly as delivered through the ICCN program, on the experience of living with cancer in the community. The study's findings have important implications for practice and research. The findings suggest that expert oncology nursing support may be an important factor in patients' adjustment to cancer and may have the potential to significantly affect their experience of living with cancer. Responding to the patients' needs and being available across the whole of the illness trajectory is the essence of ICCN service delivery. The delivery of care is prescribed by patients' unique experiences of living with cancer, and, in partnership with the patients, Interlink nurses respond to these unique needs. This service delivery model, combined with the Interlink nurses' extensive experience and knowledge of cancer, enables participants to meet the challenges of living with cancer and find the hope, courage, and strength to survive.

Unfortunately, the amount of time and the type of care delivered by community nurses are prescribed by the payor and may be restricted by payment systems that do not reimburse nurses for the therapeutic elements of nursing (Chalkey & Malcomson, 1999). Undoubtedly, this may have a significant impact on the healthcare outcomes of patients. Healthcare providers often assume that the care and support patients require to meet the demands of cancer are accessed easily within the community and are relevant to the comprehensive needs of people with cancer. Access to expert oncology nurses in the community may depend on the structure of homecare services whose mandate is to contract with generalist nurses. Eligibility criteria for supportive care through formalized homecare programs usually is restricted to patients with obvious physical care needs and impaired self-care abilities.

Healthcare systems that promote access to expert oncology nursing support for patients with cancer in the community must be created. The Oncology Nursing Society (1997) noted that the quality of care is directly related to access to oncology nurses. Agencies within the community should examine the way in which their services are delivered to ensure that the services are responsive to the needs of patients with cancer and are capable of providing the necessary oncology skill and expertise. A policy framework that supports access to specialized oncology nurses in the community and is part of a supportive care framework for patients with cancer is needed. Population-based planning that recognizes the needs of patients with cancer within the community is necessary, and the role for specialized oncology nursing expertise must be defined clearly. The ultimate purpose of ensuring access to specialist oncology nurses is to improve the quality of care experienced by patients and

their families. Skilled oncology nursing support must be recognized as part of the fabric of supportive care.

This study provides an initial understanding of the impact of expert oncology nursing support on the experience of patients with cancer living in the community. Further research should continue to explore the relationship between expert

oncology nursing support and health outcomes, such as well-being and survival.

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