

How Did Advanced Pancreatic Cancer Patients and Caregivers Communicate Their Needs: a Pilot Study

Chia-Chun Tang¹, MSN, RN, OCN, Cleveland Shields², PhD, and Diane Von Ah¹, PhD, RN FAAN¹

¹Indiana University-Purdue University Indianapolis School of Nursing

²Purdue University College of Health and Human Science

BACKGROUND

Although it is one of the leading causes of cancer deaths in the United States, little is known about how patients with advanced pancreatic cancer (APC) and their caregivers communicate their needs with healthcare providers. APC patients, caregivers, and healthcare providers face unique communication challenges related to handling high psychological distress and overwhelming information within a short period. Consequently, these communication difficulties may also affect their health-related quality of life as well as decision making process.

AIM

This pilot study seeks to **explore how APC patients and their caregivers communicate their concerns about the disease, patterns of communication, and psychological reactions with oncologists.**

The specific research questions (RQ) are:

1. What are the topics discussed in the conversation?
2. Who initiate what topic?
3. What is the message quality considering patient-centered communication?
4. How patients and caregivers expressed their feelings?
5. How oncologists response to patients' or caregivers' emotions?

METHODS

- De-identified transcripts of APC patients' audio-recorded office visits were selected from a large randomized controlled trial called the Values and Options in Cancer Care.
- Among the 37 qualified transcripts, we purposeful selected 4 transcriptions with different levels of prognosis discussion.
- Selected transcripts were analyzed in terms of **discussion topics, message quality, patients' emotional cues, and oncologists' responses to these emotional cues.**
- Message quality was evaluated based on several patient-centered clinician verbal behaviors purposed by Drs. Epstein and Street (2007).
- We used Medical Interview Aural Rating Scale (MIARS) to code patients' emotional cues (table 1) and oncologists' corresponding responses (table 2).

Table 1 Level of Cues Defined by MIARS

Level	Description	Example
Level 0	Contains no element of feeling	I told the doctor what had been said at the hospital.
Level 1	Contains hints of emotion; imply some element of emotion	It was worse than I expected"
Level 2	Clear mention of feeling	I felt worried and upset when he told me
Level 3	Expression of deepest level of feeling	It was horrific, I felt humiliated

Table 2 Interviewer's Cue Response

Response	Example or description	
Exploration of the cue	how worried were you	
Acknowledgement of the cue	Yes I know it's difficult out of hours	
Factual clarification	How long have you been feeling like that	
Block	Distancing strategy	Inappropriate reassurance No you are not...don't be silly
		Inappropriate advice
	Passing the buck	You need to talk to social worker about that
	Switching focus	Switch away from the emotion, but within the context of the patients disclosure
Overt blocking	Switch to unrelated topic and ignore the cue	

RESULTS-1

- The 4 transcripts represented 12 individuals because each contained 3 participants: oncologist, patient, and caregiver. The average word count was 3518.5 words. Oncologists, patients, and caregivers contributed to 2806.3, 731 and 463.5 words, respectively.
- **RQ1:** Among the 9 categories of consultation topics identified, physical symptoms and signs were the most frequent (n=22) followed by care procedure (n=5), drugs (n=4) and lab results (n=4).

RESULTS-2

- **RQ2:** Oncologists initiated more topics (n=35) than patients (n=8) and caregivers (n=4). Oncologists tended to initiate more pain-related topics while patients and caregivers initiated topics related to fatigue, appetite and function.
- **RQ3:** Oncologist-initiated interruptions occurred in all consultations with an average of 5.3 interruptions per consultation. Only 2 out of 4 oncologists welcomed patients and caregivers and none of them discussed the agenda or goals of the consultations.
- **RQ4:** Overall, 54 patients' and 33 caregivers' emotional cues were identified. The majority of the cues were level one, implicit emotional cues (n=80).
- **RQ5:** The most frequent oncologists' responding strategy was blocking, including switching focus or overt blocking.

CONCLUSIONS

- First study to analyze unstructured conversation to identify APC patients' concerns and how these concerns were addressed in office visits.
- More research regarding how patients and caregivers communicate about **symptoms** is needed
- Findings provide valuable insight for identifying needs and enhancing end of life care and communication of terminally ill population.