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Nurses' Perspectives on the Personal and Professional Impact of Providing Nurse-Led Primary Palliative Care in Outpatient Oncology Settings

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Abstract

Background: Palliative care (PC) workforce shortages have led to a need for primary PC provided by non-specialists. The Care Management by Oncology Nurses (CONNECT) intervention provides infusion room oncology nurses with training and support to provide primary PC.

Aims: To describe nurses' perspectives on the personal and professional impact of training and provision of primary PC as part of CONNECT.

Methods: This qualitative study consisted of in-depth telephone interviews with 11 nurses at oncology practices in Pennsylvania. Data was analyzed using qualitative content analysis.

Findings: Nurses reported a sense of personal and professional fulfillment from providing primary PC, while noting the risk of increased emotional attachment to patients. Participation improved nursing communication skills. A supportive workplace helped to minimize stress related to incorporating primary PC into busy treatment schedules.

Conclusion: Providing primary PC challenges the task-oriented paradigm of nursing practice and will potentially alter the workload and schedule of infusion room nurses.

Keywords

oncology nursing; primary palliative care; outpatient setting

Conflict of interest: The authors have none to disclose.

Background:

National Comprehensive Cancer Network guidelines dictate that palliative care (PC) should be integrated across the trajectory of advanced cancer care (NCCN, 2016). Currently, there is a disconnect between the demand for PC services and the supply of PC clinicians. This has led to a focus on primary PC, defined as basic symptom management and communication skills delivered by clinicians who are not PC specialists (Quill and Abernathy, 2013). The majority of cancer care occurs in the ambulatory care setting, often in infusion centers where oncology registered nurses (RNs) administer cancer treatments. This is an ideal setting to implement primary PC; however, at present, oncology nurses spend very little time on any PC tasks (Davison et al., 2016; Mazanec and Prince-Paul, 2014).

Capitalizing on infusion room RNs' unique proximity to patients receiving treatment for advanced cancer, Schenker et al. (2015) developed a primary PC intervention led by oncology nurses. The Care Management by Oncology Nurses (CONNECT) intervention provides oncology nurses with specialty training and support to provide primary PC in the outpatient infusion room setting, using a structured, care management approach. Working collaboratively with oncologists, CONNECT nurses focus on four major PC domains: addressing symptom needs, engaging patients and caregivers in advance care planning, providing emotional support, and coordinating care. All CONNECT nurses attend a three-day training led by experienced PC providers, where they have an opportunity to practice primary PC communication skills with standardized patients (Robbins-Welty et al., 2018). Each nurse receives a copy of the intervention manual with resources for symptom management and communication tools. CONNECT nurses receive ongoing support and follow-up after the training from the CONNECT nurse coordinator, and their schedules are modified to allow for provision of primary PC to select patients with advanced cancer. A cluster randomized trial is underway to determine effects of the CONNECT intervention on patient and caregiver outcomes (Becker et al., 2017). The experience of oncology nurses providing primary PC has not been evaluated.

The purpose of this project is to understand the personal and professional impact of training and involvement in primary PC on oncology nurses. New behaviors and role changes that result from providing primary PC have the potential for both positive and negative impact. Understanding how providing primary PC at infusion centers affects nurses is critical to inform future efforts to integrate RN-provided primary PC in oncology.

Methods:

A qualitative, in-depth interview study was conducted with oncology nurses providing primary PC as part of the CONNECT intervention. Qualitative methods were chosen as ideally suited to understand complex social phenomena from the perspectives of diverse participants (Pope and Mays, 1995). This study was approved by the University of Pittsburgh Institutional Review Board.

Setting and Sample

This study took place at University of Pittsburgh Medical Center (UPMC) Hillman Cancer Centers, a network of approximately 30 academic and community oncology clinics in Western Pennsylvania. Nine of these practices were actively implementing nurse-led primary PC as part of the CONNECT intervention. Nurses at these sites who had completed CONNECT training at least one month earlier were invited to participate in an interview about their experiences.

Data Collection

A semi-structured, in-depth interview guide was developed with input from study investigators, informed by the literature on nurse-led PC interventions and role development for professional nurses (Montgomery et al., 2016; Pavlish and Ceronisky, 2009). The interview guide included open-ended questions focused on delivering primary PC as part of the CONNECT intervention and its impact on nurses, as well as a brief demographic survey. Prior to implementation, the interview guide was reviewed by nurses with experience in oncology and PC. All questions were pilot tested for clarity. The final interview guide is included as an appendix.

Nurses received an email invitation to participate from the first author (KF), a Doctor of Nursing Practice student not otherwise involved in the CONNECT study. Nurses were informed that their decision to participate would not affect their participation in the CONNECT trial or their employment at the cancer center. Nurses who responded to email invitations were contacted by KF with details about the study and provided verbal informed consent, which included assurance that their interview responses were anonymous. Interviews were conducted by KF with details about the study and provided verbal informed consent, which included that their interview responses were anonymous. Interviews were conducted by KF via telephone and audio-recorded. Stem questions were read to nurses, with follow-up probes used to explore key ideas. Participants received a \$25 gift card for their time.

Analysis

All interviews were transcribed verbatim and anonymized by KF. Anonymous interview transcripts were analyzed using qualitative content analysis, a research method to systematically describe the meaning of qualitative data (Schreier, 2012). This analysis focuses on the personal and professional impact of participating in CONNECT. Study team members with backgrounds in PC (YS), oncology (JS), and nursing (MR and KF) read sample transcripts and met to develop an initial coding framework. A codebook was developed and refined based on interdisciplinary team feedback and applied to all interviews by KF. The coding framework evolved as common themes emerged, and data were grouped into categories. To enhance the credibility of qualitative findings, all data analysis steps were documented, input was solicited from investigators with a range of perspectives, and respondent validation was conducted with participating nurses (Mays and Pope, 2000). ATLAS.ti Version 1.6.0 was used for qualitative data analysis.

Results:

Interviews occurred over a six-week period in June-July 2017 and again over a four-week period from January-February 2018. Among the 14 nurses who were eligible to participate, 3 initially declined due to lack of time. Interviews were conducted with the remaining 11 nurses, at which point thematic saturation was reached, meaning no new themes emerged from the data. Interviews ranged from 19 to 37 minutes (mean 26 minutes). Participating nurses had 3 to 15 months (mean 8 months) experience implementing CONNECT. Table 1 includes additional participant demographic data.

Three key themes emerged from analysis: (1) RNs benefit from the unique one-on-one care and support provided to patients by CONNECT through a sense of personal and professional fulfillment, however they also experience emotional risks related to closer connections with patients; (2) RNs felt that participating in CONNECT enhanced their communication skills with patients, particularly in discussing goals of care and advance directives; and (3) feelings of increased stress, frustration, and guilt related to time spent on CONNECT were minimized with support from leadership, coworkers, and the CONNECT nurse project manager. Below each theme is described further, with additional supportive quotes included in Table 2.

Personal and Professional Fulfillment

All nurses who participated in the study mentioned the personal benefit they felt came from the one-on-one care and support provided through CONNECT. Many nurses reported feeling more focused and engaged during these conversations, which in turn led to feelings of personal satisfaction. As one nurse stated,

“I think it just allows us to have the extra chunks of time with one patient, that, in an infusion center unfortunately have gotten lost...When I sit down to do a CONNECT visit with a patient, I’m engaged in it. I take the time I need, and I give that to the patient where normally I wouldn’t have been able to”. Nurses also mentioned feeling a sense of personal accomplishment related to this different type of work. “I love it. I definitely have felt rewarded...like I’ve actually accomplished some things at the end of the day...I think it’s had a great impact on me overall”. Nurses felt more involved and connected with individual patients and noted that CONNECT allowed them to have a more in-depth view of what patients are experiencing.

However, several nurses also referred to the alternative side to closer relationships with patients and the risk of becoming overly attached. One participant revealed, “I think it’s been a little bit hard in some regards...You’re spending much more intense one-on-one time with that patient, so you tend to get a little bit more connected to the patient”. As stronger nurse-patient bonds develop, some nurses felt vulnerable. One nurse commented, “you tend to get more involved...You’re more aware of their life and who they are as a person...and it’s not as easy to detach yourself from that person when something happens.” While none of the nurses reported feeling burnt out presently, this was mentioned as a potential. As one nurse said:

“I think the only thing I would keep an eye on with some of the nurses is just after a while...you do tend to get more attached to these patients than you would normally... You’re spending a lot more extra time with them and tending to get to know them a little bit better. So then I think it’s a tougher loss when that patient does die. So I think it would just be important to make sure the nurses are not getting burned out after a while”.

New Communication Skills

All of the RNs described communication skills gained through participation in CONNECT. These skills came from the communication training that each RN attended, as well as increased experience with difficult conversations as part of conducting CONNECT visits. The most commonly described impact on communication skills was a growing level of comfort with traditionally challenging conversations, including those focused on goals of care or advance directives.

At CONNECT training, RNs had the opportunity to role play difficult conversations with standardized patients, while being supervised and coached by experienced PC clinicians. This experience, as well as the intervention manual that included suggested or “go-to” phrases for each component of the CONNECT intervention, were reported as useful in many scenarios where nurses struggled to find the right thing to say. Most nurses reported feeling less anxiety and discomfort with difficult conversations as they continue to expand their experience. One nurse commented:

“When it comes to a normal conversation, you’re really not sure what to say. And they gave you some scripted things that you can say to patients to get through it. Like about the advance directives and stuff – they gave you things to say, to get through the ice. And that helped a lot. Because sometimes you don’t know the right thing to say but if you’ve at least kind of got a starting point then you can go from there...”

Many also noted that their enhanced communication skills translated to all of their patients, not just CONNECT participants. They found the technique of asking open-ended questions to be especially useful. One nurse noted, “It’s taught me to ask more open-ended questions. It kind of gets you to the root of what’s actually going on. Instead of saying just how do you feel today, and they say okay...now I go more into what that actually means”. Most also believed they had become a better listener after implementing CONNECT, as highlighted by one nurse, “It’s allowed me to...kind of have that pause to let patients elaborate more. Sometimes that’s tough as a nurse – we just want to jump in...I think it’s helpful when we can kind of step back for a second and let the patient elaborate and reflect a little bit more”.

Stress and the Work Environment

Many nurses reported feelings of stress, frustration, and even guilt due to time spent on CONNECT visits. One nurse remarked on the increased workload: “it’s definitely a lot of extra work to try to squeeze into our normal daily routine”. Another nurse said “I feel guilty about that sometimes... someone else is kind of picking up your slack as you’re doing your CONNECT visit”. Many nurses spoke about modifying CONNECT visits so they could

better accommodate their busy treatment schedules. Sometimes visits were cut short or occurred at later dates than originally planned because of time constraints. Nurses also talked about feeling uncomfortable taking time to “just sit and talk” rather than participating in traditional nursing care. One nurse said:

“[What has not worked well is] the process of having a nurse taken away from the treatment area. Especially in our setting...Obviously staffing is short everywhere, but to take time away and to expect other nurses to take care of your patients while you’re trying to have this conversation is very difficult. As a nurse, you want to take care of all of your patients. You want to do everything for all of them. So to pull yourself away to just talk...to be with just that one patient...it makes it very difficult”.

These negative feelings were decreased when nurses perceived clinic leadership and coworkers to be supportive and helpful. Encouragement from the nurse project manager was also described as important. As one participant said:

“I think having a nurse manager that’s able to allow you the time to do it...we need that extra support. You don’t feel guilty that when you have a patient with CONNECT it’s time away from everybody else. I think you have to have a good support system behind you, that the other nurses understand that you’re only going to maybe have two patients that morning as opposed to four or five, because you have a CONNECT patient”.

Discussion:

In this in-depth interview study, oncology nurses generally reported a positive personal and professional impact from providing primary PC via the CONNECT intervention. Deeper relationships with patients helped lead to a sense of personal and professional fulfillment, much of which was accomplished through advances in communication skills. Emotional risks related to these nurse-patient interactions and added stress in the work environment were two potential negative effects. To our knowledge, this is the first qualitative study exploring the impact of primary PC provision on oncology nurses.

It’s important to relate these results to general practice and nursing care. Effective communication in cancer care may improve patient outcomes, including increased patient satisfaction, less stress and anxiety for patients, and improved quality of life (Uitterhoeve et al., 2010). Nurses have been known to overlook patients’ social and emotional needs when focusing on physical care and other tasks (Baer and Weinstein, 2013). Participation in CONNECT refocuses nursing practice from a traditional, task-oriented approach to concentrating more on patients’ emotional and psychosocial needs. However, the data reveals the challenges nurses face with this transformation. Nurses spoke highly of feelings of reward, fulfillment, and satisfaction by having a different type of relationship with patients, but at the same time they felt guilty because they viewed other clinic nurses providing traditional nursing care as doing more work. The notion that RNs view their practice as treatment-oriented tasks and that “just talking” to patients about important issues,

such as symptom management and goal setting, is not considered to be as valuable is provocative and should be explored in future research.

Therapeutic communication skills are not typically a part of standard nursing education at the RN level, and advance directives and goals of care discussions can be uncomfortable for many nurses, especially those who are inexperienced. Nurses need to seek out opportunities to further their knowledge and experience in these areas. One national training program that aims to address this education gap is the End of Life Nursing Education Consortium (ELNEC), which provides specialized PC education through a “train the trainer” approach (Ferrell et al., 2010). The CONNECT training also helps to bridge this education gap for nurses with opportunities to practice and receive feedback on communication skills with standardized patients. In addition, CONNECT enables nurses to use their communication skills when conducting primary PC visits with advanced cancer patients and provides ongoing support and resources.

It is also known that healthcare providers who work in oncology and PC are subject to high rates of burnout, which can negatively affect workforce retention in these specialties (Kavalieratos et al., 2017; Wu et al., 2016). Job satisfaction and a supportive work environment are two known protective factors that decrease the risk of burnout (Kamal et al., 2016). An article by Wu et al. (2016) looked closely at compassion fatigue and burnout versus a lesser-known concept of compassion satisfaction among oncology nurses. Compassion fatigue is typically described as exhaustion and frustration secondary to emotional attachment to patients and the intrinsic need to help others. Burnout is driven by the environment, including time and resource constraints. Conversely, compassion satisfaction is the positive feeling derived from helping others. A cohesive team and positive work environment were the most important factors identified in decreasing compassion fatigue and burnout, and therefore increasing compassion satisfaction (Wu et al., 2016).

The results of this study mirror these findings. CONNECT participation seemed to promote job satisfaction overall, however there was a fine line between feeling accomplished and feeling overwhelmed depending on the clinic environment. CONNECT nurses seemed to feel more at ease with their new role if the work environment was perceived as supportive and the schedule was conducive to one-on-one visits with patients.

Conclusion:

Overall, nurses who participated in CONNECT felt they were impacted in a positive manner, describing both personal and professional benefits from delivering primary PC. New RN practice skills, including PC communication techniques, challenge the task-oriented paradigm of nursing practice and have the potential to greatly alter the traditional workload and schedule of infusion rooms. Modifications in staffing models and supportive work environments may help to ensure sustainability of oncology nurse-led primary PC.

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APPENDIX

Interview Guide

A. Intervention (CONNECT)

1. What about the CONNECT intervention has worked well?
2. What about the CONNECT intervention has not worked well?
3. What recommendations do you have for improving the CONNECT intervention?
4. Tell me how you feel the CONNECT intervention has impacted patients.
5. Do you believe CONNECT is reaching your patients with the greatest palliative and supportive care needs?
6. Describe how the CONNECT intervention has impacted families.
7. Do you think CONNECT is reaching families with the greatest palliative and supportive care needs?
8. Do you have experience with any other ways of providing palliative or supportive care to patients with advanced cancer? (For example, referring patients to palliative care specialists, palliative home care, etc.) Tell me about how CONNECT compares with other interventions you are familiar with.

B. RNs as CONNECT Clinicians

1. How has being a CONNECT nurse impacted your nursing practice?
2. How has being a CONNECT nurse impacted you personally?
3. Tell me about your emotions as a clinician while using CONNECT. How do your emotions change from before each CONNECT visit to during your time with patients? Has this changed with more experience?
4. Describe how the CONNECT intervention has impacted oncologists at your clinic.

C. Setting

1. Tell me about what has been most helpful in implementing the CONNECT program within your clinic.
2. Tell me about what has been most challenging in implementing the CONNECT program within your clinic.
3. Describe what you feel will be necessary to continue using CONNECT within your clinic after this research study.

D. CONNECT Training and Implementation

1. Describe how the CONNECT training you attended prepared you to participate as a clinician in the CONNECT study.
2. Describe how supervision sessions with the CONNECT nurse coordinator have impacted your role in the study.

E. Other General Comments: What else should we know about CONNECT that has not already been addressed?

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Implications for Practice:

Understanding how participation in CONNECT impacts RNs both personally and professionally will help improve delivery of nurse-led primary PC. Ensuring personal and professional growth for RNs providing primary PC will strengthen provision and improve sustainability of CONNECT and other nurse-led primary PC interventions developed in the future.

TABLE 1

Characteristics of nurses participating in in-depth interviews (N=11)

	N (%) or Mean (SD)
<i>Female</i>	11 (100%)
<i>Age</i>	37.2 (11.2)
<i>Race/Ethnicity</i>	
<i>Caucasian</i>	10 (91%)
<i>Asian</i>	1 (9%)
<i>Highest level of education</i>	
<i>Bachelor's of Science in Nursing (BSN)</i>	7 (64%)
<i>Associate's Degree in Nursing (ADN)</i>	4 (36%)
<i>Oncology Certified Nurse (OCN)</i>	4 (36%)
<i>Years of Nursing Experience</i>	11.6 (8.4)
<i>Years of Oncology Experience</i>	10.3 (9.4)
<i>Years Working in Current Location</i>	3.9 (3.9)
<i>Months of CONNECT Experience</i>	8.2 (4.6)

TABLE 2

Key Quotes

<p><i>Theme 1: Registered nurses benefit from the unique one-on-one care and support provided to patients by Care Management by Oncology Nurses (CONNECT) through a sense of personal and professional fulfillment, however, they also experience emotional risks related to closer connections with patients.</i></p>	<p>You feel a connection with these patients. And then you feel a little closer with them once you really get to know them...CONNECT gives you a little bit more of an in-depth look at what they go through.</p> <p>The most satisfying thing about being a CONNECT nurse is just the overall feeling that you are improving the quality of their life.</p> <p>I think every oncology nurse needs to take this [training]. It absolutely changes the way you talk to patients, the way you interpret what the patients are saying...I can't say it enough, I just think I've absolutely benefited as a nurse.</p> <p>It has opened my eyes...when I sit down with my patients it just broadens the discussion. It's taught me to be a little more aware. With CONNECT I feel that I give the highest level of customer service and customer satisfaction – that if that were my mom in that chair, or my brother, that there isn't any better care that they could receive other than what I do for them while they're in the clinic.</p> <p>Hearing that they [the patients] are actually getting something out of it is very rewarding.</p> <p>You're really sitting and paying attention on a one-to-one basis.</p> <p>I get a lot of job satisfaction knowing that I'm helping somebody not just through treatment, but helping them future plan. It's really...good to know that I'm helping people to move forward a little bit with their future planning. And you can tell they really appreciate it, so that makes me want to keep doing it and to help more patients that way.</p> <p>You're developing these deeper relationships with patients. You're seeing these patients at their worst. You're getting to know them, you're getting to know their family, what their issues and concerns are. You kind of, well obviously after stuff like that, you're going to grow attached to these people. Whenever something happens to them or when you're finished with your CONNECT visits with them it's difficult. I'm more stressed.</p>
<p><i>Theme 2: Registered nurses felt that participating in CONNECT enhanced their communication skills with patients, particularly in discussing goals of care and advance directives.</i></p>	<p>I think it [CONNECT] helps you to listen to the patients a little better, as far as just kind of realizing all of the things that go on in their lives.</p> <p>It's beneficial to other patients too...there's times where I will "pull a CONNECT" with them.</p> <p>I feel more comfortable with them [advanced directive conversations]. You know, after you've done it a couple of times you tend to have a script going that can kind of get you through it. You know what you're going to say.</p> <p>I think it kind of opens your eyes. To have those [goals of care] conversations a little sooner...and it's given me the experience to having that conversation. It's not something I was comfortable with before. And it's definitely getting a lot easier. So, you know, then I can have more of a positive impact with patients.</p> <p>Once you've talked about some of those things so many times your ability to approach it and your verbiage and things get better and better and better as you do it more and more. So, I'm definitely more comfortable with it.</p> <p>You know, the more that we do these CONNECT visits, as with anything else, the easier it gets.</p> <p>It [communication] has definitely changed. I do find myself saying things and phrases that I would not normally have said, like "can you tell me a little more about that" and "how does that make you feel" and</p>

all those things that are taught in the CONNECT class that normally are probably not part of my communication.	
I'm more comfortable to ask... to ask the harder questions.	
I think it's hard because... we have a whole schedule of patients getting treated, and so it's increased our stress and definitely increased stress on the other nurses, the non-CONNECT nurses, because they've had to pick up our load.	Theme 3: Feelings of increased stress, frustration, and guilt related to time spent on CONNECT were minimized with support from leadership, coworkers, and the CONNECT nurse project manager.
It's just extra support for us, and if you have questions or you feel like you've done something wrong, you can always go to [the nurse project manager] and she always has good ideas. She always comes up with strategies to help you.	
I don't feel like I take it [stress] home with me, like I don't take the burden home with me as much – but I definitely feel like that's because [the nurse project manager] and the other CONNECT nurse are just so supportive. It's just so important to have some kind of support system like that.	