

MISPERCEPTIONS REGARDING PALLIATIVE AND HOSPICE CARE AMONG CANCER PATIENTS

What Can We Learn from Patient-Reported Treatment Decision Making?

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BACKGROUND

Despite NCCN guidelines and clear definitions of palliative care and hospice care, patients often have misperceptions about these forms of care and how they can be beneficially integrated into their care plan. Previous research focuses on communication between healthcare professionals (HCPs) and patients about the benefits of both forms of care.^{1,2}

However, misinformation about palliative and hospice care (PHC) persists, including conflation of the key principles of PHC. Notably, there is persistent confusion differentiating between PHC as well as a general lack of knowledge about palliative care. This study aims to identify beliefs that underlie the understanding of PHC among cancer patients.

METHODS

An online survey was conducted of individuals with a cancer diagnosis (n=1,517) to better understand their health care experiences. Measures included agreement scale and open-ended questions to assess patients' understanding of PHC. Responses to agreement-scale questions were evaluated using descriptive statistics. Open-ended question responses were analyzed using Dedoose™ qualitative data analysis software. Interrater reliability of initial coding was calculated using pooled Cohen's Kappa. An exploratory approach was taken in the analysis and initial codes were grouped into thematic categories and confirmed through thematic network/framework analysis using Dedoose™ software.

RESULTS

There was a broad range of patient misperceptions regarding palliative care, hospice care, and how they are used in cancer care. The majority of respondents (81%) stated that their HCP played a role when deciding on their treatment plan. Despite this, only 46% were confident they knew about the treatment's impact on their daily life, 56% were confident they knew about the potential side effects of treatment, and 57% felt they had all of the information they needed.

Respondents defined PHC in a variety of ways that reflected different levels of accuracy, including how these forms of care fit within the larger context of cancer care. Nearly one third (30%) did not know about palliative care compared to 4% who were unaware of hospice care. In general, 20% of respondents conflated palliative care for hospice care and 2% confused hospice care for palliative care. Themes identified across both PHC fell into four main categories:

- Framing PHC concepts as positive, negative, or defeatist [Table 1]
- Identification of the goal(s) of care [Table 2]
- Definitions that imply a partial or comprehensive understanding of PHC concepts [Table 3]
- References to personal experience [Table 4]

Table 1.

Framing (n=272)			
Positive	76% (207)	Hospice	65% (134)
		Palliative	35% (73)
Defeatist/Giving Up	13% (34)	Hospice	76% (26)
		Palliative	24% (8)
Negative	11% (31)	Hospice	77% (24)
		Palliative	23% (7)

Table 2.

Goal of Care (n=3,043)			
End-of-Life	41% (1,240)	Hospice	84% (1,046)
		Palliative	16% (194)
Quality of life	28% (856)	Hospice	46% (391)
		Palliative	54% (465)
Pain Management	10% (314)	Hospice	40% (126)
		Palliative	60% (188)
Treatment Involvement	10% (291)	Hospice	37% (107)
		Palliative	63% (184)
Symptom Control	5% (138)	Hospice	14% (19)
		Palliative	86% (119)
Emotional Support	4% (124)	Hospice	38% (45)
		Palliative	64% (79)
Cure Discovery	3% (78)	Hospice	22% (78)
		Palliative	78% (61)
Legal Matters	<0.01% (2)	Hospice	100% (2)
		Palliative	0% (0)

Table 3.

General Knowledge		
Hospice Care n=1,593	Complete understanding	4% (67)
	Partial understanding	61% (966)
	Do not know/unaware	4% (61)
	Conflation of hospice care	2% (35)
	Timing of hospice care	4% (69)
	Unresponsive	25% (395)
Palliative Care n=1,522	Complete understanding	5% (79)
	Partial understanding	31% (469)
	Do not know/unaware	30% (453)
	Conflation of hospice care	20% (307)
	Timing of hospice care	2% (23)
	Unresponsive	13% (191)

Table 4.

Personal Experience (n=940)			
Personal Relevance	46% (434)	Hospice	54% (236)
		Palliative	46% (198)
Family Involvement	21% (194)	Hospice	85% (165)
		Palliative	15% (29)
Setting	15% (137)	Hospice	91% (124)
		Palliative	9% (13)
Healthcare Professional / Team Involvement	13% (120)	Hospice	53% (63)
		Palliative	48% (57)
Caregiver Mention	6% (53)	Hospice	72% (38)
		Palliative	28% (15)

CONCLUSIONS

Oncology patients are often misinformed about the benefits of palliative care. Gaps in palliative care understanding involve the patient conflating palliative care with hospice care. Patient understanding of hospice care is more concrete; yet often lacks an understanding of the timing of care. Hospice is frequently cited as being "end-of-life care" or a means to "die with dignity". This follows a parallel concern of patients making treatment decisions without optimal information.

A potential factor behind this misunderstanding may be a lack of effective communication between patient and HCPs. Palliative care may be mentioned by HCPs, but not discussed with enough empathy or depth, leading to patient misunderstanding, and ultimately the lack of inclusion in treatment plans. HCPs may hesitate to have these conversations perhaps to avoid hurting or stigmatizing the patient or because HCPs hold inaccurate beliefs about the patient.

Patients do not generally hold a negative association about hospice care. Most patients who defined hospice care within a contextual "frame," framed it positively and as beneficial to the patient. Additionally, patients frequently mention the benefits of PHC for their family. When starting conversations about both types of care, HCPs should be upfront and honest about the options available and incorporate the entire family into discussions.

	What does hospice care mean to you? How do you see it being used in cancer care?	What does palliative care mean to you? How do you see it being used in cancer care?
Framing	"End of life care. When there is no hope." "Dying away from my family and those I care about. Being locked away in a strange room and being given so much pain killers that I wouldn't even know it what day it is. I believe hospice hastens your death"	"Just a different way to say hospice care. Used when there really is no hope." "Treating body, mind and soul. It's very important to have support through all aspects of life during cancer."
Goal of Care	"Taking care of you just before death." "Aid in dying."	"Taking care of the whole patient. Emotionally as well as physically." "Making life as normal as possible"
General Knowledge	"Hospice is end of life care. You have to agree to go off treatment. Hospice will keep you comfortable but won't treat your disease. If you rally and start to do better, you can go off hospice care and go back on treatments" "At death's door"	"Running out of options. One step before hospice." "Just a different way to say hospice care. Used when there really is no hope." "I don't understand what palliative care is" "Never heard of it."
Personal Experience	"Had a bad experience with hospice and was discharged. I feel like I didn't die fast enough for them. My doctors say I should go back, but I can't forget the lies and awful treatment." "...They were there to help my mother be a caregiver at the end of my dad's life. It's extremely important to have that support."	"I have a palliative care doctor, she is awesome and is very helpful in keeping my pain under control. She is giving me a better quality of life."

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