

# THE ROLE OF COMMUNICATION IN CANCER CARE

SCIENTIFIC PAPERS FROM THE UBC CANCER CARE COMMUNICATION RESEARCH PROGRAM

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A research collaboration between UBC and the BC Cancer Agency

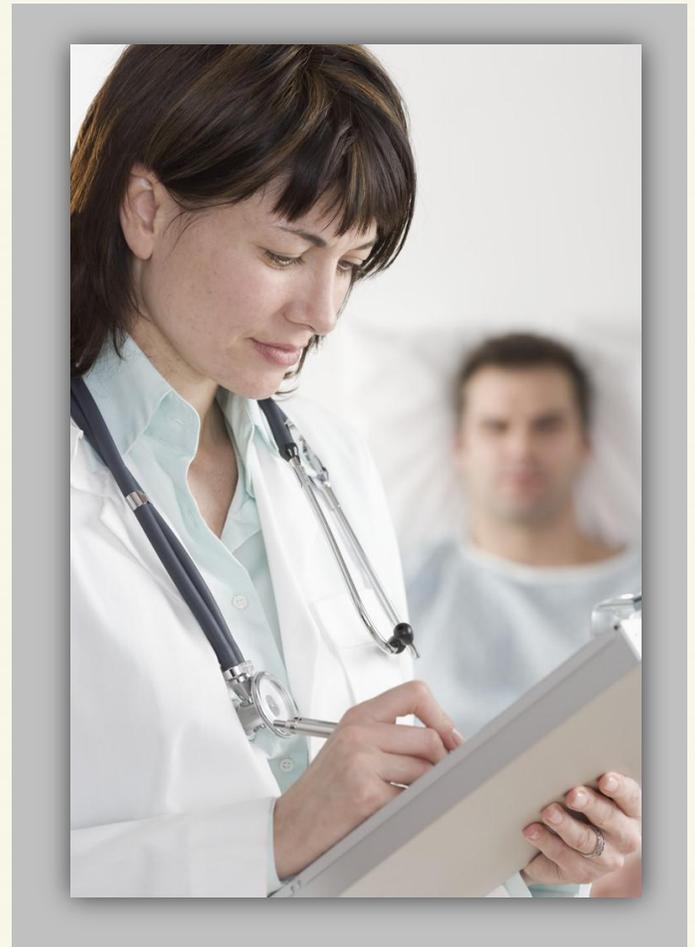
The selection of published reports below indicates the work of our research team as we investigate the cancer communication challenge from the perspective of patients living with, through and beyond cancer. Each study examines a distinct aspect of the communication puzzle, and concludes with specific recommendations for health care professionals and cancer care systems toward ensuring that all patients have access to high quality communication throughout their cancer experience.

## COMMUNICATION ISSUES AT VARIOUS STAGES OF THE CANCER JOURNEY

### The Time of Diagnosis

Thorne, S., Oliffe, J., Kim-Sing, C., Stajduhar, K., Harris, S.R., Armstrong, E.-A., & Oglov, V. (2010). **Helpful communications during the diagnostic period: An interpretive description of patient preferences.** *European Journal of Cancer Care*, 19(6), 746-754.

Patients tell us about the importance of such subtle aspects as professional demeanor, receptivity, sensitivity to the nuances of medical and statistical terminology, attention to time and space, and understanding emotional processes during the vulnerable time of learning one has cancer. Their recommendations help us understand not only the kinds of communications that may be most helpful to patients at this time, but also the contexts in which certain communications may or may not be most helpful.



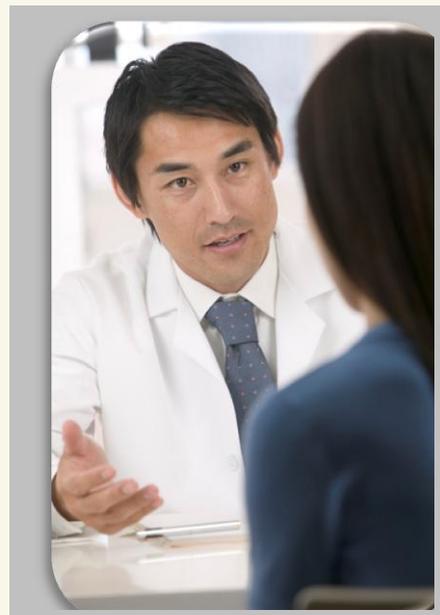
*“I’m sure she could have used a whole whack of different words that would have made no sense to me at all. But she had the ability to bring it down to my level so I could understand and see what was going on. She was a fabulous communicator.”*

*“If I feel that the health care professionals that I’m dealing with treat me like I’m just a case, I’m more in a state of agony.”*

Thorne, S., Armstrong, E-A., Harris, S.R., Hislop, T.G., Kim-Sing, C., Oglov, V., Oliffe, J.L., & Stajduhar, K.I. (2009). Patient- real time and 12-month retrospective perceptions of difficult communications in the cancer diagnostic period. *Qualitative Health Research*, 19(10), 1383-1394.

We compared patients’ descriptions of problematic communication experiences they had encountered during the time of being diagnosed with cancer with their reflections on those experiences a year later. Although many patients had taken active steps to seek out effective communication after their bad experience, the effects of the early distress were still present. These patient reports of the dynamics of poor communication help us better appreciate how indirect messages, disrespectful attitudes, the failure to individualize, or inappropriate levels of information can add to the patient burden at this vulnerable stage, and why it is imperative that we take steps to prevent them.

*“I recall asking, ‘Doctor, Can you give me any hope?’  
And he replied ‘That’s not my area.’”*



## Information and Treatment Planning Discussions

Oliffe, J., Thorne, S., Hislop, G., & Armstrong, E.-A. (2007). Truth telling and cultural assumptions in an era of informed consent. *Family and Community Health*, 30(1), 5-15.

In this analysis, we drew on the perspectives of patients of ethnic minority backgrounds who helped us reflect on how dominant thinking about informed consent influenced their cancer communication experience. Patients enlightened us on the importance of subtle variations in how information was titrated and conveyed, the importance of body language in communication, the role of the family in decisions relating to bad news, and variations on the value of autonomy.

*“Too directly giving information  
can crush the spirit.”*

Thorne, S., Hislop, T.G., Kuo, M., Armstrong, E-A. (2006). Hope and probability: Patient perspectives of the meaning of numerical information in cancer communication. *Qualitative Health Research*, 16(3), 318-336.

In this study, we considered the special role that statistical information plays in patients understanding of and feelings about their cancer. From the patient perspective, we documented the many ways in which numbers were interpreted to calculate and manipulate the odds of various events occurring, to influence optimism and hope, and to steer decision-making. This analysis led to recommendations for balancing the value of “full disclosure” against the patient’s need for careful timing and sensitivity in relation to statistical information.

*“Sometimes even those figures from research are really questionable. Depending on funding, you know, they can change the numbers and present that this many persons will be this way and that many persons will be the other way. Yes, I was told the figures but, you see, I’m alive.”*

*“He didn’t instill a sense of panic, nor did the surgeon, nor did my doctor. Nobody did. So it just sort of set the tone and I thought, ‘Okay, I can go through this.’”*

**Thorne, S., Oliffe, J., & Stajduhar, K. (2013). Communicating shared decision-making: cancer patient perspectives. *Patient Education and Counseling, 90(3), 291-296.***

Patient accounts of their conversations with health care professionals around treatment decision making focused attention on the setting and tone of these discussions, the attitudes conveyed by health care professionals in these difficult decisions, the way probability information was conveyed and the critical messaging around hope. Although most patients valued the general philosophy of shared decision making, they found it highly distressing when clinicians were reluctant to express an expert opinion as to the best course of action.

*“It just doesn’t seem like there’s also a right answer and so doctors are doing I think a crazy thing and they’re just asking patients what they want. And that’s unbelievably stressful.”*

**Thorne, S., Oglov, V., Armstrong, E.-A. & Hislop, T.G. (2007). Prognosticating futures and the human experience of hope. *Palliative and Supportive Care, 5, 227-239.***

In this study, we combined insights obtained from cancer patients with those from patients with various chronic diseases to expand our understanding of how communications involving future projections interact with the human experience of hope. Patients explained the ways in which these kinds of messages shape their capacity to make sense of and live with a serious illness, and they provided many suggestions for health care professionals to ensure that their technical communications about disease progression were always handled with sensitivity for the thoughts and feelings that characterize everyday life for their patients.

*“The way I would say it is that, when you get a diagnosis of cancer, or any life-threatening illness, you need to be committed to life. You need to put all your energy into life-giving experiences— people, situations, places—everything that could be life giving to me. And any thoughts of death just took me to more of a fatalistic attitude.”*



## **Transition into Survivorship**

**Thorne, S.E. & Stajduhar, K.I. (2012). Patient perceptions of communications on the threshold of cancer survivorship: Implications for provider responses. *Journal of Cancer Survivorship, 6(2), 229-237.***

When patients come to the conclusion of their chemo or radiation therapy treatment, their contact with oncology experts can be significantly reduced, with ongoing follow-up assigned to their family doctor or another primary care service. Rather than feeling relieved by the end of treatment, many patients find that “going back to normal” is impossible and they have difficulty meeting their information and monitoring needs. In this analysis, we present patients’ recommendations for the kinds of communications that might ease the abruptness of this transition and help patients work out how to manage their survivorship.

*“I totally feel like I got shown the door, and I’m on the other side of the door, and that door is closing.”*

*“I felt very encouraged and very positive. I felt I was not alone and I was going to be taken care of. I guess I felt that I was going to get better because I had all these people on board, and by hook or by crook we were going to fix this situation.”*

## Advanced Cancer/ Recurrence

**Stajduhar, K. I., Thorne, S., McGuinness, L., & Kim-Sing, C. (2010). Patient perceptions of helpful communication in the context of advanced cancer. *Journal of Clinical Nursing*, 19(13-14), 2039-2047.**

When cancer is incurable and patients are facing the end-stages of their journey, new challenges arise in relation to their communications with health care professionals. Some of the issues advanced cancer patients described to us include a heightened attention to the passage of time, the capacity to demonstrate care and compassion, acknowledging fears, and balancing honesty with hope. Although it can be difficult to communicate about issues associated with the end of life, patients explain ways in which skilled health care communication helps meet their needs and supports them in this phase of their experience.

*“The doctor said something to me that I will never forget, word for word at that first visit after the diagnosis ... He said, ‘I can’t lengthen your life and I won’t shorten it, but I promise to be with you every step of the way and make it as comfortable as possible for you. And that is all it took for him to calm some of the fears I had.’”*

**Thorne, S., Hislop, T. G., Kim-Sing, C., Oglov, V., Oliffe, J.L., & Stajduhar, K.I. (in press). Changing communication needs and preferences across the cancer care trajectory: Insights from the patient perspective. *Journal of Supportive Care in Cancer*. Early view ahead of publication: DOI10.1007/s00520-013-2056-4**

In this report, we summarize the key insights we have illuminated about each of the changing stages of communication over the various phases of an individual cancer experience. Although this summary cannot provide the depth and detail of the individual stage reports, it helps to put each stage into the perspective of movement over time, in the dynamic and fluid human context of what people need and value in terms of their interactions with the health care professionals guiding their care. We argue here for the vital role that time and trajectory play in determining the complexities of individual variation and common patterns, suggesting future directions for professionals seeking to achieve excellence in cancer care communication.

*“My doctor kept me focussed, and didn’t let me go to the dark side. She’s very good at explaining things, reframing it and putting it in a way you can understand. And she’ll give it another leaning so that its not all bleak – another way that you can look at this. Its not false hope, just saying there’s a chance there. And so I think that’s very helpful, just the fact that she’s not giving up on you.”*



*“You have to feel like you’re a part of it. . . You’re not just a cancer entity. You are also treated as a person.”*

## **COMMUNICATION CONCERNS OF PATIENTS ACROSS THE CARE TRAJECTORY**

**Thorne, S., Taylor, K., Stephens, J., Hislop, G. & Kim-Sing, C. (2013). Guinea pigs and gratitude: The difficult discourse of clinical trials from the cancer patient perspective. *European Journal of Cancer Care*, 22, 663-672.**

In this report, we describe patient descriptions of how communication between them and their clinicians can change when it comes to discussing clinical trials. Patients experienced considerable confusion in the “grey zone” between science and treatment. They had questions with regard to whose interests it would serve for them to participate in drug research and whether the information they were being provided was motivated by persuasion or support. The accounts of these patients remind us how complex these questions are and how challenging it can be to communicate effectively in a delicate situation such as deciding whether or not to participate in clinical trials.

*“I didn’t know what they were testing. All I knew was that they were seeing if this combination of drugs was going to be effective on my tumor. But other than that I felt pretty ignorant about the whole, like why they were doing it or what exactly they were doing.”*

**Thorne, S., Oliffe, J.L., Stajduhar, K.I., Oglov, V., Kim-Sing, C. & Hislop, G. (2013). Poor communication in cancer care: Patient perspectives on what it is and what to do about it. *Cancer Nursing*, 36(6): 445-453.**

While it is always helpful to find ways of making good communication better, patients also remind us of the need to address poor communication directly. This report uncovers three distinct kinds of poor communication from the patient perspective, each of which allows us to envision a different approach to the problem. “Ordinary misses” are everyday missteps for which maturation and socialization may be an adequate solution. “Systemic misunderstandings” are assumptive gaps between patients and professionals, which may be addressed through qualitative and patient-oriented research. “Repeat offenders” are a subset of clinicians whose communication patterns become a particular source of patient distress. Managing the communication of a problematic subset of clinicians will likely require strategic interventions at the level of organizational culture and models of care.

*“I think over the years what has happened is they keep it so impersonal that they disassociate themselves from their own feelings. There seems to be a lack of empathy anymore, cause who knows what kind of feelings they have about procedures they do every day.”*

*“It’s like, you’re just this thing going on this conveyor belt, and people are talking about what they’re seeing, but there’s a person attached to that.”*

Thorne, S.E., Kuo, M., Armstrong, E.-A., McPherson, G., Harris, S., & Hislop, G. (2005). “Being known:” Patient perspectives on human connection in cancer care. *Psycho-Oncology*, 14, 887-898.

Patients told us how important it was for them to have a human connection with the health care professionals involved in their cancer care. However, there were many variations in what it meant for patients to feel “known” by their clinicians, and an approach that might be effective with one patient might be unhelpful to another. Their stories revealed the importance of individualized communication from one human being to another as a core foundation of feeling safe and well cared for throughout the cancer experience.

*“She knew enough to give me information she knew would be right for me.”*

Thorne, S.E., Hislop, T.G., Stajduhar, K. & Oglov, V. (2009) Time-related communication skills from the cancer patient perspective. *Psycho-Oncology*, 18(5), 500-507.

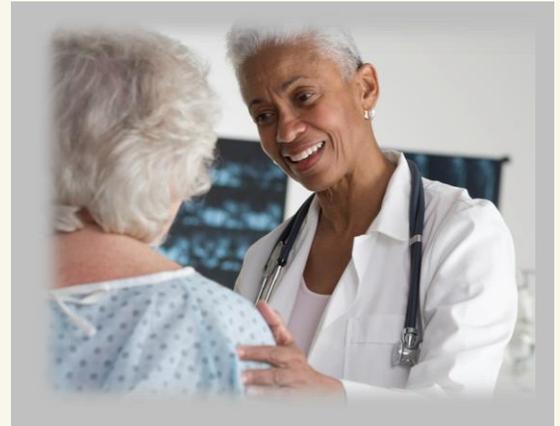
Patients fully understand the time-pressures that busy professionals face in a fast-paced health care system. However, they also see wide variations in how different professionals communicate and manage these pressures. In this report, patients describe some of the ways in which time pressures have made it difficult to obtain the information, guidance and support they need and have compromised their ability to live as well as possible with cancer. On the other hand, they also tell us about skills that some of their clinicians have discovered to ensure that the lines of communication remain as open as necessary, even when time is a challenge.

*“She was extremely busy, but the three minutes she had with you, she was totally focused on you.”*

Thorne, S.E., Hislop, T.G., Armstrong, E.-A. & Oglov, V. (2008). Cancer care communication: The power to harm and the power to heal? *Patient Education and Counseling*, 71, 34-40.

This report documents patients explanations for the mechanisms by which they think communication makes a difference in whether they do well, or do not do well, with cancer. In this analysis, we considered the beliefs and understandings patients had with regard to how communication could facilitate or complicate care coordination, provide or detract from their emotional comfort, enhance or diminish their sense of understanding about what was happening to them, and nourish or destroy a sense of hope.

*“When we have helpful communications it helps us to be in charge and not to be depressed, because I think cancer thrives on stress and depression.”*



**For further information about the Cancer Communication Project, contact the Principal Investigator:**

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**Thank you for your interest in this work!**