



Communicating good care: A qualitative study of what people with urological cancer value in interactions with health care providers



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A B S T R A C T

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Purpose: Communication with health care providers is important to help meet cancer patients' information and support needs. It can significantly affect the extent to which patients feel cared for, respected and involved, and it can influence a range of cancer care processes and outcomes. This paper presents findings from a study which explored urological cancer patients' experiences of care, focussing on insights into what they appeared to value in their interactions with health care providers and why.

Method: In-depth interviews were undertaken with 20 men and 6 women with different types of urological cancer at a range of times since diagnosis. Interviews were audio-recorded, transcribed and thematically analysed using an established interpretive approach.

Results: Patients valued being treated as someone who mattered and was worthy of care; being recognised and responded to as an individual; and experiencing support for autonomy/agency. Reasons for their valuations related to the implications of communicative interactions for the ways patients thought health professionals related to them 'as persons'. Our findings highlight the value of relational aspects of communication for: indicating to patients what clinicians think of their worth; facilitating individualised care; and enabling patients to contribute to their own care.

Conclusions: Efforts to improve health care provider–patient communication should attend not only to the transfer of information about the condition and its management but to the range of features of interactions that can signal to people how health care providers relate to them as persons.

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Introduction

Communication between health care providers and patients is essential for good quality care in several senses. Communication has many facets, can take diverse forms and serve multiple purposes. In the context of cancer care, communication with health care providers can be important to help meet patients' needs for information and other forms of support and can influence a range of cancer care outcomes both positively (e.g. Clayton et al., 2005; Fogarty et al., 1999; Kim et al., 2004; Neumann et al., 2007; Roberts et al., 2005; Schofield et al., 2003; Schneider et al., 2004) and negatively (Thorne et al., 2008), impacting for example on treatment adherence (Roberts et al., 2005; Schneider et al., 2004), patient anxiety and depression (Fogarty et al., 1999; Schofield et al., 2003), and patient satisfaction (Kim et al., 2004). A small but growing body of evidence suggests that communication with

health care providers can significantly affect the extent to which patients feel cared for, respected and involved (Burkitt-Wright et al., 2004; Fosbmdr, 1994; Kruijver et al., 2000; Step et al., 2009; Thom, 2000; Burkitt-Wright et al., 2004). These latter studies can be interpreted as suggesting that patients seem to value communication at least in part because of what it signals about health care providers' attitudes towards them, and thus about the interpersonal aspects of health care provider–patient relationships. They point to the significance of what has been referred to as health professionals 'seeing the person in the patient' (Goodrich and Cornwell, 2008) or treating patients 'as persons' (Entwistle and Watt, 2013). Good communication can therefore be valued both in its own right as a key element of patient-centred health care delivery (Epstein and Street, 2007; Street et al., 2009) and for its contributions to patients' health status and abilities to lead the kinds of lives they want to live (Entwistle et al., 2012). Despite this growing body of evidence, there remains a need to better understand how health care providers can act to facilitate or inhibit effective communication from the perspectives of patients and further research is needed to help focus communication research

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and teaching on what patients themselves value (Rosser and Kasperski, 2001).

Health services struggle to ensure consistently good communication between clinicians and patients, and a need to improve communication between health care providers and people affected by urological cancers has been recognised (National Institute for Clinical Excellence, 2002; Lee and Latini, 2008). The National Institute for Health and Care Excellence (formerly National Institute for Clinical Excellence) emphasised the importance of ensuring that health care providers are “sensitive to potential problems with communication” which can lead to “unintended distress” amongst patients (National Institute for Clinical Excellence, 2002, p. 54 and p.57).

A particular lack of research relating to communication in the context of urological cancers has also been noted (National Institute for Clinical Excellence, 2002; Arora, 2008). Although more studies have been published recently, these relate almost exclusively to prostate cancer, and attend to only a limited number of communication issues, focussing particularly on information needs for treatment decision-making (Sinfield et al., 2009). Urological cancers can raise some particular issues for communication as there are many sensitivities around sexual, urinary and bowel function. It is therefore important that people with these cancers are included in studies of communication.

This paper presents data from a qualitative study conducted among people with a urological cancer as part of an evaluation of a urological cancer care centre established in north-east Scotland in January 2008 (Skea et al., 2011). We examined what patients said about communication to identify what they appeared to value in their interactions with health care providers. We considered why particular aspects of communication mattered to them, and what the implications of these might be.

Methods

Patients were eligible to participate in this study if they had been diagnosed with a urological cancer and treated at the hospital where the Urological Cancer Care (UCAN) centre’s main facilities are located (UCAN Centre, Aberdeen Royal Infirmary, UK). We sought to interview a diverse sample including men and women with different urological cancers.

We used two recruitment strategies. Both required patients to ‘opt in’ by making contact with a researcher. First, hospital staff used a health service database to identify eligible patients diagnosed with a urological cancer between 2007 and 2008. Patients were sent a study information leaflet and an invitation letter explaining that a researcher wanted to hear from patients about issues relating to their care and treatment as well as their views about communication with clinicians. Second, patients who attended a meeting at the urological cancer centre for those who were registered as peer supporters for newly diagnosed patients were informed of the study and asked to indicate their willingness to be contacted by the researcher to take part in an interview.

72 people were approached by hospital staff: 22 volunteered contact details and 19 were interviewed. 14 people volunteered contact details after attending the peer supporter meeting and 7 were interviewed. In purposively sampling from those who volunteered contact details, attempts were made to include both men and women and to ensure people with different cancer types were represented.

The total sample of 26 included 20 men and 6 women, aged from 37 to 80 years, who had been diagnosed with cancers of the prostate (6), bladder (6: 2 female; 4 male), kidney (8: 4 female; 4 male) or testes (6). All were white British and lived in Aberdeen city, Aberdeenshire, Moray or Orkney.

We used telephone interviews to minimise participant burden and to avoid excluding people who lived in remote areas. The study was approved by the North of Scotland Research Ethics Committee. All participants gave written consent before participating in a telephone interview.

At the start of the interviews, participants were encouraged to provide a narrative account of their cancer journey – in other words to tell how they came to discover they had cancer and to discuss what had happened to them since that time. They were then asked about their reactions to their diagnosis, information and support needs (around diagnosis and subsequently), interactions with health professionals, and views about the care they experienced. Interviews lasted 40–80 min and were audio-recorded and transcribed.

Transcripts were analysed thematically using an established interpretive approach (Ritchie and Spencer, 1994). Following initial familiarisation with interview transcripts, the authors developed a thematic coding framework based on discussions about both a priori questions and issues identified as emerging from the interview data. Initial codes (text labels) from this framework (including codes relating to communication with health professionals) were then systematically applied to the transcript data. NVivo 8 text management software was used to mark specific pieces of interview data that were identified as corresponding to the thematic index codes. More generally, NVivo 8 was also used to help organise the data to facilitate further analytic consideration and interpretation.

In the findings below, the individual patients who were the source of particular quotations are identified by pseudonyms.

Results

Everyone who was interviewed mentioned examples of communication with health care staff, including nurses, in their evaluative reflections on the service. Patients often commented positively about communication, although some reflected negatively on specific encounters.

Patients’ reasons for valuing aspects of communication varied, but our analysis of these reasons led us to recognise that they could mostly be understood in terms of communication having implications for the ways patients felt related to as people. We present the study findings under three main themes that are interlinked and can all be associated with the notion of patient- or person- centred care. These are perceptions that health care staff had 1) treated the patient as someone of value in themselves, someone worthy of care; 2) recognised and responded to patients’ individual needs and unique identities; and 3) recognised and supported patients’ autonomy and/or agency. Within each theme, we illustrate the kinds of communicative behaviours or ways of relating that were associated (positively or negatively) with the evaluative perceptions of what health care staff had done or achieved, and how these behaviours had impacted on patients’ experiences.

1). *Being treated as someone who matters and is worthy of care*

Several patients commented positively on situations in which they felt that health care staff interacted with them “as a person” and not simply “a number” (Albert, Bladder cancer), and as a person who was worthy of care rather than as someone staff could not be bothered to help. Their accounts suggest that staff could demonstrate to patients that they mattered and were worth caring for in various ways including, for example, by

- i) Interacting warmly and signalling personal recognition by using and remembering the patient’s name;

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