



## From an illusion of certainty into a reality of uncertainty: A longitudinal qualitative study of how people affected by laryngeal cancer use information over time



Anne Taylor <sup>a,\*</sup>, M. Wells <sup>b</sup>, G. Hubbard <sup>c</sup>, A. Worth <sup>d</sup>

<sup>a</sup> School of Health Science, University of Stirling, Stirling, FK9 4LA, UK

<sup>b</sup> NMHAP Research Unit, School of Health Sciences, University of Stirling, Stirling, FK9 4LA, UK

<sup>c</sup> Cancer Care Research Centre, School of Health Sciences, University of Stirling, Highland Campus, Centre for Health Science, Old Perth Road, Inverness, IV2 3JH, UK

<sup>d</sup> Wellcome Trust Clinical Research Facility Western General Hospital, Crewe Road, South Edinburgh, EH4 2XU, UK

### ARTICLE INFO

#### Article history:

Received 30 October 2014

Received in revised form

4 March 2016

Accepted 9 March 2016

#### Keywords:

Laryngeal cancer

Information

Patient and carer experience

Qualitative methods

Uncertainty

### ABSTRACT

**Purpose:** Patients diagnosed with laryngeal cancer and their families face unique challenges. Providing information is an essential component of care. However little is known about the way in which they use information. This study aims to explore the different types of information used by laryngeal cancer patients and their carers from diagnosis into the follow up phase.

**Method:** The study adopted an interpretive longitudinal design using qualitative interviews at two specific time points. Twenty laryngeal cancer patients and 17 carers were interviewed. Data were analysed using Framework Analysis.

**Result:** Two main categories of information: professional and experiential, were found to be used, drawn from a range of sources. The information received at diagnosis appeared to contribute to an 'illusion of certainty' that life would return to normal at the end of treatment. However, as patients progressed into follow-up, many were propelled into a 'reality of uncertainty' due to the "disconnect" between the expectations both patient and carer developed from information received over the cancer trajectory.

**Conclusion:** The findings from this longitudinal study suggest that people affected by laryngeal cancer use two broad categories of information derived from a range of different sources and influenced by their own experiences. Health professionals need to situate information in the context of the individual's understanding and prior knowledge of health and illness to help generate more realistic expectations of treatment outcomes. The level of uncertainty experienced by both patients and their carers after treatment suggests a clear need for continued supportive care.

© 2016 Elsevier Ltd. All rights reserved.

## 1. Introduction

National and international policy initiatives are influencing major changes in an attempt to reduce the burden of cancer and provide the best cancer care to patients and their family members (DOH, 2011a; WHO: *The European health report: Charting the way to well-being*, 2012; Lawler et al., 2014). These initiatives aim to provide better communication across all sectors of health services to improve care pathways for patients, carers and their families (DOH, 2011a; *Better Cancer Care, An Action Plan*, 2008). A central

tenet of UK government policy such as Liberating the NHS: An Information Revolution (DOH, 2011b) and Improving Outcomes: A strategy for cancer (DOH, 2011a) is that: "people should have access to accurate, high quality, comprehensive information delivered in the way they want; have their personal information needs considered and discussed at every contact with health professionals" (DOH, 2004). In Europe, a recent initiative aimed at reducing the disparities in cancer health care across European countries identified access to information and support and patient-orientated cancer education as key areas on which to focus (Lawler et al., 2014).

The provision of tailored information is widely regarded as essential to an individual's understanding of what is happening and to his or her involvement in treatment and care decisions (Shea-

\* Corresponding author.

E-mail address: [a.d.taylor@stir.ac.uk](mailto:a.d.taylor@stir.ac.uk) (A. Taylor).

Budgell et al., 2014). There is now a wealth of evidence to support the broad categories of information needed by people who are affected by cancer, around diagnosis and treatment (Shea-Budgell et al., 2014; Ankem 2006; Rutten et al., 2005 & Adams et al., 2009). However, this body of evidence primarily focuses on the information needs of people affected by more common types of cancers such as breast, colorectal and prostate, whilst people affected with laryngeal cancer could be viewed as a “poor relation” due to the research attention paid to them.

Laryngeal cancer is one of a group of cancers associated with the head and neck. Globally head and neck cancers represent the sixth most common cancer, with Scotland having one of the highest prevalence rates in Europe (Rapidis and Scully, 2009; Cognetti et al., 2008). Within the UK 7000 people are diagnosed with a form of head and neck cancer each year (Health and Social Care Information Centre, 2012) and in Scotland, cancers of the head and neck account for 6.1% and 2.7% of male and female cancers respectively (NHS Scotland, 2014). Cancer of the larynx is predominantly a cancer of older males with a median age of sixty years (Cognetti et al., 2008). The male to female ratio in the UK is approximately 4.5:1 (Lee et al., 2010) with an increase in the incidence of European females noted (Eurostat, 2011; Office for National Statistics, 2008). Recent Scottish figures highlight how incidence and mortality increase steadily in accordance with social deprivation, with the most deprived patients having the greatest incidence of laryngeal cancer combined with the poorest prognosis (ISD Scotland, 2010).

Laryngeal cancer is often a highly visible disease where patients face unique difficulties with disfigurement, changes to body image and sexuality, and impairment to social functions such as eating, drinking, and speech due to the side effects of radical treatments such as radiotherapy, surgery, and chemotherapy (Machtay et al., 2008; Penner 2009). The effects of these treatments have also been shown to impact negatively on carer's quality of life due to the associated burden of care and the complex challenges they experience, with a lack of information provision contributing to an increase in their psychological distress (Rogers et al., 2006; Baghi et al., 2007; Verdonck-de Leeuw et al., 2007). Since the first major report exploring the impact of head and neck cancer (Edwards, 1998), studies have continued to report how patients receive insufficient information beyond the treatment phase on the overall physical and psychological impact of their treatment (Pollock et al., 2008; Ziegler et al., 2004; Newell et al., 2004; Birchall et al., 2002). Many patients report experiencing unmet needs in the post treatment phase leading to feelings of uncertainty and loss (Lang et al., 2013; Newell et al., 2004) with Llewellyn et al. (2005) suggesting that the vulnerability patients experience during this time could be explained by the information they receive in the pre-treatment phase leading to the development of unrealistic expectations. Influential studies by Wells (1998) and Semple et al. (2008), identified that one of the most vulnerable periods in the cancer trajectory is the initial post-treatment period, when both patients and carers have little support from the specialist multi-professional team with a lack of information upon which to draw (Pollock et al., 2008).

Improvements in cancer outcomes and survival rates (Lawler et al., 2014; NHS Scotland, 2014) mean that an increasing number of people are living with laryngeal cancer, and managing a range of social, physical, and psychological difficulties within an experience of uncertainty (Lang et al., 2013). Snapshots of the types of information this group of patients want and need have been provided from concurrent and/or retrospective accounts (Pollock et al., 2008; Ziegler et al., 2004; Newell et al., 2004) with few qualitative studies exploring the information and supportive care needs of carers (Adams et al., 2009; Rogers et al., 2006). It is clear from the evidence that many patients and their family members are ill

informed and unprepared for the period beyond their treatment (Beaver et al., 2010; Pollock et al., 2008; Wells, 1998; Edwards, 1998). There is a dearth of longitudinal research into the experiences of patients and carers affected by laryngeal cancer, with few studies exploring whether the types of information received in the pre-treatment phase influence the post treatment phase, as suggested by Llewellyn et al. (2005). This study therefore aimed to explore the different types and sources of information used by laryngeal cancer patients and their carers from diagnosis into follow up.

## 2. Methods

### 2.1. Design

A longitudinal qualitative study was designed to recruit from four clinical sites based in the West of Scotland. A longitudinal design was adopted to capture the impact, consequences and outcomes that would occur from diagnosis into follow up (Murray and Sheikh, 2006) rather than capturing these changes at one specific time point. Semi structured interviews were conducted at two specific time points, and an interpretive descriptive approach, using framework analysis, was used as the method for data analysis (Ritchie and Lewis, 1994).

### 2.2. Participants

People with a new diagnosis of laryngeal cancer were approached to participate in the study. Criterion sampling was adopted, with the main criteria being the stage of tumour (Stage I to Stage IV). As the stage of tumour dictates the treatment pathway, it was felt that different types of information would be used by people diagnosed with different stages of disease. In order to gather a wide range of experiences, efforts were also made to include patients of different ages and gender. Potential participants (patients and their main carers) were identified and recruited from head and neck oncology clinics by the clinical nurse specialists (CNS). Interested participants were informed about the study and asked permission for their contact details to be passed to the main researcher (AT). Willing participants were contacted after 48 h and the study discussed in more depth. For those participants who agreed to participate, a suitable date and time was arranged for the first interview to take place. All interviews were audio recorded and transcribed verbatim.

A total of 20 patients (15 male & 5 female) and 17 carers (11 wives, 2 husbands, 3 daughters and one brother) agreed to participate in the study. Of the 20 patients, 10 were diagnosed with early stage disease, for example T1N0 or T2N0 and 10 were diagnosed with advanced disease (3 with recurrent) for example T3palsy; T3NOMO & T4N2 according to the TNM staging criteria. Treatment pathways were laser surgery (n = 1), radiotherapy (n = 7), chemo-radiation (n = 4) and laryngectomy (n = 8). Participants ranged from 42 years–81 years old and were from a range of socio-demographic areas in the West of Scotland as reflected by their occupations, including factory worker, lorry driver, sales director, retired legal consultant. No participants withdrew over the course of the study, but two participants died during the follow-up phase, with one bereaved carer agreeing to the 2nd interview.

### 2.3. Data collection

Semi-structured interviews took place in patients' homes on two occasions, between September 2007 and May 2009. All interviews were conducted by the first author, who was unknown to the participants and not involved in their care. The first interview

Download English Version:

<https://daneshyari.com/en/article/5868631>

Download Persian Version:

<https://daneshyari.com/article/5868631>

[Daneshyari.com](https://daneshyari.com)