



Review Article

# “They Just Kind of Take You Under Their Wing”: A Qualitative Study of Palliative Care Patients Experiences

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## Abstract

Palliative care is a treatment option designed to honor the choices of patients and improve their quality of life when facing life-threatening illness or injuries. The concept of palliative care is not new, yet it remains an enigma in healthcare. There is often confusion among health care providers as to when or if this treatment option should be discussed with patients. Patients have misleading perceptions about what's entailed with palliative care. This descriptive qualitative study explored the phenomenon of patient acceptance of palliative care services. Semi-structured interviews were used to collect data among six palliative care patients with cancer as the prominent diagnosis. Using an iterative inductive coding approach three major themes emerged about palliative care: Choice, Multiple Benefits and Helpful Navigation. All study participants were unaware of the scope of palliative care services. Participants shared that they didn't exactly know how they became involved in the palliative care program but were appreciative of enrollment. Regardless of how the participants entered the palliative care program they all strongly extolled the services they received.

**Keywords:** Palliative care; Patient choice; Cancer care; Consult team; Qualitative methods

## Introduction

The concept of palliative care is not new, yet it remains an enigma in healthcare. Palliative care, as a treatment approach for individuals with life-threatening illness, gained momentum in the United States in the 1960's as a component of the modern hospice care movement developed in the United Kingdom during the same period of time [1]. Palliative care can be defined as an interprofessional and personalized health-care model that honors the choices of and improves the quality of life (QOL) for patients and families faced with life-threatening illness or injuries [2,3].

Despite this broad definition, there is still widespread confusion around the concept of palliative care among healthcare providers. Health care professionals interchange and utilize terms such as end-of-life-care and hospice care when referencing palliative care [1,2]. In addition, the ideal time for initiation of palliative care discussions continues to be a challenge for health care providers [4,5]. It is important that health care providers offer patients evidenced-based options for care to enable them to make informed decisions on treatment options [6].

Pattson, Carr, Turnock, and Dolan stress the important role health care providers have in helping families and acting as patient advocates to inform them about palliative care [7]. Yet there are still some health care providers that are still not comfortable or supportive with referring to palliative care based upon lack of education regarding services available in palliative care.8 Patients too have gaps in knowledge regarding palliative care and could benefit from improved

communication or embedded protocols to introduce the palliative care concept early in the course of treatment [5,6].

Palliative care is not solely applicable to terminal conditions or care [1]. Palliative care applied early in life-threatening conditions, emphasizes support and relief of symptoms, and is delivered in conjunction with life-prolonging therapies, such as chemotherapy and radiation [3]. Palliative care can be initiated at the time of diagnosis or injury, delivered throughout the continuum of that condition, and includes curative or restorative treatment [2]. Metzger, Norton, Quinn, & Gramling stated that often palliative care is introduced to assist with establishing goals of care [9]. This qualitative study explores the phenomenon of patient acceptance of palliative care services including facilitators and barriers to enhance understanding and motivating factors.

## Method

Institutional review board approval was obtained from the healthcare agency where the research took place, and the sample was drawn. A qualitative descriptive design was used for this study. Descriptive qualitative methods are useful when researchers desire straightforward narrative descriptions of events or phenomena in everyday language [10]. This method also allows for wide ranges of responses within the context of the current event.

All patients with a cancer diagnosis enrolled in the same palliative care program were invited to participate in the study. The invitation to participate was extended during a scheduled appointment, by the nurse practitioner (NP) who

coordinated palliative care services. If potential participants indicated a willingness to participate in the study, the NP reached out to the nurse researchers, shared contact information and the nurse researchers then scheduled interviews with participants at a time and place that had been mutually agreed upon. Written informed consent was obtained at the time of the interview.

The sample included six participants, four females and two males between the ages of 35 and 74 years, with five identifying as white. Three participants lived alone and three lived with a significant other or married partner, all had attended some college with one participant having a graduate degree.

Semi-structured interviews were used to collect data. Data were collected until saturation was met. All interviews were audiotaped and transcribed verbatim for analysis by the three members of the University research team. Thematic analysis was used to analyze transcripts. Each researcher independently analyzed and coded the data set and then met virtually to come to consensus about themes. This type of analysis demonstrates triangulation and bolsters trustworthiness of findings.

## Results

A total of six qualitative interviews were conducted by two researchers. Five of the interviews took place in the participant's home and one interview was conducted at the participant's clinic.

Participants shared the impact of their cancer diagnosis related to their daily lives and their interaction and participation with palliative care. Three distinct themes were identified from the analysis: (a) Choice; (b) Multiple Benefits; and (c) Helpful Navigation.

### Choice

One common theme noted in all interviews was the lack of awareness on options for palliative care service. Most participants reported they were unaware they had been referred to a palliative care provider until they were contacted to establish services. One participant shared, "I guess I didn't realize that there was a choice, I thought it just was part of this." The comment highlighted that they felt the palliative care services were part of their treatment plan. Another went on to say that they didn't know when or how they were introduced to the palliative care program as they stated, "Well I'm not really sure. When I was being diagnosed I got really sick and a lot of decisions were made by my family on my behalf. So I don't really know when that decision was made." All participants were clear in that they were participants of the palliative care program, but they didn't realize they made a choice or how the choice was made to enter the palliative care program.

All participants reported receiving ongoing treatment for their current cancer diagnosis. Participants indicated an understanding that palliative care was an additional supportive resource to assist them in reducing physical and emotional suffering while improving quality of life. However, several

patients reported poor understanding of the benefits of palliative care when it was first introduced.

*I had a vague understanding of what palliative care was, and I knew that there was a distinction between palliative care and hospice, but I didn't know all the specifics, having not been, you know, a cancer patient prior. And I remember the doctor walking out, and then my mom turning to me and saying, you tell him you don't want that. So, that's sort of the first time that I remember being introduced to it in terms of my treatment.*

*Well, okay, in the very beginning, I heard about palliative care and hospice. But nothing was really explained to me at that time. And then somewhere along the road, somebody brought it up, and did I want to do that. And I said, yeah, I'll do that. And it was still a while before anybody said anything else.*

Several participants acknowledged that the subject of palliative care had been discussed at several points of time in their care, but they had been overwhelmed to identify a specific point in time when palliative care started. One patient stated the following which was echoed by several other participants about starting palliative care, "truthfully I had so much going on in my brain at that time ...I was like, flabbergasted." Another patient went on to say, "I mean the term palliative care came up, it's like yeah, okay, whatever." Five of the six participants thought that everyone that attended the clinic would receive palliative care services and that the choice was related to the types and number of services they would use in the program.

### Multiple Benefits

All participants highlighted the importance of "so many services" that were "readily available" when they were enrolled in palliative care. Participants expressed being overwhelmed with their diagnosis and treatment plan. Upon entering palliative care they felt the amount of benefits provided to them helped immensely. One participant stated the palliative care program was, "like another support, like another branch of the tree of my treatment team, another resource." Participants identified the importance of multiple sources of support in palliative care that helped them throughout their treatment. Due to the participants listing multiple and different benefits of palliative care that were offered and tailored for their care, all benefits were combined as one theme. Benefits that were highlighted included emotional support, pain management, family/caregiver support, and access to community resources.

### Emotional Support

Emotional support services were articulated in all interviews as an important component in their journey of care. Several comments included that the "emotional aspect of it" and the addition of the palliative care team reaching out with check-in phone calls helped. They stated that the team was, "good at giving you pep talks." They expressed that the "face-to-face contact" was important and that they didn't "get lost in the shuffle" of appointments and cancer care and treatment.

They stressed the importance of the little things making a big difference such as the "APNP will stick her head in and ask how I'm doing" or they were so impressed that all team members took time to "listen." One participant shared a story of how they were supported during one appointment:

*They remember you. They check in with you..they just kind of take you under their wing and they hold your hand, if you need it. I had gotten sick one time and one of the ladies had come over and was rubbing my hair and forehead [...] it's just nice. The other time I had almost a panic attack, and she walked me through that. She had me [...] change my subject matter to make me relax, you know, but she did it very slickly. It was good.*

Participants shared that feelings of being overwhelmed were dealt with through the additional support of the palliative care team. Several participants shared feelings of being supported and felt as if they had a positive presence of a "support group" atmosphere and that the support from the palliative care program "was just so much positive" "and caring." The emotional support was perceived in different ways by each participant, but all highlighted how the palliative care program helped them cope during this "very disruptive" time when they were "kind of overwhelmed."

### **Pain Management**

Help related to dealing with pain and pain management was expressed by four of the six participants. The fear of what would come and how to deal with cancer and cancer treatment pain were addressed with the palliative care team. One participant stated that learning about pain management was one of the "biggest" sources of information and help to them during their care. Another participant shared that using members of the palliative care team, such as the physical therapist, made a difference when "a pinched nerve in my neck" became a problem. They expressed gratitude that they were able to reach out and make an appointment, "It was like, you know, if I needed, it was there." The fear of pain was very evident as one participant stated, "I was terrified of the pain," but later went on to say that "if I have a problem [...], they'll get that rectified." They felt confident in the palliative care team listening to and addressing their needs, thus decreasing their fears about pain. Finally, the importance of "talking about the details of pain management [...]" would be a big piece missing if I didn't have that," highlighting the concerns participants had related to this issue and how palliative care addressed their individual needs.

### **Family/Caregiver Support**

Half of the participants shared how important it was for them to receive family and caregiver support for their loved ones, such as a spouse or their children. They shared that they were welcomed and able to have family members included in all the steps of their care extremely important and helpful. They talked about how impressed they were that family members' needs were addressed too. In one case the participant described how the palliative care team assisted

their daughter early on during the initial diagnosis phase. The participant stated referring to their daughter:

*Well, she was here during the diagnosis and everything, and they explained it in a way she understood too. There was a time when she was having a meltdown during one of it, and I had talked to the social worker about that, but now they ask every time how she is, how she's doing. And it wasn't so much me, it was everything that she was going through at the time.*

Another participant shared how important it was to include his spouse not only in the initial diagnosis and treatment phase, but to also include them in his palliative care plan related to goal setting. The participant shared the importance of "wanting to do regular stuff" and how he and his wife found out about a program at the local YMCA related to strength building that they could attend together stating, "I'm looking forward to it."

### **Access to Community Resources**

All the participants identified at least one or more resources in the community that they learned about in palliative care. They expressed surprise that the scope of services was so far reaching and stated, "I didn't know everything that Palliative care could offer." Examples of resources used by participants ranged from assistance with identifying medical transportation providers, assisting with initiating and putting into place advanced care planning services, grocery shopping and delivery, support group access, and assistance with managing Social Security questions. One participant stated the following about palliative care and community resources, "so many services available to me, that anything that I could want, possibly want, I had." The participants appreciated the supportive staff that listened to their needs.

### **Helpful Navigation**

The Helpful Navigation theme arose from comments shared by all the participants related to their feelings of being overwhelmed with their diagnosis, care, and future of their health. The participants shared that engagement with the "very helpful" palliative care team assisted them to "navigate" the amount of information, scheduling of many health care appointments, and dealing with understanding next steps when they were in a cloud of "chemo brain" and unable to comprehend treatment options or discussions related to their care. One participant shared that the care they received at the palliative care program was a "seamless process that...helps me to manage my disease process, and tolerate it better. And then, also know who I can contact when an issue arises." Another shared that they never felt pressured to hurry or "feel bad about asking questions." They felt that they had real time guided assistance with decision making related to their care as identified with the statement, "if I have issues, I call the center, (Palliative Care) and they connect me."

Other participants stressed the importance of having familiar, consistent faces at clinic appointments or voices

when they called to ask questions. Even though many palliative care team members were involved; the consistency was noted and appreciated. Another participant shared that "there would be a big piece missing" if they did not have a palliative care team and services. As one participant stated, "they take you under their wing and just kind of guide you through it."

Another key factor identified by three participants related to choice and engagement in care while they received assistance from the palliative care team. The participants recognized the benefit of having information shared with them related to their care. They also acknowledged that there were a great number of decisions that needed to occur throughout their treatment. Participants emphasized that they personally "were the deciding factor in any decision," related to their care. It was, "my decision", but the ability to share and be heard was integral as active participants in the palliative care process.

## Discussion

Consistent messaging regarding palliative care is essential. As some patients and families may associate a palliative-care referral with hospice care or have other misconceptions and fears, the benefits of palliative care as an adjunct therapy should be emphasized. Providers are in a unique position to foster support for palliative care due to the established relationship with patients. Provider initiated goals-of-care conversations with their patients are recommended to occur early and often in the course of treatment. Concurrently, patients and family members should be encouraged to discuss their wishes, ideally before the occurrence of a significant medical event.

According to the participants, all were enrolled into the palliative care program early in their course of treatment. All discussed the benefits they received and strongly stated they would recommend palliative care for anyone in a similar situation. Though participants reported they did not directly ask for palliative care, all shared that the early referral and initiation of palliative care services improved their quality of care.

## Limitations

The small sample size is consistent with qualitative studies. Recruitment, limited to a single palliative care service line, was also hampered by the COVID 19 pandemic. Data saturation may have been limited by the clinical diagnosis of the participants. As data saturation occurred within six interviews, the decision to conclude the study was made by the research team.

## Conclusion

The importance of palliative care was highlighted in many ways by study participants. Though participants could not clearly articulate when they officially began or how they entered into palliative care, they articulated many positive

benefits of being enrolled in a palliative care program. Participants recognized that assistance from the palliative care team provided emotional support, pain management, family and caregiver support, access to community resources and assistance in navigating the established plan of care. These program benefits highlight that while there is no question that palliative care is of vital importance at the end-of-life, the scope of palliative care is not limited to end-of-life. Benefits of engaging palliative care early in the course of treatment provides therapeutic solutions for those with complex and varied health conditions to improve their care and quality of life.

## Conflict of Interest

Authors declare that they have no conflict of interest.

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