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Understanding the impact of chemotherapy on dignity for older people and their partners

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ABSTRACT

Purpose: Chemotherapy poses challenges for older patients, with potential comorbidities, mobility and functional problems that may adversely affect their dignity. Patients may struggle with side-effects but fail to inform health professionals, impacting on clinical management and unresolved needs/concerns. This study aims to explore the impact of dignity during chemotherapy for older people and partners.

Methods: A qualitative study using semi-structured interviews of patients/partners following chemotherapy for non-metastatic cancer. Interviews were audio-recorded, transcribed and analysed using qualitative principles/thematic analysis.

Results: Twenty patients, aged 65–81, and 10 partners were recruited. 19/20 patients had adjuvant chemotherapy and one neoadjuvant treatment; 12(60%) had breast cancer and 8(40%) colorectal cancer. Four out of 20(20%) patients failed to complete the full course of chemotherapy and 5(25%) had unplanned hospital admissions. Patients/partners reported positive experiences regarding dignity and compassionate care during chemotherapy. Five main themes were associated with dignity: managing chemotherapy side-effects, personal feelings, maintaining independence, stoicism, and 'being lucky'. Although support from family/friends was high, most patients wanted to maintain their independence and did not want to become a burden. In some cases, patients struggled with chemotherapy toxicities yet often failed to inform clinical staff and played down the severity of adverse effects. This reflected their stoicism, coping strategies and motivations to 'just get on with it'.

Conclusions: Dignity is associated with maintaining independence and stoicism in coping with the impact of chemotherapy. However, some patients failed to report severe adverse effects, which has implications for clinical staff managing their care.

1. Introduction

The incidence of cancer in the UK is 1:2 (CRUK, 2015), however cancer is more common in older people, with more than 3 out of 5 cancers diagnosed in people > 65 years (CRUK, 2012). A rise in the incidence of cancer has resulted in increased demand for chemotherapy (DH 2015), however the lack of research on chemotherapy for older people poses challenges for clinical decision-making (Burdette-Radoux and Muss, 2006). Older people may have multiple comorbidities, polypharmacy issues (Hamaker et al., 2014), functional problems (Versteeg et al., 2014), cognitive impairment or difficult social circumstances, which means they may struggle with the side-effects of chemotherapy (Versteeg et al., 2014; Hurria et al., 2011; Wan-Chow-Wah et al., 2011). The number, nature and severity of comorbidities may also influence treatment toxicities (EBCTCG, 1998; Read et al., 2004) and can predict survival irrespective of cancer stage (Satariano and Ragland, 1994; Irisa et al., 2012).

The incidence of dementia is increasing rapidly, currently affecting 20% of people > 80 years (NICE, 2006). Nelson et al. (2007) identified that 39% of patients > 65 on chemotherapy had reduced cognitive function (Fitzpatrick et al., 2012), affecting memory and quality of life; however cognitive impairment may be subtle and often overlooked (Young et al., 2011).

Studies of older people on chemotherapy have identified increased toxicities from treatment (Kimmick et al., 1997; Wildes et al., 2013; Versteeg et al., 2014) and identify predictive risk factors including performance status (Wildes et al., 2013), comorbidities (Wildes et al., 2013; Tong et al., 2014; Versteeg et al., 2014), cognitive impairment, and nutrition scores (Extermann et al., 2012; Versteeg et al., 2014; Soubeyran et al., 2012). This highlights a need for careful monitoring during treatment; however, chemotherapy is mainly given in outpatient settings where there is little proactive monitoring of impact and

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chemotherapy side-effects. Since most toxicities occur after treatment administration whilst patients are at home, this places responsibility on patients and their partners to self-manage and telephone clinicians if side-effects, for example fever, severe diarrhoea, emesis or mucositis, become severe (Oakley et al., 2016). There is some evidence that patients delay reporting life-threatening side-effects (Malik et al., 2001; NCEPOD, 2008; McKenzie et al., 2011) leading to late identification (NICE, 2012), poor experience, prolonged hospitalisation, and possibly even premature death (NCEPOD, 2008). Studies have indicated that older people are less likely to contact health professionals during chemotherapy, with frailty being considered a key factor for delaying symptom reporting (Malik et al., 2001). For older people, minor changes in medication or health can result in substantial functional deterioration (Schumacher, 2005); this is also a significant risk factor for depression (Zeiss et al., 1996). The incidence of major depression doubles to 30% in people > 70 years (Alexopoulos, 2005) with a cancer diagnosis further increasing this risk. Monitoring psychological distress in this group is therefore vitally important. Patient experience surveys indicate that patients' needs are not adequately addressed during chemotherapy and older people are less likely than younger people to be given the name of a specialist nurse (Macmillan Cancer Support, 2015). Farrell et al. (2005) also identified that patients' concerns are poorly assessed by nurses during chemotherapy meaning many psychological, emotional and practical issues were not addressed. Despite this currently there is no specific evidence about the concerns and needs of older people's during chemotherapy or how this relates to their dignity during treatment.

The value of dignity is widely recognised in healthcare. However, Chochinov (2007) describes how people have to relinquish some of their autonomy to become a patient, which can adversely affect their sense of who they are as a person. This self-perception links closely with patients' dignity (Chochinov 2007). In one study focusing on patients with terminal cancer, dignity was strongly associated with "being treated with respect" and "feeling a burden to others"; the patient's perception of dignity was increased when health professionals valued the patient as a person rather than just their illness (Chochinov et al., 2006). When this 'affirmation of personhood' is achieved by health professionals and connects with a patient's self-perception, Chochinov (2002) considers that this forms the basis of 'dignity conserving care'. In contrast, when affirmation of patients' personhood is not achieved they are less likely to perceive they are being treated with dignity and respect (Wilson et al., 2005), which can undermine their perceived sense of worth or value (Chochinov et al., 2002) and exacerbate feelings of becoming a burden to others (Chochinov 2007).

Chochinov (2007) describes four key factors within dignity conserving care (A,B,C,D): attitudes, behaviours (based on kindness and respect), compassion (and empathy), dialogue (communication; acknowledging personhood and recognising the emotional impact of illness). For older people, maintaining independence is important to maintain dignity (Jacelon, 2003); other studies have also identified the importance of privacy and communication (Webster and Bryan, 2009).

Despite increasing literature on dignity within health care there remains a lack of consensus regarding what dignity means (Pringle et al., 2015), although there is a growing awareness of factors that may promote or undermine dignity (Barclay, 2016). However, studies around dignity were mainly conducted within palliative care and residential care homes. Barclay (2016 p137) suggests that the concept of dignity is multifaceted however within health care settings this relies on the patient being able to "live in accordance with his or her standards and values".

2. Aims and research questions

The aim of this study was to understand the impact of chemotherapy on older people and explore the concept of dignity for older people and their partners. This study is part of a larger project on the impact of chemotherapy on patients with cancer over 65 years.

Table 1
Patient inclusion criteria.

	Inclusion criteria	Exclusion criteria
Age	≥65 years	< 65 years
Cancer group	Breast, colorectal, lung, urology, gynaecology, lymphoma, leukaemia	Brain
Disease status	Non-metastatic	Metastatic cancer
Chemotherapy	Any regimen	Palliative chemotherapy No chemotherapy
Radiotherapy	Radical radiotherapy No radiotherapy	Palliative radiotherapy

3. Methods

3.1. Sample and setting

Ethical approval was obtained from the North West Regional Ethics Committee (13/NW/0759) alongside approval from local Research and Development (13_PSCP_18).

The study was undertaken at a regional cancer centre in North West England serving a population of 2.8M. This was a purposive sample of patients ≥65 years who had chemotherapy within the previous twelve months and met the inclusion criteria (Table 1). Potential patients were identified by clinicians, given written information about the study and referred to the research team. Patients had ≥24 h to consider participation before being contacted by a researcher; partners were also invited to participate in a joint interview with the patient. Participants were interviewed once; interviews were conducted in the home at a convenient time and date. Written informed consent was obtained prior to interview. Participants were informed that their participation in the study was voluntary and they could stop the interview at any time without giving a reason.

3.2. Data collection and analysis

We used qualitative descriptive methods (Sandelowski, 2000) to explore participants' views in depth. Interviews were inductive and used a semi-structured approach based on a series of open questions to explore participants' experiences during chemotherapy and to detail their perceptions of dignity. The interview guide included a short list of topic areas supported by cues and prompts for each open question/topic to encourage participants to recall their experiences and identify their concerns, needs and priorities during chemotherapy to enable the researcher to understand the impact of chemotherapy for each person.

The interview began with an open question: "*How did you get on with your chemotherapy?*", which the researcher explored in greater depth using prompts and further open questions to cover a range of different aspects, including physical, psychological, functional, and social issues. The concept of dignity was explored in a similar way, starting with an open question: "*People can interpret dignity in different ways, what does dignity mean for you?*" Patients and their partners were interviewed as dyads; although initial questions were directed at the patient, partners were invited to contribute their experiences throughout as each topic area was explored. Partners were also asked direct questions, for example: "*What effect did the chemotherapy treatment have on you?", "How did you feel during all this?"*

Interviews lasted 30–45 min, were audio-recorded using a Dictaphone, and transcribed verbatim.

We conducted thematic analysis to identify themes and categories within the data, considering their relationship with each other and also to the core concept of dignity (Braun and Clarke, 2006). We also used a framework approach within the analysis, since this provides a