



# Identity and home: Understanding the experience of people with advanced cancer



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## ABSTRACT

The purpose of this study was to explore how the identity of people with advanced cancer is influenced by their experiences of living at home. A total of 28 in-depth interviews were conducted with 22 people with advanced cancer and four spouses. Grounded theory guided the collection and analysis of data. Home tours and associated field notes augmented the interview data. The analysis revealed that support of participants' identity was reflected in their abilities to live and occupy the home during daily activities, and in the ways the home and objects functioned as referents to themselves and their past. Threats to their identity ensued as the home environment became unmanageable during daily activities and as homecare professionals and assistive devices entered the home. By supporting people with advanced cancer in maintaining daily activities in the home and reducing changes in the home caused by homecare it is possible to reduce loss of identity.

## 1. Introduction

Governments in a number of European countries and other Western countries are increasingly shifting the provision of healthcare for people with advanced cancer from institutional settings to the home (Boeckxstaens and De Graaf, 2011; Danish Government, 2016; Williams, 2002; Wilson et al., 2014). Fortunately, this drive towards homecare aligns with the wishes of people with advanced cancer to live at home (Boeckxstaens and De Graaf, 2011; Gomes et al., 2013; Neergaard et al., 2011). We define advanced cancer in this study as a stage of cancer where it is progressive and presumed incurable (The American Cancer Society, 2014).

Research has made it evident that the home plays an important part in how a person forms his or her identity and that home may even support reconciliation and continuity in identity during times of illness (Korpela, 1989; Manzo, 2003; Molony, 2010; Proshansky et al., 1983; Rowles and Chaudhury, 2005). However, while identity and home have received considerable attention among different population groups, such as older people (Dahlin-Ivanoff et al., 2007; Haak et al., 2007; Rowles and Chaudhury, 2005; Tanner et al., 2008), to our knowledge, no prior studies have explicitly explored the intersection between identity and home among people with advanced cancer. Nonetheless, it is important to specifically address the challenges of living at home

with advanced cancer, such as the debilitating loss of abilities, increased dependency on others, biographical disruption, and the prospects of impending death (Osse et al., 2005; Peoples et al., 2017; Reeve et al., 2010). Even more importantly, studies of people at the end of life have indicated that a person's sense of identity and relationship with home can assume heightened and new meanings as illness progresses and as death draws near (Carlander et al., 2011; Lala and Kinsella, 2011; Morgan, 2012; Morgan et al., 2015; Raunkiær, 2007). With the purpose of exploring how the identity of people with advanced cancer is influenced by their experiences of living at home in the face of such challenges, this study responds to the call for knowledge to support healthcare of dying people (Collier et al., 2015).

## 2. Background

Sixsmith's (1986) tripartite conceptualization of home as "physical", "social", and "personal" provides a generic basis from which we can comprehend how home and identity are shaped by daily life with a life-threatening illness. The "physical home" comprises the spatial layout of the home and arrangements of furniture which, in a dynamic interplay with inhabitants, structures and channels how daily life can unfold and supports how daily activities can be performed (Angus et al., 2005; Rubinstein and de Medeiros, 2005; Sixsmith, 1986).

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However, as illness impedes physical or mental abilities, daily routines in the home may need to be reworked (Meijering et al., 2016). The loss of abilities to maintain daily activities can force people with advanced cancer to question and revise even the most prevailing ways of thinking about themselves (Carlander et al., 2013; Devik et al., 2013; Morgan et al., 2015; Payne, 2009). The “social home” has at least two core functions. First, it provides an arena of social exchange and opportunities for maintenance of relationships with family and friends (Oswald and Wahl, 2005; Sixsmith, 1986). Research has found that to people at the end of life, the feeling of ‘being at home’ is not only bound to a specific physical place, but also to the function of place that allows for engaging in home-like daily activities and socializing with loved ones (Broom and Cavenagh, 2011; Collier et al., 2015; Rigby et al., 2010). Second, the home may serve as a “social boundary”, that shields inhabitants from outsiders (Graham, 1989). With the prerogative of homecare professionals to enter the home and utilize it as a workspace, the social boundaries protecting the privacy of the home become malleable. Homecare of people with advanced cancer includes a range of various services, such as housecleaning, grocery shopping, wound care, medication, and psychosocial support (WHO, 2014). Undoubtedly, homecare professionals seek to deliver high quality services to support independent living in ways that do not infringe on daily life and on the meaning of home. Nevertheless, the blurring of boundaries between private and medical spaces may compromise the meaning that the home has to the identity of those living there by engendering connotations of disability and illness (Angus et al., 2005; Aplin et al., 2015; Appelin and Berterö, 2004; Dyck et al., 2005; MacArtney et al., 2016; Milligan, 2000). Twigg (1999) has argued that the delivery of homecare represents an encounter in which identities and power struggles of the home and the body (to be cared for) are contested and negotiated. In the case of one man who received palliative homecare, Dyck and O’Brien (2003) have shown that meanings of identity and home became fluid and took on new forms as the home environment became the main place of both socializing and care. As a “personal” place, the home and its objects, such as furniture and collectables, can be central signifiers of privacy and biographical meaning and roles within social networks, and thereby symbolic sources of identity (Dyck et al., 2005; Rubinstein, 1989; Sherman and Dacher, 2005; Twigg, 1999). When personalizing the immediate environment with objects of value, people at the end of life can derive a sense of security and autonomy (Rigby et al., 2010). By handling and using objects, memories associated with these objects become tangible and present (Otto, 2005; Rubinstein, 1987). However, the delivery of homecare may diminish the aesthetics of the home by the rearrangement of furniture and introduction of assistive devices or hospital equipment (Angus et al., 2005). For instance, a hospital bed introduced into the home can diminish the recognizability of the home and be perceived as a symbol of deteriorating health (Bowden and Bliss, 2008).

### 2.1. Theoretical perspective

In order to focus on the aspects of identity of people with advanced cancer that are connected to their experiences of living at home, we draw on the work of Breakwell (1986) as well as Twigger-Ross et al. (2003), Twigger-Ross and Uzzell (1996). According to Breakwell (1986), a person's identity is closely tied to how the person perceives him- or herself as formed through relationships and interactions over time (Breakwell, 1986). In explaining the processes underpinning the formation of identity through relationships with places, Twigger-Ross et al., (2003), Twigger-Ross and Uzzell (1996) have usefully extended Breakwell's (1992, 1986) identity theory. At the core of their framework, Twigger-Ross and Uzzell (1996) propose that four processes (distinctiveness, continuity, self-esteem, and self-efficacy) guide the formation of identity through relationships with places. Distinctiveness refers to a sense of being different and distinct from other people

(Twigger-Ross and Uzzell, 1996). Continuity describes the experience of sameness over time. Self-esteem and self-efficacy concern the subjective emotional sense of self-worth and ability. These processes represent modalities desirable for identity development, which people seek to attain or maintain through their place relationships (Breakwell, 1986; Twigger-Ross and Uzzell, 1996). Threats to identity occur if one or several of the identity processes become unmaintainable. Twigger-Ross and Uzzell's framework is not specific to the home. However, the four identity processes are general to the relationships people have with places and are therefore relevant to understanding relationships people with advanced cancer have with their home.

Taken together, with the drive towards home-based care and the expectation that people with advanced cancer should remain at home for as long as possible, we need to know more about the subjective consequences of the entwining of daily life and care in the home (Wilson et al., 2014). Accordingly, the purpose of this inquiry was to explore how the identity of people with advanced cancer is influenced by their experiences of living at home.

### 3. Materials and methods

To address the particular focus on identity-home relationships as dynamic and always being in a process of becoming, we used a constructivist grounded theory approach. Constructivist grounded theory is well-suited for providing explanations about how identity and self-perceptions are negotiated and formed in response to context through action and interaction in daily life (Bryant and Charmaz, 2014; Charmaz, 2016, 2005).

#### 3.1. Recruitment and sampling

We worked with nurses employed in homecare to recruit participants. Those nurses worked in different types of settings: a center for cancer and health, community care teams, a palliative hospital homecare team, and a hospice palliative homecare team. The nurses presented eligible participants with oral and written information about the study. If eligible participants agreed to participate, the first author was provided with their information (age, diagnosis, marital status, frequency of homecare, type of home). Eligible participants were then contacted via phone by the first author and enrolled into the study.

Participants were initially recruited using the following inclusion criteria: 18 years or older, living at home, receiving homecare, and identified (by nurses, doctors, and/or themselves) as having advanced cancer. People living in hospices or nursing homes were excluded. In keeping with constructivist grounded theory principles, sampling continued but was informed by preliminary findings from the analysis of incoming data and emerging analytical ideas from early participants (Charmaz, 2014). For instance, preliminary findings indicated that participants constricted their daily activities to manageable areas of their home. Therefore, we modified recruitment to maximize variation of eligible participants by different home types (apartments, one- and two-story houses).

A total of twenty-two people with advanced cancer and four spouses were enrolled in the study. The spouses asked to participate in order to provide their partners emotional support. The participants with advanced cancer and the spouses who wanted to participate gave written consent. The study was granted permission by the Danish Data Protection Agency (J.nr. 2013-41-1740) and conformed with national guidelines for ethical conduct in research<sup>1</sup> (The National Committee on Health Research Ethics, 2017). Table 1 presents an overview of the

<sup>1</sup> In Denmark, where this study was conducted, only research that entail biological sampling, testing of pharmacological and hospital equipment on human subjects need permission from regional or national ethics committees. Therefore, we did not need ethical approval for the inclusion of the participants with advanced cancer or their spouses.

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