



Contents lists available at ScienceDirect

## European Journal of Oncology Nursing

journal homepage: [www.elsevier.com/locate/ejon](http://www.elsevier.com/locate/ejon)

## Searching for the new normal: Exploring the role of language and metaphors in becoming a cancer survivor

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### A B S T R A C T

#### Keywords:

Focus group method  
Cancer language  
Metaphor  
Survivor  
Survivorship  
Oncology nursing

**Purpose:** This qualitative exploratory study was grounded in local patient and service user experiences and was designed to investigate how the language and metaphors of cancer influence personal and social adjustment after completion of a course of treatment.

**Methods:** The study employed a focus group design, in which eighteen people, recruited through regional networks and support groups, participated. Meetings elicited participants' stories and focused discussion on key words and common phrases in the cancer lexicon. Data from transcribed focus group recordings were analysed thematically and organised into descriptive categories concerned with the interpretations of common terms and how these influenced the management of identity and emotions.

**Results:** The thematic categories emphasised the importance of language in the way participants managed their illness and sought to control their feelings and their interactions with others. Interpretation of findings revealed a strong central idea linking participants' accounts, which was that language, metaphor and euphemism are central to adjustment and the forging of an altered identity as a survivor of cancer diagnosis and treatment.

**Conclusions:** The findings are consistent with what is already known about the language and metaphors of cancer, with language being an important mechanism for managing uncertainty. From participants' accounts it also appears that there may be subtle but important differences in professional and lay understandings of cancer language and metaphor. This suggests a need for oncology nurses to elaborate their broad understanding of communication skills and move toward a more detailed understanding of the language used during interactions with patients.

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### Introduction

It has long been recognised that effective communication is fundamental to delivering quality healthcare, sustaining personal dignity and supporting patient decision-making and choice (DH, 2003, 2010; Francis, 2013). In the UK National Health Service (NHS) clear and meaningful exchanges between nurses and patients are known to improve patient satisfaction and health outcomes (National Patient Safety Agency, 2006; Macmillan Cancer Support, 2012), however complaints about the NHS often originate from poor communication (Parkinson, 2012). In the current context of UK healthcare services the importance of effective communication between health professionals and patients is

highly topical, largely as a result of serious failures of care within the NHS system which have assumed national prominence and considerable media attention (Flynn and Mercer, 2013; Francis, 2013; Keogh, 2013).

In the delivery of healthcare services nurses have more interpersonal interactions with patients and their families than any other professional group (Cutcliffe and McKenna, 2005; NMC, 2007). This places nurses in a position to positively influence communication exchanges through the use of facilitative language that promotes patient satisfaction and understanding. For nurses working with cancer patients at the various stages of their illness, the need for effective communication is crucially important and there is a substantial body of knowledge around the impact of communication on the patients' experience of cancer care and treatment (Kirklin, 2007; Chapman et al., 2003; Penson et al., 2004).

Research has shown that the comprehensibility of language is central to the way individuals understand and interpret their

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disease, and the provision of appropriate information, conveyed in an acceptable and accessible manner, is known to promote positive well-being and adjustment in the patient (McIlmurray et al., 2001; Corner et al., 2007; Hodgkinson et al., 2007). This is particularly evident during times of transition in the person's disease state such as at the time of cancer diagnosis, recurrence or end-of-life (Stajduhar et al., 2010). It is also known that poor communication is most often associated with the negative outcomes of emotional distress, confusion and fear (Desme et al., 2013; Van Weert et al., 2013).

Oncology nurses are involved throughout the patient's cancer pathway and their role often entails complex discussions on a range of physical, emotional and social issues (Dougherty, 2010). It is recognised that communication in the oncology setting can be particularly challenging, as the nurse has to manage sensitive and emotionally-charged information (Goldsmith et al., 2013). Consequently, oncology nurses are required to develop advanced skills and competence in communicating with patients (Tay et al., 2011), where open and empathic approaches help to reduce the distress of patients and their families when breaking bad news or addressing cancer recurrence or spread.

While there is substantial research in the domain of nurse-patient communication, less is known about how the language, metaphors and euphemisms of cancer impact on the survivorship experiences of patients once their treatment is complete. The growing body of evidence related to cancer survivorship suggests that the way people talk *to* and *about* people affected by cancer may influence their readjustment to everyday life and the quality of their experience as a cancer survivor (Corner et al., 2006; Bellizzi and Blank, 2007). The language used by nurses and other health-care professionals during this period can affect how patients view their identity and sense of self and it has long been recognised that information, supportive social networks and professional aftercare are important in facilitating adjustment (Corner et al., 2007; Hodgkinson et al., 2007). However, recent research has suggested that people still have a high level of unmet need in the transition phase, particularly in relation to psychological and social support needs (Armes et al., 2009). It has also been suggested that the language of cancer can aid individual adjustment in the survivorship period (Rancour, 2008), providing a route through which personal growth and development may be achieved.

The way people talk about cancer is an important part of both understanding the disease and facilitating the healing process (Czechmeister, 1994; Gibbs and Franks, 2002; Reisfield and Wilson, 2004). However, lay language associated with social and media representations of cancer differs from the language patterns and practices of nurses and other health professionals. A study by Rot et al. (2012), found that men with prostate cancer were often unaware of the meanings contained within the vocabulary and terms used by professionals to describe their treatment and its side effects. Similarly Casarett et al. (2010) found that figurative language used to explain diagnostic tests, symptoms and treatment effects can aid understanding and facilitate effective communication, but can also obscure important information and give rise to false hopes and misunderstanding. Other evidence also reinforces the proposition that cancer language and metaphor has potential to induce both positive and negative patient experiences (Chapman et al., 2003; Kirklin, 2007; Penson et al., 2004).

In addition to the professional construction of cancer language, individuals may generate their own language through which to express their feelings and emotions, using particular words and metaphors to define their identity as a person living with cancer. The use of metaphors, imagery and symbolism by patients is commonplace (Harrington, 2012) but their use is a deeply unique and personal experience, shaped by the individuals' disease

situation and their coping style. The use of metaphors has also been explored by Lanceley and Clark (2013), who suggest that figurative language facilitates the expression of feelings and emotions. They describe how the language of cancer is frequently euphemised to reduce the emotional charge of the disease, but at the same time euphemism may encourage emotional expression.

Individuals also use alternative descriptions to distance themselves from distress and as a defence strategy to protect against the threatening nature of cancer, for example through militaristic terminology such as 'battle', 'war' and 'fight', all of which reflect the invasive nature of the disease as something to be actively overcome (Hanne and Hawken, 2007; Kirklin, 2007; Penson et al., 2004).

Our everyday work within the local cancer network, and with patient and family support groups, had indicated to us that whilst communication with nurses and other health professionals was a central aspect of peoples' experiences, the language of cancer was equally important to them. Listening to patients' stories led to us convene a meeting with patients to see if they would be interested in pursuing research in this area. This meeting generated a heated discussion about the language of cancer once active treatment had been concluded. In this context the study being reported here was stimulated by these ideas. The cancer survivors were interested to explore whether the common words and phrases used in talking about cancer, which had affected them, had a similar impact on other people who had completed a course of cancer treatment.

## Aims

In this context, the aim of this exploratory study was to gain an insight into how survivors experience the common language and metaphor of cancer.

It was expected that the study findings would indicate whether further investigation in this area would be worthwhile and so inform the direction and design of a larger study to facilitate enhancement of the quality of services delivered to patients.

## Design

A qualitative design using focus group discussions to collect data was employed to gain insights into how individuals interpreted and assigned meaning to cancer language, and what influence this had on their survivor experience. This approach allowed the researchers to gain first-hand accounts of the participants' world and to understand the meanings they attached to linguistic interactions with nurses and other health professionals (Sagoe, 2013).

## Sample

Study participants were drawn from across the three regional cancer networks in the Northwest of England. A purposive sample of people, whose course of active treatment for cancer had ended, was recruited through the regional cancer networks, local support groups, and the Trust's Patient Council.

A recruitment advertisement and participant information sheet were circulated electronically by the local cancer network office and potential participants were offered four dates, at different community venues, across the network localities, where focus group meetings would be held. Interested volunteers were asked to contact the researchers by phone or email to 'sign up' to attend one of the meetings. The recruitment advertisement also provided the researchers contact details for anyone requiring further information.

A total of eighteen people participated in the focus groups: seven men and eleven women, aged between 45 and 85 years, who had been treated for a diverse range of cancers. As it was not

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