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Occupational Engagement and Quality of Life for People Living at Home with Advanced Cancer

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Thesis for doctoral degree (PhD)
Research Unit of General Practice
Institute of Public Health
University of Southern Denmark
2017
Occupational Engagement and Quality of Life for People with Advanced Cancer who live at home

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In loving memory of my father who passed away during the first year of my PhD,
and to loved ones who lived and died of cancer
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Paper I: Managing occupations in everyday life for people with advanced cancer living at home.
Paper II: Perceptions of quality of life by people with advanced cancer who live at home.
Paper III: Belonging and quality of life as perceived by people with advanced cancer who live at home.
ABSTRACTS

English abstract

**Background:** Worldwide the number of people living with advanced cancer is growing, and due to improved cancer treatment, people are able to live for extended periods with advanced cancer. Cancer at an advanced stage can have a profound influence on the lives of those affected and may lead to reduced quality of life. A consequence may be that death becomes a present factor, influencing possible hopes and dreams the individual might have.

This research project and its studies are framed within the larger ‘Activity, Cancer and Quality of life at Home Project, which employed different research methods to describe and explore occupational needs, and to gain insight to subjective experiences of complex situations of individuals. The overall objective of the research in this dissertation was to enhance the understanding of occupational engagement and perceived quality of life for people with advanced cancer who live at home. The project is based on a qualitative descriptive and explorative design employing different qualitative methods, and consists of the following three studies:

**Study I:** The aim was to describe and explore how people with advanced cancer manage occupations in their everyday lives. Semi-structured interviews and content analysis were employed. Seventy-three participants took part in this study.

**Findings:** The findings suggest that people with advanced cancer experience occupational difficulties. The participants developed strategies to compensate for these difficulties; however some strategies proved to be counterproductive, since they took time and energy from more personally meaningful occupations, which influenced the participants’ quality of life.
Study II: The aim was to explore how people with advanced cancer perceive quality of life. Semi-structured interviews and a thematic approach were used. Ten participants took part in this study.

Findings: The findings suggest that people with advanced cancer perceive quality of life as closely related to being able to maintain continuity while adjusting to experience of loss and discontinuity in daily life at home. The findings also indicate that quality of life was associated with belonging for people with advanced cancer.

Study III: By drawing on empirical findings and the theoretical concept of belonging, the aim was to gain a deeper understanding of the ways in which belonging is perceived as an aspect of quality of life by people with advanced cancer who live at home. Nine participants took part in this study using a combination of semi-structured interviews and photo-elicitation. Data from 18 interviews and 77 photographs were analyzed thematically, drawing on four dimensions of belonging.

Findings: The findings suggest that maintaining a sense of belonging was associated with quality of life and was identified as a complex and challenging process when living with advanced cancer. The data support the theoretical dimensions of belonging described in occupational science and contribute with knowledge about artefacts as mediators of belonging.

Dansk resumé (Danish abstract)
Antallet af personer som lever med en fremskreden kræftsygdom er stigende på verdensplan og på grund af forbedret behandlingsmuligheder er det nu muligt at leve i længere tid med en fremskreden kræftsygdom. At leve med fremskreden kræft kan have en afgørende indvirkning på hverdagslivet og kan medføre forringet livskvalitet. En konsekvens kan være en øget bevidsthed
om døden, hvilket kan indvirke på de drømme og planer som en person kan have lagt for sit nuværende og fremtidige liv.

Dette PhD projekt er en del af et større ergoterapeutisk forskningsprojekt: ‘Aktivitet, kræft og livskvalitet i eget hjem’, som benyttede en bred vifte af forskningsmetoder til at beskrive og udforske aktivitets behov og subjektive erfaringer. Det overordnede formål med PhD projektet er at opnå en øget forståelse af aktivitetsdeltagelse og oplevelse af livskvalitet for personer som lever i eget hjem med en fremskreden kræftsygdom. Projektet har et deskriptivt og explorativt design der anvender forskellige kvalitative metoder og som består af tre studier med tilhørende delmål:

Studie I: Målet var at beskrive og udforske hvordan personer med en fremskreden kræftsygdom klarer aktiviteter i deres hverdagsliv. Semi-strukturerede interviews blev benyttet. 73 personer deltog.

**Resultater:** Resultaterne peger på at personer med fremskreden kræft oplever aktivitetsproblemer. Deltagerne udviklede strategier for at kompensere for aktivitetsproblemer, men nogle af disse strategier viste sig at være kontraproduktive, da de tog tid og energi fra mere personlige og meningsfulde aktiviteter, hvilket indvirkede på deltagernes livskvalitet.

**Studie II:** Målet var at udforske hvad livskvalitet betyder for personer med fremskreden kræft.

Semi-strukturerede interviews og foto-elicitation blev benyttet. Ti personer deltog i studiet.

**Resultater:** Resultaterne peger på at personer med fremskreden kræft, oplever livskvalitet som forbundet med kontinuitet i hverdagen, mens de fortløbende må foretage tilpasninger i relation til de forandringer og tab de oplever i hverdagen. Resultaterne pegede endvidere på at tilhørserforhold til andre indvirker på oplevelsen af livskvalitet.
**Studie III:** Målet var at opnå en dybere forståelse af oplevelsen af livskvalitet for personer med fremskreden kræft, ved at trække på empirisk og teoretisk viden om begrebet ‘belonging’. Ni personer deltog i dette studie som benyttede semi-strukturerede interview og foto-elicitation.

Data fra 18 interviews og 77 fotografier blev tematisk analyseret, ved at trække på fire dimensioner af ‘belonging’.

**Resultater:** Resultaterne peger på at muligheden for at fastholde tilhørsforhold var relateret til oplevelse af livskvalitet, og at fastholdelse af livskvalitet kan være en udfordrende og kompleks proces når livet nærmer sig sin afslutning. Resultaterne understøtter nuværende teoretisk viden om ‘belonging’ indenfor aktivitetsvidenskabelig og bidrager med viden om at genstande kan fungere som middel til at opnå tilhørsforhold.
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This dissertation is the result of three exciting, challenging and hard years and many people have provided their support, knowledge and inspiration along the way.

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To my wonderful Danish and American family and friends; thank you for your love and for always being there for me and cheering me on.

Last but not least, to Jaz, Sophie and Chris, I can safely say that I could not have done this without your constant love and support - you are the most important part of my life and truly the foundation of my quality of life!
Before I was diagnosed with esophageal cancer, I rather jauntily told the readers of my memoirs that when faced with extinction I wanted to be fully conscious and awake, in order to “do” death in the active and not the passive way. And I do, still, try to nurture that little flame of curiosity and defiance: willing to play out the string to the end and wishing to be spared nothing that properly belongs to a life span (Hitchens, 2012, p. 73).

INTRODUCTION

The introductory quote above is from Christopher Hitchens’ (1949-2011) book Mortality, in which he describes how he experienced living and dying of esophageal cancer (Hitchens, 2012). In the quote, Hitchens shares how he wants his remaining life to be and the way he hopes his life will end: “to ‘do’ death the active and not the passive way ... wishing to be spared nothing that properly belongs to a life span” (Hitchens, 2012, p. 73). Furthermore, the quote expresses how living with an approaching death is indeed also part of life, and where the dying person is a whole person with a desire to continue being fully engaged in living. Thus, the quote thereby captures the main focus of this dissertation, which is to explore how people living at home with advanced cancer are able to create a life worth living, while faced with the approaching end of their life.

The overall objective of the research project presented in this dissertation was to enhance the understanding of occupational engagement and perceived quality of life for people with advanced cancer who live at home. The research project is nested in a larger occupational therapy research project; the Activity, Advanced Cancer and Quality of Life at Home Project (ACQ Project) (Brandt et al., 2016; Peoples., Brandt, Wæhrens, & la Cour, 2017), and is based on qualitative descriptive and
explorative approaches employing different methods depending on the aim of the specific study within this project.

The objective of the ACQ Project was to develop and evaluate an occupational therapy based intervention program that enables people living at home with advanced cancer, to optimize their management of occupations and increase their quality of life. The ACQ Project included participants from two Danish university hospitals. The ACQ Project consisted of three studies: 1) a cross-sectional study, 2) the development of an occupational therapy intervention program, and 3) a test of the effectiveness of the developed intervention program by a randomized controlled trial including an economic evaluation. The studies within this dissertation are based on data and participants from one of the two hospitals who participated in the cross-sectional study of the ACQ Project.

The cross-sectional study employed different research methods to describe and explore needs, and to gain insight to subjective experiences of complex situations of individuals and to measure quality of life. The ACQ Project managers wanted the participants’ subjective experiences to have a more profound role in the PCQ Project, which became the focus of this dissertation. The author was particularly responsible for the collection of data from one of the two hospitals who were part of the cross-sectional study. Hence, particularly the first study was informed by the cross-sectional study. The subsequent studies were both planned and conducted by the author. The topic for Study II with its focus on subjective quality of life originated from Study I, where several participants had talked about how occupational difficulties negatively influenced their quality of life. Moreover, in Study I, one participant had made a comment about the difficulties she experienced while completing a health-related quality of life assessment as part of the ACQ
The participant expressed that she found it difficult because objectively she was seriously ill (indicating a low score on the assessment) but when she looked at her everyday life in general, she experienced an everyday life with much quality (see manuscript II). This evoked my curiosity and led to Study II which was a qualitative study that explored perceptions of quality of life. Some findings from Study II, suggested that dimensions of belonging was associated with quality of life and these findings led to further exploration in this regard, which led to Study III.

Dissertation structure
This dissertation is based on three manuscripts placed in the last section of the dissertation. The remaining section being structured around four large sections. The first section introduces the background and existing research relevant to the overall purpose of the dissertation as well as the specific research aim of each study. The second section presents the research design and methods. The third section presents a general discussion of the findings, followed by the last section which addresses and discusses methodological considerations, implications and suggestions for future research.

List of publications


BACKGROUND

Cancer and advanced cancer
Worldwide the number of people living with cancer is continuously growing, and due to an aging population with the risk of cancer increases with age (WHO, 2017), it is anticipated that the number of cancer incidence will rise from 14 million worldwide in 2012 to 22 million within the next two decades (WHO, 2017). In Denmark, a total of 39,000 citizens out of 5.4 million are diagnosed with cancer annually, approximately 29,000 are currently living with cancer and nearly 15,500 die from cancer every year; leading to approximately 30% of all deaths in Denmark (Sundhedsdatastyrelsen, 2016). However, while the incidence of cancer continues to rise, improved cancer treatments and earlier diagnosis, means that the risk of dying from cancer continues to decrease (Hashim et al., 2016; WPCA, 2014). In Denmark more than half of the people diagnosed with cancer live a minimum of five years after being diagnosed (NORDCAN, 2014).

The term advanced cancer is commonly used to describe a type of cancer in which a cure is no longer expected (American-Cancer-Society, 2017). Yet, it is possible to offer treatment that can, to some extent, control the illness by slowing the growth of the cancer which can potentially prolong life and alleviate symptoms such as pain and fatigue (American-Cancer-Society, 2017). Receiving treatment may allow people to be able to live several years with advanced cancer (American-Cancer-Society, 2017; Coleman et al., 2008; Sundhedsstyrelsen, 2012; WPCA, 2014).

Living with advanced cancer
Living with advanced cancer may have a profound influence on the lives of those who are affected, with regards to daily living as well as physical, psychosocial, and existential aspects of life (Elmqvist, Jordhoy, Bjordal, Kaasa, & Jannert, 2009; la Cour & Hansen, 2012; M Lyons, N. Orozovic,
As a consequence of having cancer along with the side-effects of treatment, advanced cancer may lead to physical deterioration and subsequently result in decreased functioning (la Cour, 2008; Morgan, Currow, Denehy, & Aranda, 2015; Morgan & White, 2012). Advanced cancer may also result in severe emotional and existential distress and concerns about the future. Moreover, death becomes a present factor in life which may influence possible hopes and dreams the individual might have (Dalgaard, 2012; Willig, 2015). Ellingson et al. (2013) described the experience of living with a life-threatening illness as, “entering a world with no future” (p. 168). Or, as Hitchens described it: “I’m not fighting or battling cancer – it’s fighting me” (Hitchens, 2012, p.115), indicating the constant presence and consequence of cancer where cancer is not something a person necessarily learns to live with, but rather just lives with because he/she does not have a choice in the matter. This may generate existential concerns about the limited time the person may have left to live, having to leave loved ones and of the importance of both living in the present moment and living for the present moment (Ellingsen et al., 2013; la Cour & Hansen, 2012).

Research shows that people living with advanced cancer have a desire to continue living their life as they did before their illness, by maintaining their usual roles and occupations (Haug, Danbolt, Kvigne, & Demarinis, 2015; Mills & Payne, 2015; Morgan, 2012; Sviden, Tham, & Borell, 2010). However, cancer in an advanced stage can lead to the disruption of a familiar life and negatively influence their ability to engage in valued occupations, resulting in the loss of meaningful relationships (Appelton et al., 2015; Grov, Fossa, & Dahl, 2010; Haug et al., 2015; Krigel, Myers, Befort, Krebill, & Klemp, 2014; la Cour, Nordell, & Josephson, 2009; M. Lyons, N. Orozovic, J. Davis, & J. Newman, 2002; Morgan, 2012). Furthermore, having cancer may lead to feelings of isolation.
(Håkanson & Öhlén, 2016; Mills & Payne, 2015) and a sense of being disconnected from life (Bueto & Zago, 2015; Davies & Sque, 2002).

People with advanced cancer may experience occupational difficulties that may result in disengaging in occupations they used to enjoy and previously contributed to meaning in their life (la Cour, Nordell, et al., 2009; M. Lyons et al., 2002; Morgan et al., 2015). Ability to manage occupations may help to preserve daily living (Eva & Wee, 2010b; Lala, 2011; Morgan, 2012), and contribute to the quality of the life that remains (Ashworth, 2014; Hammell, 2004b; Krigel et al., 2014; Sviden et al., 2010; Willig, 2015). Vig et al’s (2003) study of terminally ill older men revealed that although active occupational engagement improved quality of life for the participants such engagement also worsened the men’s symptoms.

Research has identified that people with advanced cancer have unmet needs related to their occupations (Harrison, Young, Price, Butow, & Solomon, 2009; Johnsen, Petersen, Pedersen, Houmann, & Grønvold, 2013; Moghaddam, Coxon, Nabarro, Hardy, & Cox, 2016; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009; Schenker, Young Park, Maciasz, & Arnold, 2014; Taylor & Currow, 2003). A Danish study of 977 participants found that 58% had moderate difficulties and 31% had severe difficulties related to work and their daily occupations (Johnsen et al., 2013). Furthermore, research has shown that people living with advanced cancer have a desire to both manage their occupations better and add new occupations to their lives (K.D. Lyons, Svensborn, Kornblith, & Hegel, 2015; Morgan et al., 2015). Although studies have found that people with advanced cancer experience difficulties in managing occupations, only a few studies have specifically explored how these difficulties are managed and how this impacts quality of life (Lala, 2011; K. D. Lyons, Erickson, & Hegel, 2012; Sviden et al., 2010).
Quality of life
Improving quality of life is often the ultimate goal in healthcare interventions, end-of-life care and palliative care. There are multiple ways of understanding quality of life, which is reflected in the numerous definitions and quality of life models that are found in the literature (Bergland & Narum, 2007). The World Health Organization (WHO) defines quality of life as the following:

“Quality of life is the individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL, 1997, p. 1).

The WHO definition reflects quality of life as subjective and multi-dimensional by taking personal, social and cultural dimensions into account. An example of a generic quality of life model influenced by occupational therapy is “The Quality of Life Model” (Unit, 2016). This conceptual model has been developed by the Quality of Life Research Unit at the University of Toronto in partnership with the Department of Occupational Therapy and the Centre for Health Promotion (Unit, 2016). In this model, quality of life is conceptualized as the degree to which a person is able to enjoy the possibilities of his or her life in regards to three life domains: being domain, belonging domain and becoming domain. The being domain encompasses physical, psychosocial and spiritual being. The belonging domain includes physical, social and community belonging. The becoming domain encompasses practical, leisure and growth becoming (Unit, 2016).

Quality of life has been investigated from a variety of perspectives and by scholars of different disciplines. For example, in regards to age and gender (Campos, Ferreira, Vargas, & Albala, 2014; Kirchengast & Haslinger, 2008; Scott, Plagnol, & Nolan, 2010) or as a cultural phenomenon reflected in ethnicity, worldview and spirituality (Ashing-Giwa, Padilla, Bohorquez, Tejero, &
While independence and the social environment (e.g. the family and the community) have been identified as important contributors to quality of life in Western societies, independence may not have the same importance in non-Western societies (Iwama, 2006; Selin & Davey, 2012).

Within health care interventions and cancer research, quality of life is mostly investigated by use of standardized health-related quality of life instruments that are based on predefined categories or domains, which allow for comparisons over time and across populations (Phillips, 2006). Primarily, quality of life instruments define quality of life as good physical health and absence of symptoms (Hammell, 2013; Moons, Budts, & De Geest, 2006). Health-related quality of life has been criticized for reflecting on a ‘deficit model’ which is primarily focused on symptoms and shortcomings rather than psychosocial and existential dimensions of the individuals experiences (Adorno & Brownell, 2014; Corr & Palombi, 2014). As health care increasingly turns to a more patient- and client-centred approach with an increasing interest in viewing the person from a more holistic perspective, other ways to understand and investigate quality of life may be relevant. This dissertation focuses on quality of life from a subjective perspective. From this perspective, quality of life is linked to the experiences of the individual and life satisfaction within the individual’s particular culture, context and value system.

**Quality of life and advanced cancer**

Research has found that quality of life for people with advanced cancer is profoundly affected (Johansson, Ödling, Axelsson, & Danielson, 2008; M Lyons et al., 2002; Osborne et al., 2014). This was also found in the ACQ project where the mean quality of life score was measured to be 57% (Brandt, 2014) by the EQ-5D (EuroQOL) (Pedersen, Brooks, & Gudex, 2003), compared to the general Danish population with a score of 85% (Sundhedsstyrelsen, 2014). One may think that a
life-threatening illness such as advanced cancer, will inevitably lead to reduced quality of life, but research shows that this may not always be the case (Hammell, 2013). This is reflected in studies which showed that living with advanced cancer may lead to an enhanced appreciation of life (Dalgaard, 2007; Hammell, 2004b; Johansson, Axelsson, & Danielson, 2006; la Cour & Hansen, 2012; Morgan, 2012). People with advanced cancer may experience a stronger sense of being part of life and a greater appreciation for the familiar routines of daily life (Haug et al., 2015; la Cour & Hansen, 2012); as well as, intensifying their emotional bonds with other (Willig, 2015). This indicates that quality of life is highly individual and a complex phenomenon that is not easily understood. Therefore, in order to investigate the complexity of how individuals perceive quality of life, it is therefore relevant to explore quality of life using a qualitative approach to capture people’s perceptions and opinions of what matters most to them when living with their life moving towards its end (Tonon, 2015).

Several studies have used qualitative methods to investigate quality of life (Buetto & Zago, 2015; Davies & Sque, 2002; Johansson et al., 2008; Osborne et al., 2014; Sviden et al., 2010; Vig & Pearlman, 2003). Sviden et al. (Sviden et al., 2010) found that people who received palliative hospital-based home care and day care, experienced feelings of competence when they were involved in occupations they valued. Osborne et al. (2014) identified occupational engagement as being linked to quality of life by people with advanced cancer. However, this study was conducted in a clinical setting and did not examine how these issues were linked to the participants’ daily life at home. Johansson et al. (Johansson et al., 2008) explored the meaning of quality of life for people with advanced cancer and showed that being at home enhanced the participants’ quality of life. Yet, another study showed that women with advanced breast cancer who lived at home, experienced feelings of being disconnected from life (Davies & Sque, 2002). Davie and Sque’s
(2002) study primarily focused on the social consequences and less on other aspects of daily life. Vig et al’s (Vig & Pearlman, 2003) study of perceptions of older men who were terminally ill on their quality of life, revealed that although their active engagement in occupations in daily life contributed to improved quality of life, it also resulted in an increase in their symptoms (e.g. increased pain). Likewise, Buetto and Zago’s (Buetto & Zago, 2015) study which explored how people with colorectal cancer undergoing chemotherapy perceive quality of life and found that loss of the familiar life was associated with reduced quality of life.

Palliative care and palliative occupational therapy within the Danish healthcare system
In Denmark and throughout most of the world palliative care is based on the WHO’s definition:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WPCA, 2014, p. 5).

Palliative care is a holistic approach that affirms life and focuses on the whole life situation of the individual and his or her relatives, in addition to focusing on enabling the best quality of the remaining life for those affected.

In Denmark, the organization of palliative care can be divided into basic and specialized palliative care (Sundhedsstyrelsen, 2011). Basic palliative care is the responsibility of the general practitioners, the municipalities and non-specialized hospital units. Specialized palliative care is performed by palliative units at hospitals, specialized palliative teams in people’s homes and hospice (Sundhedsstyrelsen, 2011). Palliative care in Denmark is divided into three phases: 1) the
Palliative care is thus not only provided to people in the terminal phase of their illness, but is also offered to people living live with a life-threatening illness during different stages of their illness trajectory (Guo & Shuin, 2005; Sundhedsstyrelsen, 2011). The participants in this project were in the late phase of their illness and received treatment in their homes by their municipalities and at out-patient clinics at their local hospital.

Denmark’s public healthcare system is financed through income tax; thus allowing people to have free access to healthcare, including palliative care. Recently, there has been a shift in the Danish healthcare system’s health care services with an increasing number of people receiving palliative home care, instead of hospital-based treatment (Neergaard, 2009; Sundhedsstyrelsen, 2012, 2016). The main reasons for this change are a lack of healthcare resources (Sabik & Lie, 2008), an aging population; as well as, an increase in people living with different types of chronic illnesses (such as advanced cancer) who benefit from having treatment, rehabilitation and palliative care provided at home (Borell, Asaba, Rosenberg, Schultz, & Townsend, 2006; Hand, Law, & McColl, 2011). For some people with advanced cancer the change in healthcare delivery is in agreement with research which showed that the home is their preferred setting for receiving care; in addition to being the preferred place to live until death. The home is central place of a person’s life (Buttimer, 1980) and is often the place where people feel most comfortable; it is an intimate, safe and familiar place and being at home may enhance the quality of the dying experience (Benzein, Norberg, & Saveman, 2001; Solomon & Hansen, 2015). Furthermore, people with advanced cancer
spend most of their time in their home (La Cour, Nordell, et al., 2009), and living at home provides the possibility to participate in decisions about daily living (Benzein et al., 2001). This makes home the setting where everyday life is lived (Eva & Wee, 2010a) and the place that offers security, intimacy and a sense of belonging (Hasselkus, 2011e). However, research have also showed that some people may feel pressured to remain in their home during the last phase of their life, which may lead to increased distress (Raunkiær, 2007). A consequence of more people with advanced cancer living at home until death, is that it also requires them to manage their daily occupations under changing circumstances due to their illness and variations in their cancer treatment, for example periods with and without daily treatment. This means that there is a growing need to gain knowledge of how best to support people with advanced cancer to be able to engage in needed and valued occupations, to enhance their quality of life while living at home with impending death.

In 2016, the Danish government launched their most current plan for cancer care and treatment in Denmark (Regeringen, 2016). This plan states that cancer care and treatment should be both planned and implemented in respect of the individual’s everyday life and within or in close proximity to the individual’s home (Regeringen, 2016). This is also in agreement with the Danish Cancer Society’s statement of interventions for people living with advanced cancer, which stresses that interventions for this group should focus on alleviation of the consequences of the cancer as well as aspects which enables everyday living, such as: psychosocial, spiritual, daily occupations and quality of life (KræftensBekæmpelse, 2010; Regeringen, 2016; WHO, 2015). However, still little is known about how to best support people with advanced cancer in living at home in accordance with their needs and wishes.
Palliative occupational therapy
The shift towards healthcare being delivered in the home environment is in agreement with Danish occupational therapy practice. As a health profession focused on maintaining and enabling occupational engagement, occupational therapy in Denmark has a long tradition of providing occupational therapy interventions in the recipient’s homes setting (Langdal & Sørensen, 2013). In Denmark, palliative occupational therapy has been practiced since the beginning of year 2000 and is still a developing area of expertise with the first official palliative occupational therapy group within the Danish Association of Occupational Therapists being established in October 2016 (Ergoterapeutforeningen, 2016). The same year the first report with recommended competences for occupational therapists within palliative care was published (Lindahl-Jacobsen, Filskov, Jessen-Winge, & Brekke, 2016). In Denmark, occupational therapists are involved in both hospital based and municipality based health care services during all three phases of palliative care. Palliative occupational therapy focuses on supporting individuals and their relatives in maintaining daily living, by enabling engagement in necessary and valued occupations, with the purpose of enhancing their overall quality of life (Burkhardt et al., 2011). Just as Danish palliative occupational therapy is a fairly new area, Danish occupational therapy research within palliative care is also a growing area with its primary focus on people with cancer (Brandt et al., 2016; la Cour & Hansen, 2012; la Cour, Josephsson, & Luborsky, 2005; la Cour, Ledderer, & Hansen, 2015; la Cour, Nordell, et al., 2009; Lindahl-Jacobsen, Hansen, Wæhrens, la Cour, & Søndergaard, 2015). Occupational therapy research within palliative cancer care has primarily targeted; clinical settings (Fredslund, Høgdal, Christensen, & Wessel, 2015; la Cour, Josephsson, Tishelman, & Nygård, 2007; Lindahl-Jacobsen et al., 2015), community rehabilitation (la Cour & Cutchin, 2013) and people’s own
home. The studies within this project, as well as the ACQ Project, contribute to the growing field of knowledge of palliative occupational therapy in people’s own home.

FRAMEWORK FOR UNDERSTANDING

Occupational Science and Occupational Therapy

The studies in this dissertation are situated within Occupational Science (OS) and Occupational Therapy (OT) which rests upon the core assumption that humans are perceived as ‘occupational beings’ and occupational engagement is linked to quality of life (Wilcock & Hocking, 2015d; E. J. Yerxa, 1989). OS is a young interdisciplinary academic discipline concerned with knowledge generation and actions in regards to “the study of the human as an occupational being, including the need for and capacity to engage in and orchestrate daily occupations in the environment over the lifespan” (Clark, 2006; Pierce, 2014; Rudman et al., 2008; E. Yerxa et al., 1989, p.6). OT is a client-centred profession that is based on scientific and professional knowledge (G. Kielhofner, 2009), involved in promoting health and quality of life, through occupations (WFOT, 2012). Occupational therapists support people across the lifespan who experience occupational difficulties engaging in occupations they need, want or are expected to do (AOTA, 2011).

In this research project, Wilcock and Hocking’s definition of occupation is used: “all that people need, want, or are obliged to do across the sleep-wake continuum, individually and collectively” (Wilcock & Hocking, 2015d, p. xi). Occupation is viewed to be essential for human existence and to provide purpose and meaning in life (Hasselkus, 2002; Polatajko, Davis, et al., 2007). Occupation is believed to be a universal phenomenon that influences and is influenced by the environment and context in which it occur (E. J. Yerxa, 2014), in the sense that occupation is often not just about doing but about doing for a particular reason; for example preparing the children’s lunch for
school, driving the car to work, or going to dinner with friends (C.H. Christiansen & Baum, 2005; Law, 2002; Townsend & Polatajko, 2007). Moreover, occupations are not only linked to what people do, but also include why people do what they do, how they feel about the things they do, when and where they do it and how they engage with others through their doing (Polatajko, Backman, et al., 2007; Wilcock & Hocking, 2015d). The term ‘occupation’ in itself is neutral, in the sense that it is a concept that is given value and meaning by people within a specific culture and context (Iwama, 2006; Polatajko, Davis, et al., 2007). In some cases, occupational engagement may increase health and quality of life, but in other cases occupational engagement, or lack thereof, can lead to stress, boredom and isolation: thereby resulting in poor health and reduced quality of life (Hammell, 2009a; Stewart, Fischer, Hirji, & Davis, 2016). Specific occupations can mean different things to different people, which might change over time as a result of what the person encounters; such as, the consequence of being diagnosed with a serious illness such as advanced cancer and living with an approaching death (Lala, 2011).

**Quality of life from an occupational perspective**

From an occupational perspective, understood as “a way of looking at or thinking about human doing” (Njelesani, Tang, Jonsson, & Polatajko, 2014, p. 233), occupational engagement is considered to be a basic human need which may influence meaning and quality of life (C.H. Christiansen & Baum, 2005; do Rozario, 1994; Hammell, 2004b; Hasselkus, 2011b; Wilcock & Hocking, 2015d). From this perspective, the ability to do things that are personally meaningful is considered to enhance the overall quality of an individual’s everyday life (Corr & Palombi, 2014; Doble & Santha, 2008; Maley, Pagana, Velenger, & Humbert, 2016; M. Pizzi, 1992). Furthermore, Hammell (Hammell, 2013) stresses the importance of acknowledging quality of life as the value a
person places on occupations, rather than how well that person performs these occupations. A definition of quality of life from an occupational perspective is provided by Townsend and Polatajko:

"Quality of life from an occupational perspective, refers to choosing and participating in occupations that foster hope, generate motivation, offer meaning and satisfaction, create a driving vision of life, promote health, enable empowerment, and otherwise address the quality of life" (Townsend & Polatajko, 2007, p. 373)

A strong emphasis of Townsend and Polatajko’s definition is the proposed link between quality of life and occupational engagement. The ‘Quality of life model’ mentioned above is another example of a model that views quality of life from an occupational perspective (Unit, 2016).

Several occupational scientists have studied how different groups of people perceive quality of life from an occupational perspective; for instance, how occupational engagement contributes to perceived quality of life during times of severe illness. Such as, among people living with high spinal cord injury (Hammell, 2004b), multiple sclerosis (F. Reynolds & Prior, 2003), severe mental illness (Laliberte-Rudman, Yu, Scott, & Pajouhandeh, 2000) or traumatic brain injury (Conneeley, 2003). Shared findings among these studies were connections between perceived quality of life and the capability of maintaining both valued occupations and significant relationships. Several studies have also explored quality of life for people living with advanced cancer; for instance, in a clinical environment (Jacques & Hasselkus, 2004; la Cour et al., 2007), with a focus on physical decline (Morgan et al., 2015; Morgan & White, 2012) and in regards to specific types of occupational engagement (la Cour et al., 2005; Unruh, Smith, & Scammell, 2000). However, studies that explore quality of life, or aspects hereof, as perceived by people with advanced cancer
who live at home are still limited (Dalgaard, 2012; la Cour, Nordell, et al., 2009; Lala, 2011; Raunkiær, 2007, 2016). Studies from the perspective of people living at home with advanced cancer may provide knowledge of what becomes important in everyday life at home and how occupational engagement may contribute to quality of life when living with life approaching its end.

**RESEARCH OBJECTIVE**
The overall objective of this research project was to explore occupational engagement and perceived quality of life for people living at home with advanced cancer.

**Specific aims corresponding to the three studies**

**Study I:** To describe and explore how people with advanced cancer manage occupations at home.

**Study II:** To explore how people with advanced cancer who live at home perceive quality of life.

**Study III:** To gain a deeper understanding of the ways in which quality of life is perceived by people with advanced cancer, drawing on empirical findings and the theoretical concept of belonging.

**MATERIAL and METHODS**
Methodology is the overall approach to research and encompasses both philosophical assumptions and research (Bogdan & Bilken, 2007; Finlay, 2006); thereby positioning and shaping research (Creswell, 2007) and constituting the position toward the reality or nature of the phenomena that are subject to the research study (ontology), how the researcher understands knowledge, how knowledge is obtained (epistemology) and the methods used in the study (Crotty,
1998). This section provides a description of the methodological underpinnings of the studies within this dissertation and outlines my position as a researcher.

**Research design**

This research project and the inherent studies are framed within the larger ACQ Project, which employed different research methods to describe and explore needs, and to gain insight to subjective experiences of complex situations of individuals. Due to the descriptive nature of the qualitative data in cross-sectional study used in this project, a qualitative descriptive and explorative design was chosen for this project (Colorafi & Evans, 2016). A qualitative descriptive and explorative design is characterized by lower levels of interpretation and thereby “stay closer to their data and to the surface of words and events” (Sandelowski, 2000, p. 336; 2010) and is grounded in the general principles of naturalistic inquiry (Colorafi & Evans, 2016). An eclectic approach to sampling, data collection, and data analysis techniques was used to describe, explore and elicit different perspectives of the overall research objective.

As an introduction to the following sections, Table 1 provides a short overview of the specific methods used in each of the three studies, with a more comprehensive description in the subsequent sections.
Table 1. Overview of the research aim, design and methods used in the three studies

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Study aim</td>
<td>To describe and explore how people with advanced cancer manage occupations at home.</td>
<td>To explore how people with advanced cancer living at home perceive quality of life.</td>
<td>To gain a deeper understanding of the ways in which belonging is perceived as an aspect of quality of life by people with advanced cancer.</td>
</tr>
<tr>
<td>Research approach</td>
<td>Qualitative descriptive and explorative.</td>
<td>Qualitative descriptive and explorative.</td>
<td>Qualitative explorative.</td>
</tr>
<tr>
<td>Data generation</td>
<td>Interview questions and informal observation</td>
<td>Semi-structured interviews, photo-elicitation interviews and informal observations.</td>
<td>Semi-structured interviews, photo-elicitation interviews and informal observations.</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Content analysis.</td>
<td>Thematic analysis.</td>
<td>Thematic analysis.</td>
</tr>
</tbody>
</table>

**Research setting**

Human phenomena are best understood when they are explored in the setting in which they occur and in close proximity to where people’s life unfold (Dillaway, Lysack, & Lurborsky, 2006). Due to the objective of this project, the research setting for the studies in this project was in the homes of the participants or its immediate surroundings (e.g., the garden or a workshop). Conducting research in the participants’ homes provided the possibility of ascertaining insight to the participant’s everyday life, their daily occupations and their reflections about quality of life during advanced illness through interviews, impressions and informal observations in their home environment, surrounded by their personal effects (e.g. family photos and personal belongings); thus, allowing the researcher to get to know the person. Conducting the interviews in the participants’ homes also had the intention to meet them in familiar and safe surroundings, which
contributed them feeling more relaxed and comfortable which allowed them to be ‘more themselves’ (Sivell et al., 2015).

Out of the 73 participants, 53 participants lived in a house with access to a garden, 20 participants lived in an apartment or a townhouse. Forty-six participants lived in a small town or a rural area within driving distance to shops, banks etc., and 27 lived in a larger town or in a city (Appendix B).

**Participants and sampling**

Out of a total of 164 participants, the subsample for Study I consisted of 73 participants which constituted participants from one of the two hospitals as part of the cross-sectional study of the ACQ Project, comprising people who lived on the island of Funen, the second largest island in Denmark. Patients to be recruited to the study were approached by contact nurses on two oncological departments at a Danish university hospital if they fulfilled the following inclusion criteria: age 18 years or older, diagnosed with cancer (all types), were currently receiving palliative care, having an estimated survival time of at least four-months (by an oncologist), had a functional level of 1 to 3 on WHO Eastern Cooperative Oncology Group (ECOG) Performance Status (indicating degrees of functional difficulties), lived at home or in sheltered housing, lived on the island of Funen and were able to participate in an interview. Participants living in hospice or a nursing home were excluded.

Participants, who fulfilled the inclusion criteria and expressed an interest in participating were contacted by the author, who then provided additional information about the purpose of the project, the conditions of the study and finally obtained their informed consent (Appendix C).
The sample for Study II and III consisted of a subsample from Study I. Due to a prolonged amount of time it took to collect data for the cross-sectional study, 39 participants had already died by the time of sampling for Study II and Study III. The remaining 34 participants were invited to participate in Study II and Study III; first by mail and later by telephone. Of these, 22 people declined due to a worsening of their condition or a lack of interest. Twelve participants agreed to take part in the study, but two died before data-collection began and one did not want to participate in photo-elicitation. Thus, the final sample was comprised of ten participants for Study II and nine participants for Study III (Figure 1). Informed consent was obtained before data collection was initiated (Appendix C).
Screened by contact nurses at three oncological outpatient clinics at Odense University hospital

**STUDY I**

Eligible (n=135)
- 18 years or older.
- diagnosed with cancer (all types).
- received palliative care, an estimated survival time of at least four months (by an oncologist).
- a score of 1-3 on WHO Performance Status.
- lived at home or in sheltered housing, on the island of Funen (Denmark)
- able to participate in an interview.

Declined (n=33)
Reasons:
- Lack of energy (19)
- Did not find the project relevant (4)
- Involved in too much on a daily basis (3)
- Did not want visits in their homes (3)
- Other reasons (2)
- Unknown (2)

Stated an interest in participating in the project and agreed to be contacted by telephone by a research assistant in regard to a possible enrolment in the cross-sectional study (n= 102).

73 agreed to participate in Study I

39 died between Study I and data collection for Study II and Study III

**STUDY II and III**

Eligible (n= 34)
Participants from Study I who were still alive by the time of data collecting for Study II and Study III, were invited by letter to participate in Study II and Study III.

Letter to 34 eligible participants and contacted by telephone a week later.

12 agreed to participate in Study II and Study III.

22 declined when contacted by telephone
Reasons:
- Worsening of condition/hospice (15)

2 died before data collection was initiated

10 agreed to participate in Study II

1 declined photo-elicitation

9 agreed to participate in Study III

**Figure 1. Recruitment flow chart**
Table 2 shows a summary of participant characteristics for all three studies. For a more detailed overview of the participant characteristics, see Appendix B.

Table 2. Summary of participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants</strong></td>
<td>n = 73</td>
<td>n = 10</td>
<td>n = 9</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mean</td>
<td>68,1 years</td>
<td>68 years</td>
<td>66,7 years</td>
</tr>
<tr>
<td>- Range</td>
<td>36–89 years</td>
<td>57–85 years</td>
<td>57–85 years</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Women (n = 34)</td>
<td>Women (n = 5)</td>
<td>Women (n = 5)</td>
</tr>
<tr>
<td></td>
<td>Men (n = 39)</td>
<td>Men (n = 5)</td>
<td>Men (n = 4)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td>Married (n = 48)</td>
<td>Married (n = 6)</td>
<td>Married (n = 6)</td>
</tr>
<tr>
<td></td>
<td>Single (n = 25)</td>
<td>Single (n = 4)</td>
<td>Single (n = 3)</td>
</tr>
<tr>
<td><strong>Geography</strong></td>
<td>City (n = 19)</td>
<td>City (n = 2)</td>
<td>City (n = 1)</td>
</tr>
<tr>
<td></td>
<td>Town (n = 8)</td>
<td>Town (n = 1)</td>
<td>Town (n = 1)</td>
</tr>
<tr>
<td></td>
<td>Small town (n = 21)</td>
<td>Small town (n = 5)</td>
<td>Small town (n = 5)</td>
</tr>
<tr>
<td></td>
<td>Rural area (n = 25)</td>
<td>Rural area (n = 2)</td>
<td>Rural area (n = 2)</td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td>Retired due to age (n = 44)</td>
<td>Retired due to age (n = 6)</td>
<td>Retired due to age (n = 5)</td>
</tr>
<tr>
<td></td>
<td>Retired due to illness (n = 12)</td>
<td>Retired due to illness (n = 4)</td>
<td>Retired due to illness (n = 5)</td>
</tr>
<tr>
<td></td>
<td>On sick leave (n = 4)</td>
<td>On sick leave (n = 0)</td>
<td>On sick leave (n = 0)</td>
</tr>
<tr>
<td></td>
<td>Employed (n = 9)</td>
<td>Employed (n = 0)</td>
<td>Employed (n = 0)</td>
</tr>
<tr>
<td></td>
<td>Unknown (n = 4)</td>
<td>Unknown (n = 0)</td>
<td>Unknown (n = 0)</td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td>Lung (n = 19)</td>
<td>Lung (n=1)</td>
<td>Colon/rectum (n = 2)</td>
</tr>
<tr>
<td></td>
<td>Colon/rectum (n = 14)</td>
<td>Colon/rectum (n = 2)</td>
<td>Prostate (n = 2)</td>
</tr>
<tr>
<td></td>
<td>Prostate (n = 11)</td>
<td>Prostate (n = 2)</td>
<td>Cervix (n = 2)</td>
</tr>
<tr>
<td></td>
<td>Cervix (n = 9)</td>
<td>Cervix (n = 2)</td>
<td>Breast (n = 3)</td>
</tr>
<tr>
<td></td>
<td>Breast (n = 7)</td>
<td>Breast (n = 3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other types (n = 13)</td>
<td>Other types (n = 2)</td>
<td></td>
</tr>
<tr>
<td>**WHO’s ECOG Performance status *</td>
<td>1: (n =31)</td>
<td>Participants were not re-scored prior to Study II and III</td>
<td>Participants were not re-scored prior to Study II and III</td>
</tr>
<tr>
<td></td>
<td>2: (n = 34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3: (n = 6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not stated: (n = 2)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*1: Restricted in performing physically strenuous activities, 2: Capable of performing all self-care activities, capable of performing light housework, 3: Capable of performing only limited self-care activities.

**Pilot interviews**

Pilot interviews were conducted before data collection for each study. The purpose was to evaluate how the chosen methods worked in practice.

**Study I**: Four participants participated in the pilot interview for Study I, which was carried out as a pilot for the cross-sectional study. The purpose was to assess the research methods.
and the length of the data collection which was set to a maximum of two hours in respect for the participants. As a result of the pilot interviews, changes were made to the sequence of two questions in the interview guide to provide a more natural flow to the interview.

Data from the pilot interview was not included in Study I.

**Study II and III:** A pilot interview was conducted with one participant in order to assess how the semi-structured interview guide and photo-elicitation worked as methods which could facilitate reflections on quality of life. During the pilot interview a participant talked about how her view on quality of life had changed after she got cancer, which resulted in adding one question to the semi-structured interview guide which addressed possible changes to how quality of life was perceived before and after the illness. Moreover, after the pilot interview was conducted, it became clear that it was necessary to develop a document containing what info was needed for the photo-elicitation (Appendix F). This document contained information about how to avoid producing photographs with recognizable images as well as necessary contact information. Data from the pilot interview was included in Study II and Study III.

**Data collection**

The studies of this dissertation employed a combination of methods, also referred to as ‘method or data triangulation’, in order to enhance the overall understanding of the topic being studied (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014; Denzin & Lincoln, 2011). Over a period of 24-months, data from all three studies was collected using semi-structured interviews, informal observations performed in the participant’s home environment and photo-elicitation.
Interview

The interview is the method for data collection that is most used in qualitative research (Brinkmann & Tanggaard, 2010). The rationale for using the interview as the primary research method for all three studies was that interviews made it possible to talk directly with the participants’ themselves to hear their own thoughts and reflections about occupational engagement and quality of life when living with advanced cancer.

The interviews were conducted between the participants and the author. A few times, relatives (usually a spouse) would participate in the interview to support the participant during the interview; for instance, by giving a hint to trigger a memory, or by adding comments based on the participant’s answers. One example was when one participant’s spouse inserted a comment about the garden, which prompted the participant to talk about his passion for flower and how he enjoyed working in the garden. In order to enable thoughts, reflections and experiences of the participants, a conversational tone was applied to the interviews (Kvale, 1996b).

To facilitate the participants’ perspectives and experiences, a semi-structured interview guide based on the aim of each study, was used for all three studies. The semi-structured interview format was viewed as an appropriate way to explore experiences from the perspective of the individual since it provided some level of structure to the interview, while also allowing the participants to steer the interview in a direction that was relevant to them. Although all three interviews were semi-structured they were conducted in different ways which are detailed below:

**Study I:** The questions used in Study I was created by the project managers of the ACQ Project. The author was part of the data collection but was not involved in the planning of the cross-sectional study. Data material for Study I constituted interviews with 73 participants, with the
The author performed 71 of the 73 interviews (the last two interviews were performed by a researcher at the University of Southern Denmark). The interviews lasted between 17-minutes and 53-minute. The interviews in Study I were structured around four open-ended questions: 1) “Please describe a typical day?”, 2) “How do the occupations your day consists of work for you?”, 3) “Have any of your daily occupations changed or have they taken on a new meaning after you were diagnosed with cancer?” and 4) “How do you organize your everyday life?” (Appendix D). Data was generated between February 2013 and May 2014.

**Study II and III:** Data was collected in the homes of the participants and included two visits over a period of two weeks from October 2014 to January 2015:

1) During the first visit, semi-structured interviews were used to explore understandings of quality of life. The semi-structured interviews applied a less structured approach and allowed more time for the participants to elaborate than the interviews in Study I, since these interviews had been part of a larger data collection with a total timeframe of two hours. A semi-structured interview-guide with a few open-ended questions and suggestions to follow-up questions provided a loose structure for the interview (Appendix G). After the initial question “What does quality of life mean to you?”, the interview followed the answers of the participants, and additionally questions were asked when it was relevant. The participants were invited to tell about specific situations that they associated with quality of life or lack thereof. Furthermore, the participants were asked to reflect upon situations that contributed to joy to their lives. Some of the questions would elicit extensive descriptions of past events and how these influenced present experiences. An example of this is illustrated by the following question; “Can you tell me about an experience or a day that was especially good
or enjoyable?”, which provided extensive and detailed descriptions. The first interview lasted between 30-minutes to 1-hour and 40-minutes.

2) The second interview also focused on perceived quality of life; thus, augmenting the first interview and was intended to gaining a deeper and more nuanced understanding of quality of life. During the second visit, photo-elicitation interviews were performed based on participant-generated photographs. The interviews were carried out by going through each photograph, asking the participants to describe the photograph in detail, inviting them to share their thoughts and reflections about the photograph and how it related to quality of life (Appendix H). The photo-elicitation interviews lasted between 43-minutes and 2 hours and 12-minutes.

**Informal observations**
The interviews took place in the homes of the participants, which provided the opportunity to ask the participants to augment the interviews by showing the author around in their home, garden, workshops etc. which enabled the author to observe everyday life situations during the visit. The author participated in the occupations that occurred during the visit, such as helping to set the table for coffee, looking through photo albums or helped with repotting summer flowers. The latter was a result of asking a participant to show the author his workshop and his work there, after he had talked about his passion for flowers, and how he each year in his workshop would grow flowers from seeds for his garden. Field notes were recorded immediately after each interview to promote better recall of the observations and reflections that were made.

**Photo-elicitation**
Photo-elicitation was used as method for data generation in Study II and Study III. Photo-elicitation is based on the “idea of inserting a photograph into an interview” (Harper, 2002, p. 13). Photo-elicitation is rooted in disciplines such as anthropology and sociology (Pink, 2013a; Rose, 2012c)
but is increasingly used by other disciplines such as human geography, psychology, education and occupational science (Drew & Guillemin, 2014; Wright-St Clair, 2015). The rationale for using photo-elicitation in Study II and Study III was that this method has the potential to bring elements of human consciousness to mind that words alone cannot, for example in regards to phenomena that may be difficult to articulate (Harper, 2002). Photo-elicitation may thereby had the potential to provide not just more but also a different insight (Harper, 2002) into occupational engagement and quality of life when living with advanced cancer.

In the literature, the term photo-elicitation is used in different ways; such as, a specific visual method in line with other visual methods. Some such methods being; photo-essay, photo-voice (Rose, 2012a), or as an umbrella term where each visual method is placed along a continuum of participant involvement of how the photographic data is generated and analyzed. In Study II and Study III, photo-elicitation was used as a way of reflexive photography, where the photographs were generated by the participants and followed by an interview in which the participants were asked to share the interpreted meaning inherent of their photographs (Close, 2007). This was an attempt to facilitate reflections of the tacit aspects of quality of life that otherwise could be difficult to put into words. Photo-elicitation thereby enabled the participants to reflect upon quality of life in a different way, which contributed to additional reflections about quality of life during the photo-elicitation interview. This is a result of what Harper calls “breaking the frame of experience” (Harper, 2002, p. 21), where a person gains a reflective stance or a fresh perspective towards taken-for-granted aspects of an experience or phenomenon. This is due to the process of producing the photograph that serves as a thinking aid (Ball & Gilligan, 2010; Huot & Rudman, 2015) which gives the person time to reflect upon the phenomenon that is being explored (Rouse, 2013), as opposed to an interview situation that unfolds in the moment and in a
continuous dialog. The photographs thereby became more than an add-on to the interview but was a method that elicited experiences in its own right (Rouse, 2013), and became a representation of the way the participants lived.

**Transcription of interviews and field-notes**

Transcribing data material can be seen as a translation process (Green & Thorogood, 2009b), in the sense that transcribing from oral to written mode is a process that involves decisions and judgements (Kvale, 1996a). Thereby, interviews and field-notes were transcribed verbatim, with the aim being to reproduce the exact words and utterances used by the participants, including slang, swear words, hesitations and interruptions. The author developed a guideline for transcription and this was discussed and agreed upon with the ACQ Project managers (Appendix I).

All interviews and field notes (Study I, II, III) were digitally recorded, and transcripts were imported by the author into data management and coding software to QSR NVivo 10 software (QSR-International).

**Transcription for Study I** was carried out by a professional transcriber. Prior to the transcription, the guidelines were presented and discussed with the transcriber. After the transcription of three interviews, the transcriptions were viewed and discussed with the ACQ Project managers to evaluate how the guidelines worked in practice and whether any changes were necessary. No alterations were found to be necessary.

**Transcription for Study II and III** was carried out by the author. This enabled a preliminary understanding of the data material to already begin during the process of transcription. The same guidelines for transcription were used.
Data analysis
Diekelmann (2005), described qualitative data analysis as an interpretive thinking process where the researcher engages creatively with the text of the participants. In this way, the analysis becomes a process of emergent thinking that grows from cyclical reading, thinking and writing towards new understandings. This section will present the different methods for data analysis that were used for the individual studies.

Conventional content analysis
Conventional content analysis as described by Hsieh and Shanon (2005), was used as the method for data analysis in study I. Conventional content analysis was used since it is a systematic method that was perceived to be well suited for analyzing the descriptive data from the fairly large sample size in Study I. This type of analysis allowed for textual analysis as well as data counting (Hsieh & Shannon, 2005). The latter was used to identify experiences that characterize the group as a whole, not as a validation of the data, but as a way to move beyond the experience of a single person.

The analysis was performed in the following way: First, each interview transcript was read repeatedly to gain a sense of the whole content. Next, each interview transcript was carefully examined and significant text was highlighted, while at the same time words or sentences were written in the margins using the participant’s own words. Then, the coded text was combined into categories. The coded text within each category was re-read and discussed with the supervisors, which resulted in some categories were combined and new ones were added, resulting in six sub-categories. Finally, the six-sub-categories were combined into two main categories. The textual analysis was supplemented with counting of
sub-categories. This was done to identify how many participants shared similar experiences; for example, how many participants experienced difficulties in managing occupations.

**Thematic analysis**

A thematic analysis was used to interpret the data in Study II (interviews) and Study III (interviews and photographs) (Luborsky, 1993). The rationale for choosing a thematic analysis for Study II and Study II was that it provided a flexible and useful method as it allowed to analyse across the data sample (Braun & Clarke, 2006; Luborsky, 1993), for the different type of data (i.e. interview and photographs) that were used in Study II and Study III. A theme can be understood as “an abstract entity that brings meaning and identity to a current experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole” (DeSantis & Ugarriza, 2000, p. 362).

**Study II:** The thematic analysis was used in this descriptive study and carried out by searching for and identifying statements that conveyed the participants’ perceptions of quality of life. The identified statements were divided into sub-themes which were viewed to identify similarities and differences; as well as, additional aspects that could add nuances to the participants’ perception of quality of life. The sub-themes were discussed with researchers from the University of Southern Denmark, which resulted in reorganizing and merging existing sub-themes, as well as adding new sub-themes. After several iterations, one main theme with two corresponding dimensions was identified, and these were again discussed with co-researchers.

**Study III:** Drawing on both empirical data and the theoretical knowledge of the concept of belonging in OS, four dimensions of belonging were actively used in the analysis to investigate how
belonging may be associated with quality of life. Both interviews and photographs were analyzed thematically (Braun & Clarke, 2006; Pink, 2013b; Rose, 2012b).

Transcripts: The author read and reread the transcripts from both interviews to gain a sense of the overall content. The text was then read again while coding statements that conveyed quality of life. These statements were reread and separated into themes that revealed dimensions of belonging. The themes were then discussed with the co-authors and this resulted in some themes being merged and new ones being added.

Photographs: Several strategies were used to analyse the photographs: First, to identify what each photograph depicted, all images were viewed systematically using a standardized worksheet for photo analysis (National-Archives, 2017). The preliminary analysis was discussed with the principal supervisor and an experienced researcher within visual methodology from Wayne State University, USA, who both contributed with reflections and suggestions for further analysis. Then, the entire photo-material (77 photographs) was viewed as a whole together with the principle supervisor and a researcher from the University of Southern Denmark to identify and discuss possible themes.

Transcripts and photographs: The transcripts and the photographs from each participant were the analysed together, with the aim to unfold each participant’s individual narrative, and the emerging analysis was again discussed with co-researchers. In the final phase the entire data set was considered together in relation to the four defined dimensions of belonging and the study purpose. This iterative process between parts and whole and between transcripts and photographs contributed to coherence.
The researcher’s position

It is recognized that the biographical position of the researcher (e.g., gender, class, age, race, professional status, etc.) may influence the research collaboration and the nature of the data that is being collected (Hammell, 2004c). The professional and personal experiences that influenced and informed the different roles the author held during the studies, influenced and informed how the author made sense of the topics being studied. First, the author’s professional role as an occupational therapist, which entailed a preunderstanding of an assumed relation between occupational engagement and quality of life. Secondly, being a person who has experienced close relatives and friends living and dying with advanced cancer, which might have shaped and influenced understandings of what such an experience may entail; for instance, the struggle of continuing life in a personal meaningful way.

In order to clarify the author’s influence on the research, records were kept regarding decisions that were made during the research project (Finlay, 2002), as an audit trail of the author’s reflections throughout the research process. Furthermore, interpretation of the findings was subject to peer review with fellow PhD students and senior researchers at the University of Southern Denmark, as well as, with co-authors and supervisors.

Informal and formal member checking (Polit & Beck, 2004a) was carried out in the following manner; informally during data collection by recapping from time to time, which enabled the participants to elucidate or clarify if needed. Formal member checking was done before initiated the first interview for Study II and III. Member checking was here used as a way to (re)establish rapport, due to the extended period from the last visit during Study I. This was done by presenting the participants with a summary of the finding in Study I, and by asking the participants if the
author’s accounts corresponded with the participants’ recollections and intended meaning, which also enabled the participants to talk about possible changes in their life situation.

**ETHICAL CONSIDERATIONS**

Conducting qualitative research in the homes of the participants can pose several ethical issues and practical challenges. This section addresses the ethical considerations, issues and challenges encountered during this project.

Although qualitative research aspires to minimize power imbalances, any kind of research will most likely involve power issues (Karnieli-Miller, Strier, & Pessach, 2009; Sivell et al., 2015). Typically, there is an uneven balance between power and roles in a research interview, where the researcher may be perceived as being the owner of expert knowledge and with the power to set the agenda for the interview; and to a larger extent, controls the direction of the conversation. An attempt was made by the author, to minimize the aspect of power in order to build rapport; for instance, through the use of preamble and small talk prior to the interviews. Moreover, carrying out the interviews in the homes of the participants also helped to reduced power imbalance, since the home environment enabled the participants to feel more relaxed and safe.

An ethical issue of carrying out research involving people living with a life-threatening illness may be that they represent a vulnerable group and will most likely not be able to experience possible benefits of the research in which they are participating. Furthermore, the visits included interviews where potentially sensitive aspects related to their everyday life were addressed, such
as, how the cancer had influenced their life and affected their relationships with family and friends. Interviews and photographs have the ability to evoke memories, feelings and reactions that can be experienced as both enriching and distressing (Orb, Eisenhauer, & Wynaden, 2001; Rose, 2012a), which may pose a risk to the participants to discuss sensitive topics that they would have preferred not to share (Allmark et al., 2009). Thus, this was addressed and responded to in a respectful and accepting manner, by acknowledging their understandings without imposing personal opinions and offering the participants the opportunity to take breaks during the interview when needed, and accepting if they chose not to answer certain question.

Another issue was that of coercion, where the participants may have felt obligated to continue participating in the second stage of the project (Study II and Study III) because of the relationship they had established with the author during Study I. Furthermore, the author’s role as a doctoral student may also have placed the participants in a situation where it could be difficult for them to refuse to continue their participation in the project, since a refusal could jeopardize the outcome and negatively affect the author’s research/education.

A couple of times issues were observed that raised concern; for example, when a prescribed assistive aid posed a health risk for the participant. In such cases, contact information was provided to the participants or to relatives; in regards to where they could get help from their municipality.
Informed consent
The participants received oral and written information about the purpose of the project (Appendix E and Appendix F). They were informed that participation was voluntary and that it was possible to withdraw from the study at any time. Considerable consideration was given to the information that was given to the participants; including choice of language and the way the content was formulated, which was discussed with supervisors. Oral and written consent for participation was obtained in all three studies (Appendix C).

Data was handled confidentially and identifiable data such as names were anonymized. As a whole, the project complied with the Helsinki Declaration, the Danish Ethics Committee System and was approved by the Danish Data Protection Agency [Project-ID: S-20122000-96-CKH/csf].

Ethical considerations in relation to visual methodology
The principles of ethics in social science (e.g., confidentiality, anonymity and informed consent) are the same regardless of whether it is an interview, a transcript, an observation, or a photograph (Rose, 2012a). However, visual material such as photographs can pose specific ethical dilemmas, since they can produce recognizable images of the research participants. This can be seen as being in clear conflict with basic ethical principles such as confidentiality and anonymity. In this project, the participants were given information about the risk of producing photographs with recognizable images, such as faces, and how this could be avoided; for instance. One such way this could be avoided was that when it was possible the photograph could be taken from behind, which protected the identity of the person. However, it is also important to acknowledge that, for
some participants, sharing images of themselves performing daily occupations for others to see may be an important part of sharing their story (Orb et al., 2001; Rose, 2012a). Some participants may even find it dehumanizing and disrespectful if their photographs were to be anonymized (e.g. blocking their faces out) or they may experience it as objectifying or stripping them of their identity.

An illustration of this was when one participant asked to be photographed together with her dog and to show others how she looks in her day-to-day life, she wanted the photograph to be taken without her wearing her wig.

Another ethical issue is that of copyright. Legal ownership lies with the person who took the photograph, and in the case of the present project, the participants had legal ownership. Therefore, it was specified in the informed consent how the photographs could be displayed (e.g. if faces could be shown or if they needed to be blurred) and how the photographs could be used (Appendix C). This was done in consideration of the participants’ bereaved family members or close relatives who might be able to recognize images of the participant, if the participant had passed away before publication was completed.

An ethical issue that is not well addressed in the literature is that of exposure. It takes courage to share photographs of one’s life for the world to see, so to speak, since these photos reflect and express personal values and particular aspects of how the participant perceive him or herself. When the participants agreed to share their photographs in relation to this research project, they
also exposed themselves to different interpretations and understandings of their photos. Although a person may take a photograph for a specific reason, or as Battye described “a picture with a preferred reading” (Battye, 2014, p. 20), images can convey several meanings, and how the photograph is understood or interpreted by the audience could therefore be different from the person’s intended meaning.

**FINDINGS**
This section will provide a short presentation of the findings beginning with an introduction to each study followed by a brief presentation of their main findings.

**Study I: Managing occupations in everyday life for people with advanced cancer living at home**
The analysis resulted in two main categories; 1) conditions influencing occupations in everyday life, and 2) self-developed strategies to manage occupations.

Changing conditions influenced the participant’s everyday life. Thirty participants (41%) experienced an everyday life that was characterized by few sedentary indoor occupations, which some participants described as a good life with much value and quality. Others described a quiet life with few occupations as a boring life. Twenty-five participants (34%) described loss of occupations that used to be part of their everyday. The changes required the participants to reconstruct their everyday lives in new and different ways. These changes were perceived as a constant reminder of their loss and decline.

Sixty-six participants (90%) experienced difficulties with managing occupations. They tried to compensate for these difficulties by developing strategies to manage occupations and to maintain
independence; for instance, by ordering groceries on-line, by taking breaks between each occupation, dividing occupations into smaller parts and/or performing them at a slower pace as well as using assistive devices. These strategies enabled the participants to maintain a level of independence at home, but were seen to be counterproductive in some cases, since they took time and energy from more personally meaningful occupations, which influenced their quality of life negatively. These findings lead to study II that explored how people with advanced cancer perceive quality of life.

**Study II: Perceptions of quality of life by people with advanced cancer who live at home**

The participants described quality of life in the main theme of ‘Continuity and discontinuity of daily life at home’ with two corresponding dimensions: 1) Adjusting to changes in health and illness, and 2) Daily life and the hereafter.

The findings suggest that the participants experienced quality of life to be closely linked to the ability to continue their daily life, such as doing needed chores and engaging in social and valued occupations, while adjusting to changing circumstances that involved loss and discontinuity as a result of declining health. These changes resulted in a tension between experiencing losses and changes on one hand, and striving to preserve a familiar daily life under different circumstances on the other hand, which required a constant adjustment by the participants to maintain quality of life while living with life moving towards its end.

Living with advanced cancer caused existential reflections about impending death. The ability to contribute to the life of relatives served to preserve continuity in the hereafter, and seemed to be related to a sense of belonging that influenced the overall quality of the here
and now. This prompted a need to explore further how quality of life may be associated with belonging when living with advanced cancer, which was pursued in Study III.

**Study III: Belonging and quality of life as perceived by people with advanced cancer who live at home**

The study highlights that people with advanced cancer living at home associate quality of life with maintaining a sense of belonging. This was identified as a complex and challenging process that involved a struggle to sustain valued occupations while facing continuous decline and decreasing abilities that limited their possibilities for diverse ways of belonging.

Certain aspects of belonging showed to be of particular importance for the participants, including dimensions of social belonging, for example through artifacts, which also could evoke existential and spiritual concerns that may arise with impending death. More in-depth knowledge is needed to further understand in which way diverse artifacts, such as everyday objects, crafts and heirlooms, may contribute and support perceptions of belonging.

**GENERAL DISCUSSION**

The previous section provided a short presentation of the findings form each study. In this section, the findings across all three studies will be discussed against relevant research and theory. The discussion is presented below and includes the following four dimensions: 1) Adjusting to ongoing changes to continue everyday life at home, 2) Dealing with the loss of occupations, 3) Connecting through valued relationships and 4) Existential belonging through occupational engagement.
Adjusting to ongoing changes to continue everyday life at home

The participants in all three studies emphasized that having the ability to maintain and create a meaningful everyday life at home was essential to their experience of quality of life. Everyday life can be understood as life that we live, maintain, create and recreate every day (Bech-Jørgensen, 1994) and is characterized by a particular order, repetition, habits, routines and a taken-for-grantedness, where daily routines may go unnoticed until disrupted in some way (e.g., due to severe illness) (Bech-Jørgensen, 1994). In this way everyday life is where, “occasional, incidental, and unusual events also takes place” [emphasis in original] (Ferguson, 2009, p. 164). The significance of taken-for-granted aspects of everyday life was experienced by the participants (Study I, II and III) when old routines collapsed and triggered thoughts on how to reconstruct and continue their life at home in new ways. According to Atchley’s (1989) Continuity Theory, people tend to recreate or continue their life as usual when they experience changes affecting their lives (e.g. continuing the same occupations and relationships) by turning to strategies shaped by their former experiences (Atchley, 1989, 2000), or maintaining daily routines that previously characterized the person’s everyday life (Bech-Jørgensen, 1994). Other studies have showed that the ability to continue a familiar life was considered significant for people living with advanced cancer (Haug et al., 2015; Krigel et al., 2014; Vig & Pearlman, 2003). The term ‘continuity’ may reflect a static view where things remain the same, but this was not the case for most participants in this project. Rather, they described how their cancer diagnosis had resulted in physical decline and decreased abilities which constantly required them to adjust in order to maintain their familiar ways of life at home.

It is recognized that changing conditions may impede the well-established roles and routines of people living with advanced cancer and may negatively influence their everyday life at home.
(Krigel et al., 2014; la Cour, Nordell, et al., 2009; Morgan et al., 2015), which was also the case for participants in this project. These changes may relate to ‘biographical disruptions’ as proposed by Bury (1982) to describe events (such as severe illness) that may disruptively influence the structures of everyday life. Bury developed the notion of ‘biographical disruptions’ on the basis of research focused on people living with rheumatoid arthritis, for whom possible disruptions may not be temporary. Although advanced cancer may be seen as a chronic condition, cancer in the advanced stage may pose other challenges; since the illness may, at times, progress rapidly and require adjustments beyond the abilities of the individual. When functional difficulties influenced the participants’ (Study I) ability to manage occupations, routine occupations such as housekeeping became “herculean tasks” (Ehn & Löfgren, 2009, p. 107) and ‘just’ getting ready in the morning was experienced as a full day’s work. In order to compensate for these difficulties, participants in Study I developed adaptive strategies to maintain daily living, such as: taking breaks, splitting an occupation into smaller parts or performing occupations at a slower pace. These adaptive strategies allowed the participant to achieve some level of independence. It is well known that people develop strategies to compensate for difficulties encountered due to illness or functional decline (G Kielhofner, 2008; Lala, 2011; K. D. Lyons et al., 2012; Nordberg, Boman, Löfgren, & Brännström, 2014; Schkade & McClung, 2001). The strategies employed by participants in Study I are often a central part of an occupational therapy intervention and are primarily referred to as ‘occupational adaptation’. According to Schkade and McClung (2001), occupational adaptation is a natural process that is present in all humans and allows individuals to “respond masterfully and adaptively to the various occupational challenges that they encounter over a lifetime” (Schkade & McClung, 2001, p. 2). In occupational therapy literature there is a tendency to describe a person’s ability to develop strategies to overcome occupational difficulties as
something that is primarily positive, since this enables occupational engagement and functional independence. Yet for some people, such as the participants in Study I, some self-developed strategies may prove to be counterproductive. Strategies such as splitting an occupation into smaller parts or taking brakes between occupations meant that mundane occupations; such as, self-care and housework would take them relatively longer on a daily basis. Employing these strategies meant less time and energy for other more personal meaningful occupations; including, occupations that could maintain valued relationships. The issue of self-developed strategies possibly being counterproductive is not believed to have been addressed in earlier occupational therapy literature.

A majority of participants experienced that the physical consequences of having advanced cancer resulted in their daily occupations primarily took place in their homes. This was reflected in photographs provided by the participants to illustrate quality of life in Study II and Study III. Mundane occupations at home, such as; eating breakfast, fresh baked bread cooling on the kitchen counter, working in the garden and also social occupations like participating in family celebrations and taking care of grandchildren, seemed to have gained a different value. According to Wilcock and Hocking (2015c), engagement in occupations linked to places such as the home, can provide a sense of belonging. Several participants described that their view of their home had changed since their illness. Some participants experienced their home as a liberating place where they could feel safe and comfortable while occupying themselves. Other participants described life at home as characterized by fewer and more sedentary occupations since their illness (Study I), and how their home had become a place of confinement (Study II and III) that negatively affected their social belonging and quality of life.
Dealing with the loss of occupations
A third of the participants in Study I talked about loss of occupations, which had previously been a valued part of their everyday lives. To prevent loss of valued occupations, several participants in Study I and Study III struggled to find new ways to maintain their engagement in these occupations. Rowles’ (Rowles, 1981) research on space and place for older people who are confined to their home, described the importance of having access to a ‘Surveillance zone’ (i.e. the area that can be viewed from a window), which enables the person to connect with the outside world. Participants from study III, who were confined to their homes, described similar experiences. Since functional limitations prevented some participants from independently leaving their homes, a window became a means to stay connected to life which that took place outside the home and enabled engagement in valued occupations, such as bird watching (Study III). This may be related to what Bandura (1995) calls “vicarious experiences”, meaning that experiences gained through watching others engage in occupations may enhance the person or viewers self-efficacy which is believed to be crucial to occupational development and pursuits. Moreover, according to Rowles (1991) this type of experience or engagement may “…imbue life with richness and diversity that transcends what we know and what we do” (p. 265). Other studies have emphasized the value derived from being engaged in occupations without actually performing them and these experiences may be perceived as an authentic and valued form of occupational engagement for people with advanced cancer (la Cour & Hansen, 2012; la Cour, Johannessen, & Josephsson, 2009; K.D. Lyons, 2006; M Lyons et al., 2002). Furthermore, participants in Study III expressed that it was the experience of the occupation, how it made them feel and the perceived meaningfulness of these occupations which were important to them and contributed to their quality of life. The significance of occupational engagement beyond performance has been
emphasized by several occupational science scholars (Hammell, 2004a; Hasselkus, 2011b; K.D. Lyons, 2006; Rowles, 1991, 2008; Townsend & Polatajko, 2007; Wilcock & Hocking, 2015d). An understanding of occupational engagement as the value a person places on occupations can also be found in the dyad between ‘being’ and ‘belonging’ as presented by Hitch et al. (2014b, p. 249) based on Wilcock and Hocking’s (2015d) conceptualization of occupation as the synthesis of; ‘Doing, Being, Becoming, and Belonging’. In Wilcock and Hockings conceptualization ‘Doing’ is understood as the medium through which people engage in occupations, ‘Being’ is the sense of who a person is as an occupational and human being, ‘Becoming’ is the continuous process of growth, development and change throughout a lifespan, and ‘Belonging’ is understood as a sense of connectedness to other people, places, communities and times (Hitch, Pèpin, & Stagnitti, 2014a; Wilcock & Hocking, 2015a). Findings from Study II and Study III, showed that a sense of belonging emerged when the participants experienced opportunities of connecting with others, places, or artefacts through occupational engagement which contributed to quality of life. Several participants in Study I, II and III described that loosing former valued occupations had resulted in a lack of both physical and intellectual challenges. Participants, who experienced loss of valued occupations, also expressed a need to add and/or learn new occupations or to re-engage in former occupations which they found personally meaningful. The expressed need to learn new things and to be mentally challenged is also found in other studies of people living with advanced cancer (K.D. Lyons et al., 2015; Mills & Payne, 2015; Vrkljan & Miller-Polgar, 2001). Morgan et al.’s (2015) study that explored living in the face of impending death showed that the participants had a desire to learn new physical occupations when their ability to engage in familiar occupations declined. Study III findings added to this knowledge by showing that the participants’ desire to learn new
occupations was not only restricted to physical occupations; but was also related to occupations that provided creative and intellectual stimulation, such as writing their memoirs (Study III).

Several participants in all three studies described how their job had occupied the majority of their life prior to their illness, and not being able to continue working had a negative influence on their quality of life. One participant from study I described it as, “my life changed from black to white”; He meant that he from having a daily life that was active and busy, after his illness had a daily life that was mostly spent resting on the couch and like several other participants, he struggled to fill his days in meaningful ways. Additionally, this perception corresponds with Scalzo et al.’s (2016) proposed definition of ‘transition’ as an: “unanticipated and unwanted passage from one life phase, condition, or status to another following an unexpected health-related illness or trauma” (Scalzo et al., 2016, p. 464) and requires constant adjustment to ongoing changes. Moreover, Jonsson (2010) talks about ‘occupational transition’ understood as “a major change in the occupational repertoire of a person in which one or several occupations change, disappear and/or are replaced with others” (Jonsson, 2010, p. 212). Furthermore, Jonsson’s (2010) longitudinal study of occupational transition from work to retirement, found that a person’s daily rhythm and routines were significantly influenced by the structure work impose on the person’s everyday life. For several participants in this study, a transitioning to a life without work left them with too much ‘free’ time that was experienced as a constant reminder of their significant loss, which greatly influenced their quality of life.

**Valued relationships and belonging**

When living with impending death, the importance of having close and intimate relationships may
be essential to quality of life or as one participant in Study III stated, ‘a life worth living’. Loss of occupations which had provided social interactions, such as; sports and social gatherings, were emphasized by several participants as especially difficult and a need for social belonging was a common theme in all three studies. Belonging is embedded in an understanding of human occupation together with ‘doing, being and becoming’ (Wilcock & Hocking, 2015a), and can be understood as a need for or sense of being connected with other people, places, cultures, communities and times (Hammell, 2014; Hitch et al., 2014a). In Study I, the participants described how occupational difficulties, influenced their ability to maintain significant relationships. In Study II and III, the participants talked about being with other people as essential for their perceived quality of life, which some described as ‘a greater need for affection’ (Study II) and ‘a shared togetherness’ (Study III).

It is recognized that humans are social beings that perceive themselves and others through their relations; for example, a husband-wife relationship or a parent-child relation (Hasselkus, 2011d; Raunkiær, 2016). The significance of being connected with family and friends is well documented as an important dimension of perceived quality of life for people living with advanced cancer (Cohen & Leis, 2002; Gourdji, McVey, & Purden, 2009; M. A. Pizzi, 2015; Solomon & Hansen, 2015). Thus, when trying to understand the deeper significance of being socially connected when living with advanced cancer, it may best be recognized through expressions of its absence. For example, through expressed feelings of loneliness, isolation and of being excluded or cut-off from interactions with other people, which may be seen as negative connotations of belonging. Feelings of isolation and loneliness may emerge when there is a difference between a person’s desired and experienced social life (Munk, Smærup, & Hansen, 2016). Findings in this project suggest that physical problems caused by advanced cancer (e.g. pain, functional decline, etc.)
could lead to increased dependence on friends and family; in particular, in ways of maintaining social belonging. These findings indicate that the ability to maintain a sense of belonging, for some people with advanced cancer, may not be something they are able to initiate themselves, but instead have to be mediated by others which could be experienced as a threat to the individual’s sense of control and autonomy. These findings correspond with Håkanson and Öhlen’s (2016) study on connectedness of people living on a palliative care unit and showed that illness and bodily decline challenged the participant’s abilities of feeling and staying connected; which forced them to find other ways to maintain connected, where one example could be connecting through others. Other studies have shown that loneliness and isolation can be a consequence of a life near its end and to feelings of being helpless or not useful (Keesing & Rosenwax, 2011; Krigel et al., 2014; Mills & Payne, 2015). Yet, Appelin and Berterö’s (2004) study of palliative home care found that being at home made the participants’ loneliness feel less pressing, since the home environment provided them with a sense of community. However, the findings of this study were not in agreement with Appelin and Berterö’s study, since several participants experienced their life at home with a sense of too much spare time reminded them of how their life had been before the cancer; which increased their feelings of loneliness and isolation and decreased their quality of life. For participants in all three studies, feelings of isolation were, at least to some extent, grounded in loss of occupations. Furthermore, these findings are supported by studies that showed occupations which provide contact with others, are essential for physical and mental well-being (Burchett & Matheson, 2010; Hammell, 2014; Hasselkus, 2011d; Iwama, 2006; Wilcock & Hocking, 2015b). In Study I and III, this was seen when functional decline resulted in fewer opportunities for visiting others or having casual encounters with other people on a daily basis; for instance, during shopping trips to local stores.
The ability to contribute to the lives of others is linked to an increased sense of belonging (Hammell, 2014; Wilcock & Hocking, 2015c). In the present study the importance of being able to help family and friends when needed was emphasized by several participants and perhaps even reinforced by their circumstances in which they required increasing help from family members. Participants in all three studies talked about feeling helpless and useless when they could no longer fulfill valued roles; for instance, when functional limitations prevented them from supporting their relatives as they had done previously (Study II and III) or continuing with voluntary work (Study I and III). The importance of being able to contribute to others when living with a life-threatening illness has also been found in other studies (M. O. Delgado-Guay et al., 2016; Hammell, 2004b, 2009b; Lala, 2011). Delgado-Guay et al.’s (2016) randomized controlled trial investigating cancer patients wishes at end of life, showed that 31% of the participants expressed that the ability to help others as being very important.

As several participants experienced increasing difficulties with mobility (Study I, II, and III), it became increasingly important for them to find new ways to maintain a sense of belonging; for instance, by using media and the Internet as mediators to stay connected. Thus, these new mediators enabled a sense of belongingness with their family and friends, their local community and wider society and in return reduced their feelings of isolation and enhanced quality of life. Wilcock and Hocking (2015a) reported that belonging is associated with “others, places and things” (p. 136); but a possible link between belonging and artefacts (things/objects) is still not well addressed in the occupational science literature. As stated by Hocking (1997), objects can be defined as: “all discrete living and inanimate things with a concrete form, excluding people” (p. 28). Ilott (2006) and in particular Hocking (Hocking, 1994, 1997, 2000) and Rowling (2008) have emphasized the importance and value of
artefacts; in regards to personal, social, spatial and cultural dimensions of a person’s life.

Findings in Study I and Study III suggest that various artifacts may gain a new importance by serving as valuable mediators for maintaining social belonging. However, artifacts could also evoke strong existential feelings of having to part with loved ones.

**Existential belonging through occupational engagement**
Several participants shared how living with advanced cancer generated reflections on existential aspects of life; for instance, a search for purpose, meaning in and of life and thoughts on own existence. Furthermore, participants (Study I, II and III) shared how living with advanced cancer made them reevaluate relations and how this generated closer relations with friends and family. The existential concern for loss of a possible future is also found in other studies and may lead to a different awareness of the importance of living in and for the present moment (Ellingsen et al., 2013; la Cour & Hansen, 2012; Vilhauer, 2008). Participants in this project described how certain things became important to them to do and say due to an awareness of the limited time they had left to live; for example, expressing feelings to loved ones even though this had not previously been a custom in their family (Study II), completing unfinished projects around the house (Study 1) or beginning to write down the family history in order to preserve it for future generations (Study III).

Several participants in this project (Study II and III) described engaging in a wide range of occupations in existential terms, in regards to the unique meaning and feeling these generated within an individual participant. Examples of such occupations as described by the participants were; taking a walk with a son at the cemetery, working in the garden, spending time in nature or reading with a grandchild. This corresponds with an understanding of ‘occupation’ as being
inherently neutral which is given value and meaning by individuals within their specific culture and context (Iwama, 2006; Polatajko, Davis, et al., 2007). In occupational science literature, existential and spiritual experiences have been ascribed to certain occupations, including; prayer, meditation, yoga, mindfulness, arts and journaling (C.H Christiansen, 1997; Humbert, 2016; Kang, 2003; Maley et al., 2016; Rosenfeld, 2001). A common feature among the occupations named by Christiansen (1997), Kang (2003) and Rosenfeld (2001) is that they involve little or no human interaction. Yet, other studies have found that occupations involving ‘doing something together’ and fostering a sense of belonging with others may be essential to existential and spiritual experiences (Hammell, 2004a; Hasselkus, 2011c; Haug et al., 2015). Haug et al. (2015) found close relationships to be the most influential dimension of spirituality for people with advanced cancer, which findings in this project also indicated; such as, spending time together during walks in nature or during shared musical experiences.

Participants in this project expressed the need to believe in something, that contributed to both maintaining the daily life at home and maintaining hope for the future; for instance, being able to return to work (Study I), having the ability to continue their usual life (Study II) or witnessing the birth of a great-grandchild (Study III). Other studies have shown that people who live with a life-threatening illness, such as advanced cancer, have a need to believe in something (e.g., hope, meaning or a higher power) (Grønvold, 2006; Hvidt, Iversen, & Hansen, 2013; Maley et al., 2016; Moestrup & Hvidt, 2016; M.-E. H. Reynolds, 2008). Reynolds’ (2008) longitudinal qualitative study of hope in adults with advanced cancer, showed that their strong sense of hope did not change over time; but remained consistently positive throughout the study. In similar, findings in this project showed that for several participants engaging in valued occupations could contribute to life continuity and existential belonging which consequently enhanced their quality of life.
It is well known that engaging in creative occupations can generate existential experiences that may enhance a sense of belonging (Blanche, 2007; Dickie, 2004). For instance, la Cour et al.’s (2005);(2007) studies, suggested that engaging in creative occupations may create existential possibilities of connecting with life for people living with a life-threatening illness. In all three studies, participants both talked about the significance of creative occupations and provided numerous examples (e.g. woodworking, flower arranging, painting, needlework and gardening); moreover, participants described that these creative occupations provided them with tranquility and a sense of belonging. However, creative occupations also require courage in the sense that they may involve expressing difficult emotions (Hasselkus, 2011a; la Cour et al., 2005). Creative occupations can be seen as an intense expression of being (Pollard, 2006) and self-affirmation of whom one is as an occupational and human being (Wilcock & Hocking, 2015b). This is in agreement with findings in la Cour and Hansen’s (2012) study of aesthetic engagement when living with advanced cancer, which showed that occupations could serve as a means to negotiate a life heading towards death. Similarly, several participants in the inherent studies shared how creative expressions provided valued occupational experiences that contributed to quality of life while living with impending death. Disclosure of personal artefacts, such as heirlooms, has been found both to contribute to hope for people living with advanced cancer (McClement & Chochinov, 2008) and provides a way to preserve a person’s “occupational potential” (Pollard, 2006, p. 151); in the sense that his/her work, values and beliefs will be carried on after the person has died. For participants in Study I and III, creative expressions were used as existential ways of communicating something about themselves and included occupations such as; a painting, a handmade jewelry box or a knitted pair of pants for a future great-grandchild.
Hammell (2014) described how connectedness to lost family members can be linked to a sense of belonging. The ability to remember big and small events experienced with people one used to know, can be a powerful way to forge bonds and thereby, a sense of belonging (Mattingly, 2010). Moreover, engaging in occupations that are “steeped in history provides a sense of belonging to something that is both shared and ongoing” Wilcock and Hocking (2015cp. 212). In Study II and III, this was found when the participants described how living with impending death generated thoughts of their own existence and thoughts of lost relatives; for instance, during a walk through a cemetery that could spark memories of deceased relatives, through a new found interest in family history or through heirlooms. Findings from this project showed that various artifacts may gain a new significance for people with advanced cancer, in the sense that they may evoke strong existential and spiritual feelings of life moving towards its end and having to part with loved ones.

In summary
The three studies provided complementary perspectives in relation to the overall objective of the project. Collectively, they suggest that quality of life for people living with advanced cancer is associated with continuity of everyday life; including the ability to engage in valued occupations with the possibility of maintaining a sense of belonging to significant people, places and objects. However, the findings also indicated that living with advanced cancer is a complex and challenging process that may require on-going adjustment to continuous physical decline and decreasing abilities, which may challenge the individual’s quality of life when living with impending death.
METHODOLOGICAL CONSIDERATIONS

Research design
This project was nested in the ACQ Project which had some implications in regards to the inherent studies. The qualitative data from the cross-sectional study that was used primarily in Study I was part of a larger data collection from the ACQ Project, which employed multiple research methods to estimate and explore needs in order to gain insight into the situations of individuals. The qualitative questions in the ACQ Project were not intended to capture enriched accounts of the participants’ experiences, but were rather intended to capture descriptive data of how daily occupations were managed when living with advanced cancer. A consequence of this framing was that the interviews in Study II and Study III that were focused on quality of life, may have been coloured by the previous context with its focused on functional limitations and abilities. Thus, since the participants in Study II and Study III also took part in Study I, their understanding of quality of life may have been influenced by this framing in respect to certain aspects of quality of life.

In Study II and Study III the initial question to investigate quality of life was “What does quality of life mean to you”. The author’s intension with this question was to allow the participants to describe quality of life in their own words. Although none of the participants asked for a clarification of the concept, in retrospect it can be questioned how suitably this question was to elicit descriptions of quality of life, since their initial answers were rather brief, compared to the follow-up questions (e.g. “What is important in your everyday life?”). A possible explanation might be that ‘quality of life’ may not be something that is part of the everyday language. People may have an idea of what might contribute or prevent quality of their lives, but when asked about it specifically it may be difficult to put into words. For this reason photo-elicitation showed to be a
valuable way to elicit additional reflections of quality of life, both because of the process of producing the photographs that allowed the participants time to reflect and the follow-up interview that enabled the participants to share additional thoughts that was generated by the first interview.

Inviting participants to describe what quality of life meant to them, may have impelled some participants to focus on the more positive aspects of their life. In light of the seriousness of the participants’ life situation and the predominantly positive experiences they shared, this may have been the case in Study II and Study III. However, a possible outcome is that this fairly positive focus may have added an aspect of quality of life regarding how people with advanced cancer are able to construct their daily life in ways that are perceived as meaningful despite living with impending death.

Quality of life was explored from an individual and occupational perspective, this means that there may be aspect of quality of life that has not been addressed or has been overlooked; for instance, how cultural, societal and political dimensions may influence quality of life for people with advanced cancer.

**Sampling**
Different strategies were used for sampling in the studies. The participants in Study I were a sub-sample from one of the hospitals that took part in the ACQ Project (Brandt et al., 2016; Peoples. et al., 2017). The reason for selecting patients from only one of the hospitals was that the author had performed the data collection from this particular hospital and had gained valuable knowledge about this group of participants (e.g. had seen them in their homes surrounded by their personal
belongings and met their relatives) which contributed to the overall understanding of the data. Another reason for only including data from one of the hospitals was more pragmatic, since it did not seem realistic within the timeframe to include qualitative data from the total sample of 164 participants. This meant that the sample consisted of participants from a distinct geographical area of Denmark more specifically the Island of Funen; which is primarily characterized by smaller towns and rural areas. Therefore, the sample may be seen as being a selective group and may not reflect the greater population of Denmark.

Sampling for the cross-sectional study proved to be more difficult than expected, which resulted in prolonging the data collection. A rather large percentage of patients (54%) declined to participate in the project; however, when compared to other studies with the same population, the number of non-participants was within the expected amount. Reasons patients gave for not participating in the study were; lack of resources, or because their everyday life was already very busy and they could not take on another activity; for instance, their everyday life was filled with daily cancer treatments and visits by various health professionals in their homes. To increase recruitment, different strategies were initiated to raise awareness about the project and included; sending out information letters, participating in staff meetings to report the projects progress and supplying the contact nurses with a practical pocket folder with information about the project with suggested sentences they could use when they approached eligible patients about participating in the project. The difficulties concerning recruitment and prolonged data collection for Study I, also influenced recruitment for Study II and Study III. Due to the prolonged data collection from the cross-sectional study a large number of participants had died or their condition had deteriorated to such an extent that it prevented them from participating in Study II and Study III, including some of the younger participants. Therefore the sample may be seen as a selective group of older
participants, and important aspects of quality of life, for example starting a family or having younger children, may not have been explored. However, the possibility of including some of the same participants in all three studies made it possible to pursue certain findings in the subsequent studies that thereby became increasingly more focused; such as, dimensions of belonging in regards to quality of life.

The respective sample size of ten participants (Study II) and nine participants (Study III) was the result of a convenience sample. The size of the sample was partly due to working with this particular group of participants (severely ill people) and partly due to the prolonged data collection of the preceding cross-sectional study, which prevented continued recruitment.

Although the analysis showed recurring themes across the sample, data saturation may not have been reached (Polit & Beck, 2004b).

The fact that there was an even distribution between men and women in the present project may be considered a possible strength, since it is well-known that men are underrepresented in health research (Polit & Beck, 2008, 2013).

**Triangulation**

In order to enhance credibility of the studies, the methods for data collection were triangulated and included; interviews, informal observations and photo-elicitation (Maxwell, 2005). This combination of methods made it possibility to contextualize the information that was obtained during the visits in the homes of the participants. For instance, when the participants talked about specific occupations which had become difficult for them to perform, in some cases the author was able to see these difficult occupations being performed, which allowed the author
the opportunity to ask follow-up questions in this regard. The informal observation may have also provided access to a more tacit kind of knowledge, the participants themselves may not have been aware of or able to articulate. An example of this was recorded in a field note, regarding a participant who had talked about the bond she and her husband shared and how he supported her on a daily basis:

“The interview took place by a table in the living room. There were flowers and a lit candle on the table, indicating that they had prepared for the visit. The husband arranged the cups and plates, poured the coffee and then left the room. One time during the interview, he gently knocked at the door (as if he did not want to disturb) and asked if there was anything we needed. When the participant said no, he quietly left the room. His interaction was done in a respectful and considered manner, which illustrated some of the things the participant had said about her life together with her husband; a life she said was filled with respect and devotion for each other.”

During the interview, when she was asked to give examples of the support she received from her husband, in general the examples she gave were more specific and practical. Like how he would help her put her necklace on every morning or how he would hang the wet clothes up, because this task had become too difficult for her to perform. The opportunity to observe the relationship between the participant and her husband, added to the understanding of the participant’s reflections and experiences, through the subtle example of her husband’s support; which she may not otherwise have been able to put into word during the interview.

Using photo-elicitation proved to have both advantages and disadvantages. The analysis of the photographs revealed a different understanding of how occupational engagement may contribute
to perceived quality of life. For instance, one of the photographs was of a bird feeder that the participant took to show his appreciation of nature and bird watching, which also became a representation of a life, lived indoors. The photograph of the bird feeder also showed visual participation as a different kind of occupational engagement that contributed to belonging; something he had not articulated in the first interview. Another example was when a participant was asked about her quality of life and she began talking about the importance of continuing her familiar life, but she found it difficult to elaborate on this topic. In her case, her photographs of her everyday life situation, such as; eating breakfast, freshly baked bread cooling on the kitchen counter and gardening, provided a means through which she could express the more tacit “taken-for-granted” understanding of her everyday life and how this was linked to her sense of quality in her life.

However, using photographs was not appealing to all the participants and one participant declined to participate in photo-elicitation. Taking photographs was not something this participant had a lot of experience doing and he expressed that this was something he had no interest in. Although this participant’s perception of quality of life was explored in Study II, it is unknown whether photographs taken by a person who was not familiar with taking photographs would have provided different kinds of images that could have added to the overall understanding of perceived quality of life when living with advanced cancer.

The combination of semi-structured interviews and photo-elicitation also provided useful information which might not otherwise been obtained by using interviews alone, since this facilitated additional reflections, as one participant from Study III described:
“It’s been very exciting using pictures to illustrate quality of life. It made me think much more about my quality of life. In this way, it has become clearer what quality of life means to me. If I look back ten years, I could see that my quality of life was linked to me being healthy. Today, I have an incurable illness and my quality of life means something very different than being healthy. Now, I see my illness as a life condition and I feel healthy even though I’m seriously ill.”

The task of having to take photographs made this participant aware of how her view of quality of life had changed and how she now perceived quality of life from a new perspective. Thus, this provided the opportunity to explore ways in which her understanding of quality of life had changed after her illness, and also, prompted the author to add an extra question to the semi-structured interview guide concerning how views of quality of life might possibly change over time.

**Member checking**

Multiple terms are used to refer to the process of getting feedback from research participants, but with member checking being the term most commonly used (Thomas, 2017). Although ‘member checking’ may indicate the assumption that a “correct” version or reading of the data exists (Thomas, 2017; Tracy, 2010), this was not the intention of member checking for this project. Instead, it was simply a way to ensure whether the authors account corresponded with the participants’ recollections of what they communicated during the interview and as a way of building rapport with the participants. Member checking seemed to be particularly useful in
regards to the latter, as a way to (re)establish rapport, due to the extended period between data collection for Study I and the subsequent studies.

**Transferability**

In qualitative research, transferability may be understood as the extent to which the findings can be transferred or applied beyond the boundaries of the project to a wider population and in different contexts (Green & Thorogood, 2009a). Since qualitative research is situated in a specific social, cultural and historical context; human experiences are heavily mediated by the setting in which they occur. Therefore, transferability entails providing readers with a sufficient and detailed description of the research setting and the participants, as well as, the transactions and processes observed during the research, with the purpose of allowing the reader the ability to judge the applicability of the findings to other groups, contexts and settings (Finlay, 2006; Krefting, 1991). This type of transferability is also known as “analytical generalization” (Kvale, 1996b, p. 233).

A possible way to judge whether the findings in this project are transferable, is to compare them with research findings from other settings, including other groups (Patton, 2002); for example, if similar aspects of quality of life also applies to people with other diagnoses and in other countries.

In this project, efforts were made after each study to compare and contrast the findings in relation to existing research. Thus, the findings in Study I showed that people develop their own strategies to maintain valued occupational engagement, and when compared with existing research, similar findings could be found in research with the same population in Australia and USA (K. D. Lyons et al., 2012; Morgan, 2012) and with people living with heart failure in Sweden (Norberg, Boman, Löfgren, & Brännström, 2014). Moreover, the findings in Study III, suggested that belonging was a significant aspect of quality of life; which corresponded with finding from studies of people living
with other types of life-threatening illnesses, such as high spinal cord injury (Hammell, 2004b), traumatic brain injury (Conneeley, 2003) and people with a mental illness (Blank, Finlay, & Prior, 2016). However, although attempts were made to provide detailed contextual information for all three studies, there may be factors perceived as being critical to the readers, which may not have been addressed.

**IMPLICATIONS and SUGGESTIONS FOR FUTURE RESEARCH**

**Implications for practice**

Although occupational engagement and quality of life can mean different things to different people, the findings suggest that there may be common features across the three studies with relevance for clinical practice. These features will be presented below.

1. Findings indicate that quality of life could be linked to the value the individuals placed on occupations, understood as the experience or feeling the participant derived from these occupations rather than the ability to perform them. This knowledge may be useful when planning future interventions for people with advanced cancer that are focused on adaptive strategies, such as prioritizing occupations, time and resources, with the purpose of maintaining continuity and engagement in valued occupations.

2. Loss of occupations that used to contribute to daily life continuity and aspects of belonging, were found to negatively influence the participants’ quality of life. This knowledge may inform future interventions that are focused on engagement in occupations that contributes to meaningful relationships and community engagement in order to reduce feelings of isolation and enhance the overall quality of life for people with advanced cancer.
3. The findings indicate that having existential and spiritual needs met may enhance quality of life for people with advanced cancer, which may suggest that interventions that are focused on supporting people in ways to be engaged in occupations that contribute to existential and spiritual dimensions, may be significant when living with impending death.

4. The findings suggest that it may be highly subjective what may contribute to quality of life for people with advanced cancer. Client-centered interventions that are focused on the needs of the individual and are planned in close collaborations with the individual and his/her relatives have the potential to enhance a life worth living for people whose life is moving towards its end.

Suggestions for future research

This project revealed several areas where further research may be needed:

1. This project only included people with advanced cancer. However, in interventions that target people with advanced cancer, the person with cancer as well as his/her relatives may be seen as the unit of intervention. During data collections in the participant’s homes, it was observed how the relatives had a central role in creating a meaningful daily life for the participants, which was also emphasized by several participants during the interviews. Therefore, it is relevant to include the perspective of relatives in future research addressing quality of life for people living with advanced cancer.

2. Study II and Study III explored perceived quality of life, and was based on data from two interviews with two weeks in between. It could be interesting to explore whether quality of life change over time and as the person gets closer to end-of-life and if certain occupations become more or less important.
3. The findings from all three studies indicate that occupational difficulties may influence people with advanced cancer who live alone differently than from those who were cohabiting, especially as their cancer progresses. Future research with a particular focus on occupational engagement for people living alone with advanced cancer is needed.

4. Several participants talked about feelings of isolation and loneliness, and research that explores these aspects for people living with advanced cancer may contribute with knowledge of ways to prevent this. This type of research may be useful for future interventions which are focused at enhancing possibilities for belonging that improve quality of life of the level of the individual as well as on society level to address possible inequalities in health.

5. The findings suggest that artefacts such as personal items and heirlooms can serve as means through which people with advanced cancer may experience dimensions of belonging. However, further knowledge is needed to understand in which way artifacts may contribute and support feelings of belonging.

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### APPENDIX LIST

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<th>Description</th>
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<td>Appendix G:</td>
<td>Information guide, first interview, Study II and Study III</td>
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<td>Appendix H:</td>
<td>Photo-elicitation interview, Study II and Study III</td>
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<td>Appendix I:</td>
<td>Guideline for transcription</td>
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Appendix A: Literature search and search strategy

In order to obtain current national and international research with relevance to the objective and aims of the project, a literature search was performed several times throughout the research process (Petticrew & Roberts, 2006; Sandelowski & Barroso, 2007). Each phase/study of the project compelled reflecting and rethinking the work that was completed in relation to the work/phase that would follow. For instance, it became clear after Study II that additional knowledge was needed about different methods for analyzing visual material, before I initiated the analysis of data from Study III. Moreover, the findings from Study III necessitated a literature search for additional knowledge about ‘belonging’ from an occupational perspective. Several literature searches were performed:

- at the beginning of the research project to map the evidence available in relation to the overall objective of the project; for instance, to map current literature about advanced cancer in general and within the field of occupational therapy and occupational science.
- after analysis of each study in relation to specific findings of the studies, for example, occupational strategies in relation to advanced cancer and occupational therapy and the concept of belonging in relation to advanced cancer.
- at the final stage of the project (i.e., three years after the initial literature search), the first literature search was repeated in order to obtain the most recent evidence before completing the thesis.

Prior to the first literature search, a preliminary search in selected journals was performed to locate relevant key terms. A search was conducted in the following databases: Medline, Cinahl and OVID, using the key search terms occupation, manage, cancer, home, Quality of life.

The following search questions were applied:

1. What is known from the literature about how people with advanced cancer manage occupations when living at home?
2. What is known from the literature about perceived quality of life for people with advanced cancer living at home?

The findings from the reviews of the literature is integrated and presented in the following sections of the thesis (Appendix A).
**Search Strategy:**
(Final literature search - example from one database)

<table>
<thead>
<tr>
<th><strong>Search questions</strong></th>
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<tr>
<td>1. What is known from the literature about how <strong>people with advanced cancer</strong> <strong>manage occupations</strong> when <strong>living at home</strong>?</td>
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<tr>
<td>2. What is known from the literature about perceived quality of life for people with advanced cancer living at home?</td>
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<th><strong>Key terms</strong></th>
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<td>1) Occupation</td>
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<td>2) Manage</td>
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<td>3) Advanced cancer</td>
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<td>4) Living at home</td>
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<td>5) Quality of life</td>
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<tr>
<th><strong>Search period</strong></th>
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<tr>
<td>Search period was set to 2000 – 2016 in order to obtain the most recent literature.</td>
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<table>
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<tr>
<th><strong>Selected databases</strong></th>
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<tbody>
<tr>
<td>The following databases were chosen:</td>
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**Medline:**
- since it is the largest medical database of peer-reviewed research literature that also contains a large amount of multidisciplinary studies.

**Cinahl:**
- since it is a large database covering research studies for nursing and allied health professionals. Cinahl also have a large amount of qualitative studies that can be relevant when retrieving literature on perceived quality of life.

**OVID:**
- to explore EMBASE, PsycINFO, and Global Health databases, since these include literature that MEDLINE may and may not include.

<table>
<thead>
<tr>
<th><strong>Search principles</strong></th>
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<tr>
<td>It was not my purpose to conduct a complete systematic literature review of anything ever published about cancer, occupations and quality of life, but I wanted to be as systematic as possible to obtain sufficient and relevant literature. A search strategy, including a search matrix [see below], was developed to ensure a systematic search in the selected databases. To increase retrieval of relevant studies, browsing and berry- and picking techniques was applied (e.g. “related works”, author and citation search).</td>
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<tr>
<th><strong>Search matrix</strong></th>
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The same search matrix was used for all of the three chosen databases; Medline, Cinahl and Ovid. MESH terms were used when possible. Below is an example of the results from search in Medline.

<table>
<thead>
<tr>
<th>Search terms / Databases</th>
<th>1) Occupation</th>
<th>2) Manage</th>
<th>3) Cancer</th>
<th>4) Home</th>
<th>5) Quality of life</th>
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### Appendix B: Participants characteristics

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<td>Retired</td>
<td>Rural area Colon Not stated I</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>74</td>
<td>Man</td>
<td>Single</td>
<td>Town house</td>
<td>Retired</td>
<td>City</td>
<td>Lung</td>
<td></td>
<td></td>
</tr>
<tr>
<td>53</td>
<td>Woman</td>
<td>Single</td>
<td>Town house</td>
<td>Early retirement</td>
<td>Small town Breast</td>
<td>I, II, III</td>
<td></td>
<td></td>
</tr>
<tr>
<td>87</td>
<td>Woman</td>
<td>Single</td>
<td>Town house</td>
<td>Retired</td>
<td>Town</td>
<td>Breast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55</td>
<td>Man</td>
<td>Married</td>
<td>House</td>
<td>Sick leave</td>
<td>Small town Other</td>
<td>I</td>
<td></td>
<td></td>
</tr>
<tr>
<td>68</td>
<td>Woman</td>
<td>Single</td>
<td>Apartment</td>
<td>Retired</td>
<td>Small town Other</td>
<td>I</td>
<td></td>
<td></td>
</tr>
<tr>
<td>76</td>
<td>Woman</td>
<td>Single</td>
<td>House</td>
<td>Retired</td>
<td>City</td>
<td>Cervix</td>
<td></td>
<td></td>
</tr>
<tr>
<td>81</td>
<td>Man</td>
<td>Married</td>
<td>House</td>
<td>Retired</td>
<td>Rural area Prostate</td>
<td>I</td>
<td></td>
<td></td>
</tr>
<tr>
<td>74</td>
<td>Man</td>
<td>Single</td>
<td>House</td>
<td>Retired</td>
<td>Rural area Prostate</td>
<td>I, II, III</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65</td>
<td>Man</td>
<td>Married</td>
<td>House</td>
<td>Retired</td>
<td>Rural area Colon</td>
<td>I, II, III</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C: Informed consent

Informed Consent

I hereby confirm that I have received information about the project and consent to participate (see also information letter)

I participate voluntarily in the project and can withdraw at any point, without it having any influence on my present or future treatment.

☐ I wish to participate in the project (tick the box)

Name:

Date: ____________________________  Signature: ______________________________________________________________________
Informed consent

Use of photographs

I consent voluntarily that the photographs that are taken by me as the signed person in relation to this project can be used:

☐ In relation to publication of articles in professional and academic journals (tick the box)

☐ In relation with presentation at public conferences (tick the box)

☐ In relation with teaching (tick the box)

In cases where the photographs display recognizable images, such as faces, these can be used:

☐ as they are (tick the box)

☐ after any recognizable image has been removed; for instance, blurred or blacked out (tick the box)

Additionally considerations in relation to use of photographs (e.g., timeframe for use of photograph):

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

________________________________________________________________________________

Name:
**Appendix D: Semi-structured interview guide for Study I**

The questions were part of a larger data collection, conducted before and after structures assessments.

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>FOLLOW-UP QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please describe a typical day?</td>
<td>- In which way was it typical?</td>
</tr>
<tr>
<td>How do your daily occupations work for you?</td>
<td>- Do you manage the occupations independently?</td>
</tr>
<tr>
<td></td>
<td>- How does it work in relation to your family and your usual roles?</td>
</tr>
<tr>
<td>Have any of your daily occupations changed or gained a new meaning after you were diagnosed with cancer?</td>
<td>- Which and in what way?</td>
</tr>
<tr>
<td></td>
<td>- Can you elaborate on that?</td>
</tr>
<tr>
<td>How do you organize your everyday life?</td>
<td>- Have you changed any of your daily routines?</td>
</tr>
<tr>
<td></td>
<td>- In what way?</td>
</tr>
<tr>
<td></td>
<td>- Are there any occupations that are managed in a different way?</td>
</tr>
</tbody>
</table>
Appendix E: Information letters, first interview, Study II and Study III

Dear

My name is Hanne Peoples. I am an occupational therapist working as a PhD student at the University of Southern Denmark and I am involved in the research project: Activity, Cancer and Quality of Life at Home (called the AKT-project). The AKT-project is run by two partners: the University of Southern Denmark and The National Board of Social Services. The overall purpose of the AKT-project is to describe the challenges people may encounter in their daily lives when living with advanced cancer. The intention is to develop an intervention that can support people living with advanced cancer to manage daily life at home.

You have previously participated in the AKT-project, where you received a visit from me the XX/XX-XXX. At that time the visit was primarily about your daily activities and how your cancer has influenced these activities. I would also like to invite you to two interviews with the purpose of investigating how you experience quality of life in your daily life.

Both visits are expected to last approximately one hour and there will be two weeks between the visits.

I will contact you by telephone in about one week to inquire if you are interested in participating in this part of the AKT-project. If you are interested, we can make an appointment for a visit.

You are also very welcome to contact me on my mobil phone: 29 91 82 14

Kind regards

Hanne Peoples, PhD student, AKT-project
University of Southern Denmark
Tel: 29 91 82 14
Appendix F: Information letter – photo-elicitation, Study II and Study III

The next visit will be (date):

The topic for the next visit will be quality of life, but it will take a different form since we will talk about the photographs you have taken.

Before next visit:

Take photographs of objects and situations that you connect with quality of life. Be aware that there may be recognizable details on the photographs you take; this can be avoided by taking photographs of people from behind.

Two days before next visit:

Choose maximum 10 photographs and e-mail them to me using the following e-mailaddress:

hpeoples@health.sdu.dk

Next visit will be about the photographs you have taken.

If you have any questions, you are welcome to contact me – either by e-mail or by phone: 29918214.

Thank you again for your participation in this study.

With kind regards

Hanne Peoples
Appendix G: Interview-guide for first interview in Study II and Study III

The semi structured interview-guide is constructed with a short introduction followed by three broad open-ended questions, with suggestions to follow-up questions.

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>FOLLOW-UP QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introductory</td>
<td>- Short information about the purpose in relation to the first visit (Study I).</td>
</tr>
<tr>
<td></td>
<td>- Last time I visited you, we talked about your daily life; for instance, which activities you typically spend time on. This time I would like to talk with you about quality of life.</td>
</tr>
<tr>
<td></td>
<td>- Possibility of break, if needed.</td>
</tr>
<tr>
<td></td>
<td>- Right not to answer and anonymity.</td>
</tr>
<tr>
<td></td>
<td>- Informed consent.</td>
</tr>
<tr>
<td></td>
<td>- Questions before we start?</td>
</tr>
<tr>
<td><strong>What does quality of life mean to you?</strong></td>
<td>- What contributes to quality of life for you in your daily life? (In which way, how?)</td>
</tr>
<tr>
<td></td>
<td>- What can influence your quality of life? (In which way, how?)</td>
</tr>
<tr>
<td></td>
<td>- Has your illness changed your view on quality of life? (In which way, how?)</td>
</tr>
<tr>
<td></td>
<td>- Are there things that are more meaningful to you now? (In which way, how?)</td>
</tr>
<tr>
<td></td>
<td>- Can you give me an example of something that is meaningful to you?</td>
</tr>
<tr>
<td><strong>What is important for you in your everyday life?</strong></td>
<td>- How would you like your everyday life to be now and in the future?</td>
</tr>
<tr>
<td></td>
<td>- Is there something in your everyday life that you especially like to do?</td>
</tr>
<tr>
<td></td>
<td>- Can you tell me about an experience or a day that you thought was especially good / enjoyable? – What made the experience / day so good?</td>
</tr>
<tr>
<td></td>
<td>- Have you experienced situations or days where you were not able to participate or do something that was important for you? If yes, what was it and what was the reason?</td>
</tr>
<tr>
<td></td>
<td>- Where does your day usually take place?</td>
</tr>
<tr>
<td></td>
<td>- What do you typically spend time on, on a daily basis?</td>
</tr>
<tr>
<td></td>
<td>- What do you typically do when you are alone?</td>
</tr>
<tr>
<td></td>
<td>- What do you do to relax / recharge?</td>
</tr>
</tbody>
</table>
### Who do you typically spend time with on a daily basis?
- Family, friends, neighbors, others? How often?
- What do you do when you are together with others (can you give some examples?)
- What does contact to other people mean to you?
- How do you stay in contact with other people (family, friends neighbors, others?)

### CLOSING COMMENTS
Is there something about quality of life and your daily life that we have not addressed that you think is important to include?
- Do you have any questions?

### NEW APPOINTMENT
The purpose of the next visit and introduction to photography.
- The topic for the next interview will also be quality of life, but we will talk about it in a different way.
- I would like you to take pictures of objects and situations that you connect with quality of life. When I say this are there specific photographs you immediately start to think about?
- At the next visit, we will talk about the photographs you have taken (a different way to talk about quality of life)

### Information about photographs and anonymity.
Ways to avoid taking photos with recognizable images (e.g. by taking the photo in profile or from the back).
Appendix H: Photo-elicitation interview in study II and III

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>FOLLOW-UP QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTRODUCTORY COMMENTS</strong></td>
<td>- Purpose with this second interview in relation to the last</td>
</tr>
<tr>
<td></td>
<td>The topic for this interview will also be about quality of life, but the interview</td>
</tr>
<tr>
<td></td>
<td>will have a different form than last time, because the interview will be about the</td>
</tr>
<tr>
<td></td>
<td>photographs that you have taken (a different way of talking about quality of life)</td>
</tr>
<tr>
<td></td>
<td>- I’m interested in your experiences</td>
</tr>
<tr>
<td></td>
<td>- Please let me know if you need to take a break.</td>
</tr>
<tr>
<td></td>
<td>- You have a right not to answer at any time / all the information you share will be</td>
</tr>
<tr>
<td></td>
<td>anonymized.</td>
</tr>
<tr>
<td><strong>Introduction</strong></td>
<td>- Did our last conversation make you think of or remember something that you will</td>
</tr>
<tr>
<td></td>
<td>like to share?</td>
</tr>
<tr>
<td><strong>PHOTOGRAPHS</strong></td>
<td>- Please select the photographs you want to talk about and arrange them into the</td>
</tr>
<tr>
<td></td>
<td>order you wish to talk about them.</td>
</tr>
<tr>
<td></td>
<td>- Please describe each photograph:</td>
</tr>
<tr>
<td></td>
<td>o What and who does the photograph depict? (e.g. who, where and what)</td>
</tr>
<tr>
<td></td>
<td>o What were your thoughts when you took this photograph?</td>
</tr>
<tr>
<td></td>
<td>o What does the photograph mean to you?</td>
</tr>
<tr>
<td></td>
<td>o How does the photograph relate to quality of life?</td>
</tr>
<tr>
<td><strong>Are there things or situations that you would</strong></td>
<td></td>
</tr>
<tr>
<td><strong>have liked to have taken a photograph of, but</strong></td>
<td></td>
</tr>
<tr>
<td><strong>not because you did not have the opportunity?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>CLOSING COMMENTS</strong></td>
<td>Is there something in relation to quality of life and your daily life that we have</td>
</tr>
<tr>
<td></td>
<td>not addressed that you think is important to include in this interview?</td>
</tr>
</tbody>
</table>
Appendix I: Guideline for transcription

All transcripts must contain:

- Participants ID
- Date for the interview
- Date for the transcription
- Consecutive page numbers

Transcribing from oral to written mode:

- The interview is transcribed verbatim, meaning a reproduction of the actual talk, with the precise words and utterances used by the participants, including slang words, hesitations and interruptions.
- Expressions such as ‘hmm’ or ‘yes’ from the interviewer to support the natural flow of the conversations, are included in the transcription.
- If any names are mentioned during the interview, these are anonymized stating their connection to the participant, for example wife/husband/son/friend etc. If any relatives participated in the interview and mentions the participant by name, this is changed to the participants ID.
- If places are mentioned, then these are likewise anonymized.
- Pauses are marked as ... and long paused ......
- Emotional expressions such as laughter and sighs are written in parenthesis, for example (sigh)
- When words or sentences are emphasized these are written in italic, if they are extra emphasized then an underline is added to what is written in italic.
Managing occupations in everyday life for people with advanced cancer living at home

Hanne Peoples, Åse Brandt, Eva E. Wæhrens & Karen la Cour

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Managing occupations in everyday life for people with advanced cancer living at home

Hanne Peoples\textsuperscript{a}, Åse Brandt\textsuperscript{a,b}, Eva E. Wæhrens\textsuperscript{a,c} and Karen la Cour\textsuperscript{a}

\textsuperscript{a}Department of Public Health, Research Unit for General Practice, The Research Initiative for Activity Studies and Occupational Therapy, University of Southern Denmark, Odense, Denmark; \textsuperscript{b}The National Board of Social Services, Odense, Denmark; \textsuperscript{c}The Parker Institute, University Hospital Bispebjerg & Frederiksberg, Copenhagen, Denmark

\textbf{ABSTRACT}

\textbf{Background:} People with advanced cancer are able to live for extended periods of time. Advanced cancer can cause functional limitations influencing the ability to manage occupations. Although studies have shown that people with advanced cancer experience occupational difficulties, there is only limited research that specifically explores how these occupational difficulties are managed.

\textbf{Objective:} To describe and explore how people with advanced cancer manage occupations when living at home.

\textbf{Material and methods:} A sub-sample of 73 participants from a larger occupational therapy project took part in the study. The participants were consecutively recruited from a Danish university hospital. Qualitative interviews were performed at the homes of the participants. Content analysis was applied to the data.

\textbf{Results:} Managing occupations were manifested in two main categories: (1) Conditions influencing occupations in everyday life and (2) Self-developed strategies to manage occupations.

\textbf{Significance:} The findings suggest that people with advanced cancer should be supported to a greater extent in finding ways to manage familiar as well as new and more personally meaningful occupations to enhance quality of life.

\textbf{Introduction}

The number of people living with advanced cancer is increasing, and due to an aging population and more effective cancer treatments, people with advanced cancer are able to live for extended periods of time [1–3]. However, cancer in advanced stages can cause functional limitations that can make it difficult to manage occupations in everyday life [4–8]. Thus, there is a growing need to understand how best to enable occupations for people in such circumstances.

‘Managing occupations’ refers to the ability to perform and participate in necessary as well as personally meaningful occupations. It is through occupations that people structure days and organize their time [5,6,8–11]. From an occupational science perspective, the ability to manage occupations that individuals find necessary and meaningful, can influences their health [12] and contribute to quality of life [5,12–15].

Existing research points out that cancer in the advanced stages can lead to difficulties in everyday life [8,11,16]. For example, Lyons et al. conducted a study of 23 people with life-threatening illnesses and found that difficulties managing occupations may lead to disengagement in former occupations [5]. Salander et al.’s study on everyday life of 28 people with malignant brain tumour showed that the participants experienced periodical changes in their ability to manage occupations which influenced the continuity of their everyday life [9]. However, none of these studies described how the participants dealt with these occupational difficulties.

It could be argued that the everyday life becomes less important when one has a life-threatening illness, but research shows that people with advanced cancer have a desire to continue with their lives as before their illness, such as maintaining their usual occupations [6,8,16–19]. The ability to manage occupations may be a way to preserve a familiar everyday life [10,6,20,21], maintain valued daily routines [11,19] and enhance quality of life [22].
Although studies have found that people with advanced cancer experience difficulties managing occupations in their everyday lives, only a few studies specifically explore how these difficulties are managed. Identifying how people with advanced cancer manage occupations can add knowledge of how this may influence their everyday lives, as well as being useful in planning occupational therapy interventions aimed at maintaining occupational engagement.

A Danish survey of 977 people with advanced cancer found that they had unmet needs related to activities of daily living [23], and studies have recognized a need for further research on the everyday lives of people with advanced cancer, particular in large populations [8,11,20]. A literature review aimed at scoping the existing literature on activity-based occupational therapy interventions failed to identify any interventions for people with advanced cancer [24]. To address this lack of knowledge the research project ‘Activity, advanced cancer and quality of life at home’ was developed [25]. The objective of this research project was to investigate the occupational needs and problems of people with advanced cancer living at home, and to develop and evaluate the outcomes of a home-based activity intervention program [26]. The first study in the ‘Activity, advanced cancer and quality of life at home’ project was a cross-sectional study that included 164 participants from two Danish hospitals, and employed a variety of methods [25]. Material for the present study consists of data from interview questions, demographic data and the use of social services from the cross-sectional study.

The purpose of this study was to describe and explore how people with advanced cancer manage occupations in their everyday lives.

**Material and methods**

A qualitative descriptive design was applied to describe occupational management from the perspective of people with advanced cancer [27,28].

**Study participants**

A sub-sample of participants from the cross-sectional study in the ‘Activity, advanced cancer and quality of life at home’ (from one of the hospitals involved in the cross-sectional study). Participants were approached by contact nurses on three oncological departments at the hospital if they fulfilled the following inclusion criteria: 18 years or older, diagnosed with cancer (all types), received palliative care, an estimated survival time of at least four months, had a

<table>
<thead>
<tr>
<th>Table 1. Characteristics of the participants (N = 73).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic data                             n (%)</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Female                                       34 (47)</td>
</tr>
<tr>
<td>Male                                         39 (53)</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>&lt;59                                          16 (22)</td>
</tr>
<tr>
<td>60–69                                        21 (29)</td>
</tr>
<tr>
<td>70–79                                        28 (38)</td>
</tr>
<tr>
<td>80–89                                        8 (11)</td>
</tr>
<tr>
<td>WHO’s ECOG Performance Status</td>
</tr>
<tr>
<td>1. Restricted in performing physically strenuous activities 31 (43)</td>
</tr>
<tr>
<td>2. Capable of performing self all care activities, light house work 36 (49)</td>
</tr>
<tr>
<td>3. Capable of performing only limited self-care activities 6 (8)</td>
</tr>
<tr>
<td>Cancer type</td>
</tr>
<tr>
<td>Lung                                         19 (26)</td>
</tr>
<tr>
<td>Colon/rectum                                 14 (19)</td>
</tr>
<tr>
<td>Prostate                                     11 (15)</td>
</tr>
<tr>
<td>Cervix                                       9 (12)</td>
</tr>
<tr>
<td>Breast                                       7 (10)</td>
</tr>
<tr>
<td>Other types                                  13 (18)</td>
</tr>
<tr>
<td>Marital status</td>
</tr>
<tr>
<td>Married/cohabitating                         48 (66)</td>
</tr>
<tr>
<td>Single/widow/widower                         25 (34)</td>
</tr>
<tr>
<td>Geography</td>
</tr>
<tr>
<td>City                                         19 (26)</td>
</tr>
<tr>
<td>Town                                         8 (11)</td>
</tr>
<tr>
<td>Small town                                   21 (29)</td>
</tr>
<tr>
<td>Rural area                                   25 (34)</td>
</tr>
<tr>
<td>Occupational status</td>
</tr>
<tr>
<td>Retired because of age                       44 (60)</td>
</tr>
<tr>
<td>Retired because of illness                   12 (16)</td>
</tr>
<tr>
<td>On sick leave due to illness                 4 (6)</td>
</tr>
<tr>
<td>Employed                                     9 (12)</td>
</tr>
<tr>
<td>Unknown                                      4 (6)</td>
</tr>
<tr>
<td>Received assistance from social service      15 (21)</td>
</tr>
<tr>
<td>For example, self-care, shopping, cleaning</td>
</tr>
<tr>
<td>Received occupational therapy                1 (1)</td>
</tr>
</tbody>
</table>

World Health Organization (WHO) Eastern Cooperative Oncology Group (ECOG) Performance Status [29] score of 1–3 (indicating degrees of functional difficulties), lived at home or in sheltered living, on the island of Funen (Denmark) and able to participate in an interview. Participants living in hospice or nursing home were excluded.

A total of 133 participants met the inclusion criteria; however, 60 participants (45%) declined participation. The majority of nonparticipants were categorized as having a WHO performance status score of 3, and reasons given were lack of energy and excessive health related activities such as treatment and various home visits by healthcare professionals. Thus, the sample comprised of 73 participants (53% were male) and the mean age was 68.3 years (see Table 1 for further demographics).

**Pilot interview**

A pilot of the qualitative interview was carried out with four participants who fulfilled the inclusion criteria.
The pilot interview resulted in changing the sequence of two questions in the interview guide to reflect a more natural interview flow. Data from the pilot interview was not included in this study.

**Data collection**

Interview questions were conducted as part of a larger data collection in the cross-sectional study. The interviews lasted from 17 to 53 min and were conducted by the first author. A conversational tone was adopted for the interviews, to promote participant descriptions of the various aspects of how they managed occupations [30]. The interviews were structured around four open-ended questions: ‘Please describe a typical day?’; ‘How do the occupations you do every day consist of work for you?’; ‘Have any of your daily occupations changed or have been taken on a new meaning after you were diagnosed with cancer?’ and ‘How do you organize your everyday life?’ The interviews were audio recorded and transcribed verbatim.

**Study setting**

The interviews took place in the homes of the participants. The majority of the participants (82%) lived in a house and the remainder (18%) lived in an apartment. Forty-six participants (63%) lived in a small town or rural area, within driving distance to the nearest shop, bank and pharmacy.

**Data analysis**

Hsieh’s conventional content analysis was applied for textual analysis; as well as, counting of data [31]. A conventional content analysis is based on an open approach where codes and names of categories emerged from the data [31]. Firstly, each interview transcript was read repeatedly to get a sense of the whole. Next, each interview transcript was carefully read line-by-line and text describing aspects of how the participants managed occupations was highlighted; while at the same time writing keywords or phrases in the margins, using the participant’s own words. Then, the coded text was combined into categories. After that, the coded text within each category was re-read. During this process, some of the categories were combined and new ones were added, resulting in six sub-categories. Finally, the six sub-categories were combined into two main categories.

In addition to textual analysis, the analysis was supplemented with counts of sub-categories. This was not done for statistical purposes, but to identify how many participants shared similar experiences, for instance how many participants experienced difficulties in managing occupations or loss of occupations. The counting was done by reviewing each interview transcript and participant comments relating to a sub-category, were marked. Even though a participant made several comments related to the same sub-category, it was only marked once (Table 2). NVivo (a qualitative data analysis software program) version QSR NVivo 10 (London, UK) was used for textual analysis and the sub-categories were counted manually [32]. To enhance trustworthiness, an audit trail was kept throughout the research process of reflections and decisions during data collection and analysis. Interpretation of the findings was subject to peer review with researchers at the University of Southern Denmark and among the authors. Different opinions were discussed to achieve consensus.

**Ethics**

Participants received oral and written information about the study and were informed that participation was voluntary and that they could withdraw from the study at any time. Oral and written consent was obtained. The participants were given time for reflections and offered breaks during the interview, as needed. The project ‘Activity, advanced cancer and quality of life at home’ as a whole, including the qualitative interviews in this study, complies with the Helsinki Declaration, the Danish Ethics Committee

<table>
<thead>
<tr>
<th>Sub-categories</th>
<th>Conditions influencing occupations in everyday life</th>
<th>Self-developed strategies to manage occupations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Continuing everyday life</td>
<td>Leading a quiet life with few occupations</td>
</tr>
<tr>
<td>&lt;59 years</td>
<td>N = 9/56%</td>
<td>N = 3/19%</td>
</tr>
<tr>
<td>60–69 years</td>
<td>N = 7/33%</td>
<td>N = 10/48%</td>
</tr>
<tr>
<td>70–79 years</td>
<td>N = 8/29%</td>
<td>N = 12/43%</td>
</tr>
<tr>
<td>80–89 years</td>
<td>N = 5/63%</td>
<td>N = 5/63%</td>
</tr>
<tr>
<td>Total (n = 73)</td>
<td>N = 29/40%</td>
<td>N = 30/41%</td>
</tr>
</tbody>
</table>

Table 2. Content analysis of comments made in relation to the two main categories and the six sub-categories (N = 73).
System and was approved by the Danish Data Protection Agency (Project-ID: S-20122000-96-CKH/csf). Data were handled with confidentiality and identifiable details were altered.

Results

Managing occupations when living with advanced cancer was described in two main categories: (1) Conditions influencing occupations in everyday life and (2) Self-developed strategies to manage occupations, with six corresponding sub-categories (Table 2).

Conditions influencing occupations in everyday life

The participants identified three main conditions that influenced their ability to manage occupations. First, functional ability could change from day to day and during the course of the day, influencing and shaping how their day would unfold. Second, variations in their cancer treatment influenced their day-to-day rhythm, for example periods with and without daily treatments at the hospital. Third, the progression of their cancer influenced their perception of a ‘normal’ everyday life.

Continuing everyday life

For some participants, the changes they experienced allowed them to gradually become accustomed to a life with fewer daily occupations; whereas, other participants experienced that their everyday lives changed more quickly. ‘My life changed from black to white. I used to go to work and was active around the house and the garden. [But now] I’m lucky if I have two-five minutes to do something and then I’m finished’ (John, age 59). Apart from going to work and managing his house and garden, John used to be physically active on a daily basis, such as cycling to and from work, playing tennis and an active social life. Now most of his day was spent at home resting.

Leading a quiet life with few occupations

Thirty participants (41%) described an everyday life characterized by sedentary indoor occupations such as reading, watching television and doing crossword puzzles. They described this in contrast to their life prior to their cancer, which had been more active. ‘It used to be me who made the breakfast every morning, something I have done since we got married. Now it’s my wife who has to make it’ (Poul, age 72). The changes in the participant’s condition thereby also influenced well-established daily routines.

The cancer treatment resulted in periods where the participants were unable to get out of bed, only allowing few occupations on a daily basis. These periods could last from a couple of days to several weeks. These inactive periods were followed by periods where they were able to engage in more occupations inside and outside the home. ‘The week of my treatment and the week after, I am not worth very much. Then my mother moves in and takes care of most things, because I cannot do anything. Then after two weeks I am almost back to normal’ (Jane, age 38). Even though Jane was able to manage most of her occupations two weeks after her cancer treatment, her life was still influenced by her illness; she was not able to go to work and she had to rest during the day.

Experiencing loss of occupations

Twenty-five participants (34%) experienced loss of occupations that used to be part of their lives. ‘Just to be able to make some food or go to my workshop for a couple of hours every day, which I used to do and really enjoyed. All my daily activities are completely gone and it is a loss’ (Erik, age 74). Loss of occupations could be routine occupations (e.g. housekeeping) or restorative occupations outside the home. Restorative occupations could include; physical occupations (e.g. sports, daily walks or bicycling), creative occupations (e.g. gardening and woodwork), cultural occupations (as going to the theater, and movies), or work occupations (e.g. paid and unpaid). Loss of occupations influenced the quality of the participants lives. ‘I have a very boring life. I realized this when I wrote in the diary [research diary used in ‘Activity, advanced cancer and quality of life at home’]. It’s not until you do something like that, that you realize how little you do on a daily basis. I thought my God this is sad’ (Peter, age 58). For Peter, the changes had occurred over a period of time during which he gradually became accustomed to a life with few occupations. It was not until he listed his occupations for a single day that he realized how different his life had become.

Self-developed strategies to manage occupations

Sixty-six participants (90%) experienced difficulties with managing occupations and described how they developed compensatory strategies in order to maintain occupations.
Dealing with occupational challenges

Taking breaks during the day was a strategy used by many participants allowing them to manage their occupations. For example, taking one long nap in the middle of the day or taking several small breaks throughout the day. ‘I do one thing and then take a break. There are days were I exceed my limit and then I collapse and lie in bed for three days’ (Hella, age 59). Another strategy was to intentionally engage in sedentary occupations as a way of resting and to take necessary breaks during the day. Yet another strategy was to divide an occupation into smaller parts, such as vacuuming half the house one day and the other half the next day. While these strategies enabled independence, it also meant that routine occupations, such as house-keeping took relatively more time to complete.

The ability to participate in social events was influenced by how the participants felt due to their treatment and need for rest during the day. Some participants addressed this situation by planning social events in different ways. This could be by limiting their social interactions to only their immediate family or by inviting friends and family over during ‘good’ periods when they felt well, so they would not have to attend social events in the ‘bad’ periods they believed would follow.

Being able to take care of one self

Forty-three participants (63%) lived in a small town or rural area where they had to drive to the nearest shop. Therefore, not having the ability to drive could have a profound influence on their everyday lives. ‘I’m no longer able to drive, and therefore not able to do my own shopping. Instead I now order my groceries on-line from the local supermarket once a week. (…), but I miss seeing people’ (Hans, age 71). Using the Internet to order groceries once a week and have them delivered directly to his home, was a strategy that enabled Hans, who lived alone in a rural area, to be independent. However, this strategy also increased his isolation.

Setting short-term goals was a strategy used to fulfill wishes and reach long-term goals. ‘I live from day to day and have short-term goals for things I want to achieve. Right now I’m focused on reaching 55. (…) I have a grandson who will have his confirmation soon. Those are the things I’m focused on right now and when I’ve achieved them I can take the next step’ (Anne, age 53). Setting short-term goals enabled Anne to stay focused; a strategy that she described as being natural for her, as a former sports coach.

When the participants described the quality aspects of their everyday lives, it was often in connection with occupations. ‘I think that my everyday life still contains quality. The ability to perform daily activities, mowing the lawn … the joy that it was possible’ (Poul, age 72). Although the majority of the participants described everyday lives characterized by occupational difficulties, some participants also described that they had quality in their everyday lives. Managing occupations was viewed as a source of enjoyment as well as a way to maintain their everyday lives.

Requiring support from others

Fifty-one participants (70%) talked about needing assistance from others to manage their occupations; including shopping, cleaning, transportation to various appointments or taking care of pets. Family, friends and neighbours mainly provided assistance for the participants, only 15 participants (21%) in this study required social services.

Use of assistive devices was a strategy that several of the participants applied. ‘I now use a rollator when I go to the supermarket (…) [then] after I have done my shopping, one of my friends comes and picks me up’ (Marie, age 68). Marie could walk to the supermarket with an assistive device (rollator) but she was not able to return independently. Therefore, Marie had to coordinate her shopping trip with a friend, so the friend would drive to the supermarket to pick-up Marie and her groceries and drive her home. This enabled Marie to continue performing an occupation she valued.

Discussion

The purpose of this study was to describe and explore how people with advanced cancer manage occupations at home. The findings demonstrate that the participants experienced various conditions that influenced their ability to manage occupations, and developed strategies in order to maintain occupational engagement.

Conditions influencing occupational engagement

For some participants, leading a quiet life with only a few occupations was described as a simple but good life that was valued and had many qualities. As for others, a simple life with few occupations was
described as being in contrast to their life before cancer and was experienced as being boring. For instance, when Peter described how his awareness had changed when he listed his occupations for a single day, and found that the research diary in that moment became a reflection of what his life had become. For the participants these changes challenged the stability of their everyday lives, while forced them to continually construct and reconstruct their everyday lives in new and different ways. Several studies have found that the ability to manage occupations can serve as a means to deal with changes and enhance the well-being of people with advanced cancer [4,20,33,34]. This study adds new knowledge, by showing that as the participants described their experiences of being confronted with occupational changes, they did not talk about how these changes provided new opportunities, but rather how these changes underlined their sense of loss and decline.

Other studies have found that the everyday lives of people with advanced cancer can be characterized by changing conditions that influence their everyday lives [9,20]. In Salander et al.’s study, the everyday lives of the participants sometimes changed from being characterized by illness to being an everyday life that resembled their life before the cancer [9]. However, although the participants in this study also talked about the changing rhythm of everyday life, for example due to their cancer treatment, none of the participants described that their lives were not influenced and affected in some way by their illness even during their better periods. For instance, the participants still had to take their medication at specific times and had to rest during the day, and the majority of the participants were still not able to resume work or to travel as they wished.

**Self-developed strategies to continue everyday life**

Several of the participants described a desire to preserve a familiar life, meaning an everyday life where daily routines and usual occupations were maintained. A majority of the participants experienced occupational difficulties which, they compensated for by using self-developed strategies. These could be; ordering groceries on-line when the ability to shop independently was no longer possible, taking breaks between each occupation, dividing occupations into smaller parts, performing occupations at a slower pace, setting short-term goals and using assistive devices. Such strategies enabled the participants to maintain a level of independence at home. This is in agreement with others studies, which found individuals develop strategies to continue occupations in everyday life [6,35]. Although self-developed strategies enabled the participants to manage specific occupations, some of these strategies were shown to be counterproductive. Hans lived in rural area and used on-line shopping to maintain independence, but at the same time it increased his isolation since he no longer had casual social encounters while shopping. Furthermore, the strategies used by some of the participants, meant that mundane occupations such as housekeeping would take relatively longer time to complete on a daily basis leaving less time and energy for more personally meaningful occupations. To our knowledge, the issue that self-developed strategies could possibly being counterproductive has not been addressed in previously research. Although only one participant received occupational therapy, some of the self-developed strategies used by the participants (e.g. dividing an occupation up in smaller parts and taking breaks during occupational performance) are well-known strategies that are often part of an occupational therapy intervention. These findings suggest that people with advanced cancer may benefit from occupational therapy focused on other strategies such as prioritizing occupations, time and resources to enable engagement in familiar as well as more personally meaningful occupations.

**Methodological considerations**

Although categories were identified with an open approach, the researcher’s pre-understandings as occupational therapists may have influenced how data was interpreted [36]. The use of content analysis [31] allowed a combined thematic analysis as well as count of the data. Using count of data provided a description of how many of the participants shared similar experiences; thereby providing an additional dimension to the overall understanding of the phenomenon. For instance, it showed that the majority of the participants (90%) experienced difficulties managing occupations in their everyday lives. The large sample size is considered a strength for this qualitative study, since it provided variety in the characteristics of the participants. The findings thereby reflect diversity in aspects related to occupational management as experienced by people with advanced cancer.

There are also several limitations to this study: First, a rather large percentage (45%) declined participation. However, when compared to other studies with the same population, the number of non-participants was within the expected amount. Still, since the largest number of non-participants was those that
were categorized as having a level 3 score on the WHO ECOG Performance Status; the findings may not reflect people with advanced cancer who are the most ill. Second, the present study was part of the larger research project ‘Activity, advanced cancer and quality of life at home’ where the qualitative interviews were performed as part of a large selection of methods. This may have influenced the participants understanding of the questions used in the qualitative interviews.

**Conclusion**

The findings showed that the everyday lives experienced by people with advanced cancer were characterized by changing conditions that influenced their ability to manage their occupations. The participants developed strategies to compensate for occupational difficulties to help manage occupations. However, some of these strategies proved to be counterproductive by leaving less time and energy for more personally meaningful occupations.

**Significance**

The findings suggest that people with advanced cancer should be supported to a greater extent in ways to manage familiar, new and more personally meaningful occupations. This knowledge can add to the knowledge-base of occupational science by showing how people with advanced cancer manage occupations through self-developed strategies to maintain their familiar everyday lives. Furthermore, the findings may suggest that people with advanced cancer can benefit from occupational therapy intervention focused on prioritizing time and energy in order to enable engagement in familiar along with more personally meaningful occupations.

**Acknowledgements**

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**Disclosure statement**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper.

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**References**


Manuscript II

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Perceptions of quality of life by people with advanced cancer who live at home

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ABSTRACT

Title: Perceptions of quality of life by people with advanced cancer who live at home

Objectives: Improving quality of life is often the ultimate goal of healthcare interventions, including in end-of-life and palliative care. Research shows that advanced cancer may impact everyday living and quality of life. Perceptions of quality of life for people with advanced cancer who live at home, remain understudied. The purpose of this study was to explore how people with advanced cancer who live at home perceive quality of life.

Methods: A qualitative descriptive design employing individual interviews supported by a semi-structured interview guide and participant generated photographs was used for data collection. A thematic approach was used to analyse the data. Ten participants took part in this study.

Results: The analysis resulted in the main theme of ‘Continuity and discontinuity of daily life at home’ with two corresponding dimensions: 1) Adjusting to changes in health and illness, and 2) Daily life and the hereafter.

Significance of Results: The findings suggest that people with advanced cancer perceive quality of life as closely related to being able to maintain continuity while adjusting to experience of loss and discontinuity in daily life at home. This knowledge is useful for health care professionals in supporting people with advanced cancer in living personally meaningful lives that may enhance their overall quality of life.

Keywords: Cancer, continuity, daily living, discontinuity, end-of-life, qualitative research.

Words: 4389
INTRODUCTION

Research shows that advanced cancer can impact daily living and may affect quality of life (QoL) (Johansson, Ödling, Axelsson, & Danielson, 2008; M. Lyons, Orozovic, Davis, & Newman, 2002; Osborne et al., 2014; Willig, 2015). Although there tends to be an assumption that a diagnosis of advanced cancer will inevitably lead to reduced QoL (Hammell, 2013), some research shows that this may not always be the case (Dalgaard, 2012; Johansson, Axelsson, & Danielson, 2006; Morgan, Currow, Denehy, & Aranda, 2015; Willig, 2015). The quote below from an interview with a participant in a previous study by the authors (Peoples., Brandt, Wæhrens, & la Cour, 2017), indicates that evaluating QoL may not be straightforward for patients. While completing a health-related QoL assessment, the participant expressed difficulties with evaluating her current health on a scale from 0-100 (‘100’ indicating best imaginable health state) (Rabin & de Charro, 2001). When asked to elaborate on her final score of 65 on this scale, she said:

“Well, it’s because you asked for a number, and then it had to be a compromise. Because when I look at the hard facts, I can see that my situation is really bad. The doctor told me yesterday that this is my last treatment and then they cannot do anymore. But as you can see from my [research] diary this is not what characterizes my everyday life right now. I think that my quality of life is good.”

This quote highlights that although the life of this participant is approaching its end, she continues to perceive her life to have good quality, despite its limitations. This suggests that perceptions of QoL have many facets which may change with changing circumstances; it also suggests that QoL may be a complex phenomenon (10, 11).
Improving QoL is often the ultimate goal of health-care and a primary outcome of interventions within palliative care. According to the World Health Organization (WHO) (2015), palliative care is an approach that seeks to improve QoL for people facing life-threatening illnesses by attending to their physical, psychosocial and existential need. In Scandinavia, including Denmark, and other Western countries a growing number of people who live with advanced cancer receive palliative care at home (Hoefler, 2012; Sundhedsstyrelsen, 2005; Thygesen & Pols, 2015). This development seems to align with research which shows, that people with advanced cancer prefer to live at home up until their death (Higginson & Sen-Gupta, 2000; Neergaard, Brogaard, & Jensen, 2012; Neergaard et al., 2011; Regeringen, 2016; Soloman & Hansen, 2015; Thomas, Morris, & Clark, 2004).

However, some studies show that living with a life-threatening illness such as advanced cancer may disrupt one’s familiar daily life and result in disengagement from activities that used to contribute to QoL (Johansson et al., 2006; Johansson et al., 2008; Morgan et al., 2015; Willig, 2015).

In general QoL is recognized to be a dynamic and multidimensional construct including both objective (e.g. living situation, funtional status, education and employment) and subjective (e.g. life satisfaction, well-being and meaningfulness) dimensions of human existance (Vittersø, 2004). QoL for people with advanced cancer is often investigated by use of both generic and specific health-related QoL instruments, such as EORTC QLQ-C30 (Grønvold et al., 2006). Objective health-related QoL instruments are based on predefined domains that may fail to address other issues that may impact QoL when living with advanced cancer (Hammell, 2004; Moons, Budts, & De Geest, 2006), as indicated by the quote above. As health care increasingly turns towards a patient- or client-centred approach other ways to understand and investigate quality of life may be relevant, for example through qualitative
methods that are focused on eliciting understandings of the subjective dimensions of QoL. Accordingly, this study focused on examining subjectively experienced QoL.

Several studies have used qualitative methods to investigate subjectively experienced QoL or dimensions that may be linked to subjectively experienced QoL (Buetto & Zago, 2015; Davies & Sque, 2002; Johansson et al., 2008; Osborne et al., 2014; Sviden, Tham, & Borell, 2010; Vig & Pearlman, 2003). For example, Johansson et al. (Johansson et al., 2008) explored the meaning of QoL for people with advanced cancer receiving palliative care at home and identified that being at home enhanced the participants’ QoL. Sviden et al.’s (Sviden et al., 2010) study of people with life threatening cancer showed that involvement in engaging activities provided the participants with feelings of competence, but the study did not specifically focus on subjectively experienced QoL. Activity and participation by people with advanced cancer were also identified by Osborne et al. (2014) as being linked to QoL. However, this study only included participants in a clinical setting and did not examine how these issues were linked to the participants’ daily life at home. Similarly, Vig et al.’s (Vig & Pearlman, 2003) study of QoL of terminally ill older men revealed that although their active engagement in activities in their daily life improved their QoL, such engagement also resulted in a worsening of the men’s symptoms; this study however did not specify the research setting. Moreover, women with advanced breast cancer who lived at home were, shown to have experienced feelings of being disconnected from life (Davies & Sque, 2002). The study (Davies & Sque, 2002) primarily focused on the social consequences of being disconnected from life in regards to QoL and less on other aspects of daily life. Likewise, Buetto and Zago’s (Buetto & Zago, 2015) study which explored meanings of QoL in the context of chemotherapy for patients with colorectal cancer showed that loss of normality of life was associated with reduced QoL. These studies indicate that the ways in which people with advanced cancer, particular those who live at home, subjectively perceive QoL remain understudied.
Given the increasing number of people with advanced cancer who live at home and who need to manage daily life at home, it seems urgent to broaden understandings of the complex phenomenon of QoL particularly in relation to how this group of cancer patients perceive QoL. Such knowledge may inform healthcare interventions that aim at enhancing QoL for people with advanced cancer who live at home at the end of their lives. The purpose of this study was therefore to explore how people with advanced cancer who live at home perceive QoL.

METHODS

To foreground the participants’ subjective perceptions of QoL, a qualitative descriptive design was adopted, using semi-structured interviews (Kvale, 1996) and photo-elicitation interviews (Harper, 2002).

Participants and sampling

The sample constituted a subsample derived from a previous cross-sectional study of 73 participants (Figure 1) which was carried out between February 2013 and May 2014 (Peoples. et al., 2017; Wæhrens, Brandt, Peoples, & la Cour). Due to a prolonged data collection of the cross-sectional study, 39 participants had died by the time of the sampling for the present study. The remaining 34 participants were invited to participate in the present study. Of these, 22 people declined due to a worsening of their condition or a lack of interest. Twelve participants agreed to take part in the study, but two died before data-collection began; the final sample thus comprised ten participants (Table 1).
Subsample (n=73) from a cross-sectional study (participants from one of two Danish university hospitals that took part in the cross-sectional study)

**Inclusion criteria:**
- 18 years or older.
- diagnosed with cancer (all types).
- received palliative care, an estimated survival time of at least four months (by an oncologist).
- a score of 1-3 on WHO Performance Status
- lived at home or in sheltered housing, on the island of Funen (Denmark)
- able to participate in an interview.

**Exclusion criteria:**
- living in hospice or nursing home.

Participants from the cross-sectional study who were still alive by the time of data collecting for the present study were invited by letter (n=34)

Agreed to participate (n=12)

- Died before data collection was initiated (n=2)

Final sample (n=10)

Participants who had died between the cross-sectional study and initiation of data collection (n=39)

Declined when contacted by telephone (n=22)

Reasons:
- Worsening of condition/hospice (n=15)
- Not interested in participating (n=7)

Figure 1: Recruitment flow chart
Table 1. Characteristics of participants (N=10)

<table>
<thead>
<tr>
<th>Demographic data</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
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<tr>
<td>Women</td>
<td>5</td>
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<tr>
<td>2.**</td>
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<tr>
<td>3.***</td>
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<tr>
<td>Cervix:</td>
<td>2</td>
</tr>
<tr>
<td>Breast:</td>
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*Restricted in performing physically demanding activities,
** Capable of performing all self-care activities, light house work,
***Capable of performing only limited self-care activities.

Pilot interview

To evaluate the suitability of the questions in stimulating reflections on QoL the interview guide for the semi-structured interview as well as the use of photographs to stimulate additional reflections in the second interview, was piloted with one participant. As a result, one question about any possible changes in understandings of QoL following the cancer
diagnosis and treatment was added to the final interview guide. Data from the pilot interview was included in the study.

Data collection

Each participant, except one who declined the second interview, was interviewed twice, with two weeks between each interview; all interviews (n=19) were carried out by the first author in the participants’ homes and lasted from 30 minutes to 2 hours and 15 minutes. The overall aim of the interviews was to explore the participants’ understandings of QoL and any possible changes throughout their illness.

First interview: The semi-structured interviews were supported by an interview-guide with open-ended questions that reflected the purpose of the study (Sivell et al., 2015). Included questions were: “What does QoL mean to you?”, “Did your views of QoL change after your illness?” and “What is important for you in your everyday life?”

Second interview: To elicit further nuanced reflections of QoL (Rose, 2012) the participants were invited before the interview to collect new and/or existing photographs of things and situations which they associated with QoL in their daily life. These images where then used to stimulate and guide the interview.

Data analysis

Interviews were digitally recorded and transcribed verbatim by the first author. Transcripts were imported to QSR NVivo 10 software for data management and initial coding.

A thematic approach was used to analyse the data (Luborsky, 1993). Each transcript was read and re-read to get a sense of its overall content. The whole text was then read again and statements which conveyed perceptions of QoL were highlighted. These statements were re-read and divided
into preliminary sub-themes, followed by identifying similarities and differences as well as other aspects that could add nuances to the participants’ understanding of QoL. The preliminary sub-themes were then discussed with the co-authors, resulting in the reorganization and merging of some existing and addition of new sub-themes. One overarching main theme with two corresponding dimensions was identified after several iterations. Lastly, all transcripts were read again and the authors viewed and discussed the main theme and associated dimensions in relation to the research purpose.

Trustworthiness of the analysis was enhanced in the following ways: An audit trail was kept by recording reflections and decisions during data collection and analysis. Member checking was carried out in two complementary ways: Informally during the data collection and formally after initial data analysis, by asking the participants whether the researcher’s accounts corresponded with the participants’ recollections and intended meaning (Polit & Beck, 2004). Interpretation of the findings was subject to regular discussions with the co-authors and fellow researchers at the University of Southern Denmark.

**ETHICS**

Participants received oral and written information about the study and were informed that participation was voluntary and withdrawal possible at any stage of the study. Oral and written consent was obtained. Data was handled confidentially and any identifiable information that could lead to the identification of participants was anonymized. The study followed the Helsinki Declaration, national ethical requirements and was approved by the Danish Data Protection Agency (project_ID:S-20122000-96-CKH/csf).
RESULTS

The analysis of the interviews revealed that the participants’ perceptions of QoL were linked to experiences of being able to maintain and continue daily life under changing circumstances, while also adjusting to losses and discontinuities due to declining health. The participants’ described how the loss of certain aspects of their daily life influenced their QoL, and how this in turn would trigger a longing for a sense of continuity in other aspects of their life. This interdependence between wanting to preserve continuity of daily living caused by experienced discontinuity in relation to perceived QoL will be presented with reference to two dimensions: 1) Adjusting to changes in health and illness, and 2) Daily life and the hereafter.

Adjusting to changes in health and illness

When the participants described what QoL implied for them, they emphasized the importance of being able to continue their daily life as usual. This involved the ability to fulfil roles, to maintain usual routines and carry out activities that they valued. To achieve some continuity in the face of deteriorating health often required adjusting to changing abilities and functional limitations while creating ways of carrying on ‘life as usual’. For example, a male participant, describing himself as a do-it-yourself type of man who used to do all the maintenance work on the house and help family and friends, said:

“To me QoL is to be able to continue the life I have. To [be able to] participate in the usual activities, to receive visitors, to travel and to continue life at home. It has become somewhat reduced, since there’re things I cannot do anymore. (…) Originally I’m a joiner but have worked as a carpenter most of my life and I used to do all the wood work for my family (…) but I cannot do that
anymore. Instead I give advice, for example when my son wanted to build a bass guitar and we worked on it together in my workshop” (Erik).

As this quote illustrates, the importance of carrying out valued activities is balanced with adjusting to the challenges and limitations caused by ill-health, and may offer significant sense of achievement. Other participants, however had different experiences. One of these was Marie who reflected:

“I used to keep my house nice and tidy; but now the house is a filthy mess, but I don’t have the energy to do anything about it. So I just let it go.”

Like Marie, not all participants were able to adapt to the changing conditions caused by their illness, and some were forced to accept that they no longer were able to maintain ‘life as usual’.

Adjusting to changing abilities and functional limitations may not only manifest in changing activities and roles, but also in changing perceptions of QoL. While some participants described their understanding of QoL as unchanged after their cancer diagnosis, others had a different view. For example, a female participant described herself as having been a very active person who went on long walks or bike rides to stay healthy. Since her illness her daily life has changed in many ways and she now spends most of her days indoors engaged in sedentary activities. Comparing her understanding of QoL before and since her cancer diagnosis, Mona commented:

“If I look back ten years, then QoL was linked to being healthy and not sick. Today, where I have an incurable illness, QoL is something very different. Today, I see my illness as a life condition and I feel healthy even though I’m seriously ill.” (Mona).
This quote illustrates that despite life-threatening illness some people feel able to live with their illness, continue to feel healthy and experience quality in their life. However, as a result of their changed circumstances, their perception of the meaning of QoL has changed.

These above examples exemplify the importance of the continuity in previous roles and activities and also illustrate the ongoing changes the participants experienced as a result of living with advanced cancer at home. This point to the complexity of understandings of QoL by people with advanced cancer who live at home.

Daily life and the hereafter

For some participants living with their impending death caused existential reflections of continuity and discontinuity, in the sense that when certain aspects of their lives became difficult as a result of their illness other aspects became important to preserve. Living with life moving towards its end with the discontinuities this entailed for the participants thus evoked thoughts of what was worth preserving and could contribute to maintaining quality in their lives.

One participant talked about how her regular walks to the local churchyard were valued activities in her daily life. She described how she often visited the local churchyard, something she had done since she was a child living next to a church. She felt close to her ancestors there and enjoyed reading the names and professions of people she used to know. Describing that she wanted her future headstone to state her name and occupation so she could continue being part of her local community after her death, she said:

“I told my son that we should take a walk to the churchyard and pay our respect and we talked about all the people we used to know and that were buried there.”

(Elsa)
Like Elsa above, several of the participants shared how the ability to engage in valued activities generated reflections of their lives, now and projected into the future. Others seemed more concerned about the implications their death would have for the life for relatives, as expressed by Annie:

“I worry about how my son will cope when I’m gone”.

The quote illustrates reflections of concern for how her death would affect her son, who was about to leave home to live in sheltered housing. Annie emphasised the importance of being able to support and prepare her son for this transition before she died. The ability to guide her son and thereby contribute positively to the continuity and quality in his life beyond her own death can also be said to contribute to her own QoL.

Several participants shared how living with their approaching death had influenced their relationship with friends and family. One participant shared that he had been a loner most of his life and that QoL for him had been associated with being independent without having to rely on help from his family; he said:

“I told my sisters that I wanted to give them a hug once in a while, because maybe I wouldn’t be here for so long. And this is something we have never ever done before.” (Peter)

As indicated by the quote living with life-threatening illness may result in a greater need of support from relatives and which may lead to an appreciation of a different closeness. Closeness in relationships can also lead to having important goals to achieve before death, as expressed by Marie:
"QoL has to do with having something to strive for in the daily life, for example to see my future great grandchild and to still be alive to celebrate my husband’s 70th birthday."

For Marie, like other participants, setting short-term goals offered aims to live for in the here and now and was a way of maintaining a sense of continuity and quality in daily life.

The examples illustrate the tensions between creating QoL through continuity both in daily life and after the death of individuals, on the one hand, and discontinuity in the very real sense when facing impending death, on the other hand.

**DISCUSSION**

The purpose of this qualitative study was to explore how QoL is perceived by people with advanced cancer who live at home. The findings suggest that for this group of participants QoL is closely linked to the ability to continue daily life while adjusting to changing circumstances involving loss and discontinuity due to ill-health. The changes experienced as a result of declining health resulted in a need for ongoing adjustments that enabled the person to continue daily life in ways that contribute to QoL while living with an approaching death. This interdependence and tension between experienced loss and changes on one hand, and a striving to preserve a familiar daily life under different circumstances on the other hand, was balanced by the participants in order to maintain QoL.

The experience of increasing limitations and loss generated for some participants a need to hold on to some form of continuity in their daily life. This may relate to Atchley’s understanding of ‘continuity’ (Atchley, 2000). According to the continuity theory of normal aging (Atchley, 1989, 2000) by making adaptive choices people tend to maintain the same activities, behavior and relationships as they did earlier in their lives. When faced with
substantial changes caused by illness or functional decline, a person will usually try to recreate or continue ‘the familiar life’ by turning to strategies that are shaped by former experiences (Bech-Jørgensen, 1994; Lala, 2011; K. D. Lyons, Erickson, & Hegel, 2012). Although ‘continuity’ may imply a static view of things remaining the same, this was not the case for the participants in this study. Rather, they described how the cancer diagnosis had resulted in changing conditions that constantly required the participants to make adjustments to maintain the familiar ways of daily life.

It is recognized that changing conditions may impede well-established roles and activities for people living with advanced cancer (Krigel, Myers, Befort, Krebill, & Klemp, 2014; la Cour, Nordell, & Josephson, 2009; Morgan et al., 2015). This was also identified in the present study, when changing conditions and functional limitations resulted in loss of usual roles and activities. Changing conditions such as those caused by advanced cancer may require that those obligations which are linked with certain roles or activities to be rethought and prioritized in different ways (Arvastson, 2006). The constant adjustments due to changes caused by advanced cancer identified in this study have also been noted in other studies of people with advanced cancer. Morgan et al. (Morgan et al., 2015) showed that the ability to continue to live actively required constant adjustment to bodily decline for people living with advanced cancer. Similarly, Appelton et al. (Appelton et al., 2015) showed that men with prostate cancer use psychological strategies, such as positive thinking and humour, to adjust to the difficulties caused by their cancer diagnosis. The experienced discontinuities described by the participants in these and the present study may relate to what Bury (Bury, 1982) termed ‘biographical disruptions’ and which conceptualizes chronic illness as a particular type of disruptive event. Bury (Bury, 1982) developed the notion of ‘biographical disruptions’ on the basis of research of people living with rheumatoid arthritis, for whom possible disruptions
may not be temporary but may contribute to the continuous formation of a person’s life. However, adjustments to changes may not always be possible, as our findings indicate.

Although cancer likewise can be seen as a chronic condition, cancer in advanced stage is often progressive and may at times evolve rapidly. This can result in discontinuity which may require adjustments beyond the abilities of those affected, and thus impact the quality of their lives. For the participants in our study the required adjustments resulted at times in loss of previous roles and activities, which necessitated a surrender and acceptance of the current state of things, although this was not what they had hoped for and impacted on their QoL negatively.

In keeping with Burys understanding of biographical disruption, death may be seen as the ultimate disruption. This prompted some participants in our study to share existential reflections about life as it was moving towards its end and about the life they would be leaving behind. The findings showed that the expression of emotional ties and the fulfilment of commitments to others gained in importance. For the participants in our study the ability to still be actively involved in the lives of loved ones was understood as a way of preserving one’s continuity in the hereafter. Furthermore, the ability to contribute to the lives of others also provided a sense of belonging to family and wider social networks which the participants perceived as enhancing the overall quality of their remaining life (Hammell, 2014; Unit, 2016). However, to understand how continuity and discontinuity due to declining health may influence the daily life for people with advanced cancer who live at home, including the ways in which belonging may be linked to perceptions of QoL requires further research.
**Methodological considerations**

The sample size of ten participants was the result of a convenience sample. Continued sampling until data saturation was reached may have improved the overall quality of the research, but this was not possible in the context of this study. However, the analysis did reveal recurring themes across the sample which indicated some level of saturation. The prolonged data collection of the preceding cross-sectional study limited this present study, since this resulted in the inability of more than half of the participants, including younger participants, to participate. Accordingly, the sample may be perceived as a selective group of older people with advanced cancer and whose health conditions in general were better than the wider sample of the cross-sectional study.

In this study the participants were asked directly about what QoL meant to them. This allowed the participants to talk about QoL in their own words and to steer the interview in directions that reflected their view of QoL. This enabled the possibility of addressing different perspectives of QoL and contrasts with studies that rely on predefined QoL domains (Hammell, 2004; Moons et al., 2006). The use of two complementary qualitative interviews likewise proved to be valuable to exploring understandings of QoL from the perspective of the participants. The use of photographs in the second interview seemed to elicit experiences that may not have been explored otherwise. The photographs thereby supported the second interview by facilitating the foregrounding of more tacit aspect of daily life associated with QoL, aspects that had not been examined in the first interview.

During the analysis it became clear that the photographs were likely to contain additional meanings that their use to eliciting conversations could not bring forward. In particular, the analysis indicated that different ways of belonging (e.g. to family, social networks and community), that were represented in many images may also relate to perceived QoL for
CONCLUSION

This study explored perceived QoL by people with advanced cancer who live at home. The findings indicate that the participants’ perceptions of QoL were linked to the ability to maintain and continue daily life under changing circumstances, while adjusting to losses and discontinuities due to declining health. To maintain QoL the participants continuously balanced this interdependence and tension between experienced loss and change, while striving to preserve a familiar daily life under different circumstances.

Living with advanced cancer caused existential reflections about approaching death. The ability of still being able to contribute to the life of family members served to preserve continuity in the hereafter, as well as provided a sense of belonging which enhanced the overall quality of the participants’ remaining life.

The findings contribute with knowledge of how QoL is closely related to being able to maintain continuity while trying to adjust to loss and changing circumstances caused by advancing illness. This knowledge is useful for health care professionals in supporting people with advanced cancer to live personal meaningfully lives that may enhance their overall quality of life.

Competing interests: None to declare
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Belonging and quality of life as perceived by people with advanced cancer who live at home

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ABSTRACT

Title: Belonging and quality of life as perceived by people with advanced cancer who live at home.

Introduction: In a previous article, we explored how people with advanced cancer perceive quality of life, which pointed to the importance of relationships with others to the experiences of quality of life. These emerging findings resonate with the theoretical conceptualization of belonging within occupational science, prompting us to explore further how perceived quality of life may be associated with belonging when living with advanced cancer.

Purpose: To gain a deeper understanding of the ways in which belonging is perceived as an aspect of quality of life by people with advanced cancer who live at home.

Methods: Nine participants took part in this qualitative study which used a combination of semi-structured interviews and photo-elicitation to generate data. Data from 18 interviews and 77 photographs were analyzed thematically, drawing on four dimensions of belonging.

Findings: The findings highlight that maintaining a sense of belonging was associated with quality of life and was identified as a complex and challenging process for the participants when living with life moving towards its end. The data support the theoretical dimensions of belonging noted in occupational science and contribute with knowledge about artefacts as mediators of belonging which may enable valued social connections as well as evoke existential and spiritual concerns of life moving towards its end.

Keywords: Cancer, daily living, end-of-life, photo-elicitation, qualitative research.
INTRODUCTION

In a previous article, we explored how people with advanced cancer who live at home perceive quality of life (Peoples, Nissen, Brandt, & la Cour, 2017). Some of the findings suggested that being able to contribute to the lives of others as well as being part of family and wider social networks may be associated with a sense of belonging and closely relate to subjective experiences of quality of life for people with advanced cancer. These emerging findings resonate with the theoretical conceptualization of belonging within occupational science (Hammell, 2014; Wilcock & Hocking, 2015c).

From an occupational science perspective belonging is embedded in an understanding of human occupation alongside ‘doing, being and becoming’ (Wilcock & Hocking, 2015a). Occupational scientists have described ways of belonging primarily in relation to four interrelated dimensions (Blank, Finlay, & Prior, 2016; Burchett & Matheson, 2010; Hammell, 2014; Hasselkus, 2011a; Hitch, Pèpin, & Stagnitti, 2014a, 2014b; Laliberte-Rudman, Yu, Scott, & Pajouhandeh, 2000; Rebeiro, Day, Semeniuk, O'Brian, & Wilson, 2001; Wilcock & Hocking, 2015b):

1) Social belonging is achieved both through emotional and shared connections, relating to feelings of love, intimacy and well-being (Hammell, 2014; Laliberte-Rudman et al., 2000), and by contributing to the lives of others, including family, friends and peers (Blank et al., 2016; Burchett & Matheson, 2010; Rebeiro et al., 2001), and to wider communities (Hammell, 2004a; Wilcock & Hocking, 2015b),

2) Spatial belonging relates to a sense of being connected to places, such as one’s home (Hasselkus, 2011c; Rowles, 2008; Wilcock & Hocking, 2015b), to the land (Hammell, 2014), to workplaces or other places where specific occupations were pursued (Blank et al., 2016; Rebeiro et al., 2001).
3) Belonging as a form of existential and spiritual connections is associated with meaning, value, transcendence and beliefs (Blank et al., 2016; Hasselkus, 2011b), music (Roberts & Farrugia, 2013; Wilcock & Hocking, 2015a), nature and ancestors (Hammell, 2014).

4) Belonging through artifacts may be reflected in everyday objects as ways of expressing and communicating a sense of self (Hocking, 1997, 2000; Rowles, 2008), such as heirlooms which may provide continuity across generations (Ilott, 2006).

In the occupational science literature these four dimensions of belonging are commonly considered to be dynamic (Wilcock & Hocking, 2015b) in the sense that they may develop and change significance during the course of a lifetime. Further, people often experience belonging and the associated dimensions though diverse occupational engagements (Hammell, 2014; Wilcock & Hocking, 2015b).

Living with advanced cancer can have a profound influence on physical, psychosocial, and existential aspects of life and may result in loss of valued occupations (Adorno & Brownell, 2014; Haug, Danbolt, Kvigne, & Demarinis, 2015; la Cour, Nordell, & Josephson, 2009; Morgan, Currow, Denehy, & Aranda, 2015; Peoples., Brandt, Wåhrens, & la Cour, 2017). Research has shown that people with advanced cancer seek occupations, which provide personal meaning and connection with other people (Krigel, Myers, Befort, Krebill, & Klemp, 2014; Morgan et al., 2015).

Wilcock and Hocking (2015b) suggest that occupational engagement that offer contact with others and enable social interaction, provide a foundation for physical and mental well-being which is closely related to subjective quality of life (Hammell, 2014; Morgan et al., 2015; Vig & Pearlman, 2003; Vrkljan & Miller-Polgar, 2001).

From an occupational science perspective, the ability to engage in occupations that enable a sense of belonging is believed to underpin health and quality of life (Wilcock & Hocking, 2015a). Quality of life is recognized to be a multidimensional and dynamic concept, which include
objective (e.g. living situation and functional status) and subjective (e.g. life-satisfaction and well-being) features of human existence (Vittersø, 2004). In palliative care, quality of life is often investigated through health-related quality of life instruments that are based on predefined domains; these may however, fail to address subjective aspects of quality of life (Hammell, 2004b; Moons, Budts, & De Geest, 2006), such as the significance of belonging for individuals at the end of their life.

Qualitative studies have identified that people with advanced cancer have a need to belong; for example, with others (Appelin & Berterö, 2004; la Cour, Ledderer, & Hansen, 2015; Morgan et al., 2015; Solomon & Hansen, 2015) and with the environment (Saarnio, Boström, Gustafsson, & Öhlén, 2016; Unruth, Smith, & Scammell, 2000). Also, advanced cancer may lead to altered relationships (Krigel et al., 2014) and to feelings of loneliness and isolation (Mills & Payne, 2015), which may be seen as a barrier to belonging that may lead to reduced quality of life (Johansson, Ödling, Axelsson, & Danielson, 2008; Lyons, Orozovic, Davis, & Newman, 2002; Osborne et al., 2014). However, knowledge about the relationship between the dimensions of belonging and how they may be associated with aspect of quality of life is still limited.

The emerging findings from our previous study and their resonance with the concept of belonging within occupational science, prompted us to explore further how perceived quality of life may be associated with belonging when living at home with advanced cancer. This is therefore the focus of this article.

**METHODS AND MATERIAL**

This study employed a qualitative approach using a combination of semi-structured interviews (Kvale, 1996) and photo-elicitation (Harper, 2002), to elicit reflections about perceptions of quality of live by people with advanced cancer.
Participants

The sample constituted a subsample derived from a previous study of 73 participants which was carried out between February 2013 and May 2014 (Brandt et al., 2016; Peoples. et al., 2017). At the time of sampling for the study presented in this article, 39 possible participants had died. The remaining 34 participants were invited to participate in the present study; of these 22 declined participation. Twelve participants agreed participation, but two died before the data-collection was initiated and one did not want to take part in photo-elicitation; a total of nine participants were included in the study: five women and four men (Table 1).

Table 1. Profile of participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Type of cancer</th>
<th>Living circumstances</th>
<th>Photographs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peter</td>
<td>57</td>
<td>Colon cancer</td>
<td>Living alone in a house in a small town. Retired due to illness.</td>
<td>Photographs depicting: Daily life at home, work, the garden</td>
</tr>
<tr>
<td>Annie</td>
<td>57</td>
<td>Colon cancer</td>
<td>Living with her husband and son in a house in a small town. Retired due to illness.</td>
<td>Photographs depicting: Daily life at home, family celebrations, the garden</td>
</tr>
<tr>
<td>Marie</td>
<td>68</td>
<td>Breast cancer</td>
<td>Living with her husband in a townhouse in a small town. Retired due to age.</td>
<td>Photographs depicting: Daily life at home, taking care of grandchild, knitting, watching television, playing computer, physical training.</td>
</tr>
<tr>
<td>Elsa</td>
<td>70</td>
<td>Endometrial cancer</td>
<td>Living with her husband in a house in a small town. Retired due to age.</td>
<td>Photographs depicting: Life at home for instance cooking, knitting, crossword puzzle, flowers, theater program, car, family birthday, a farmers marked.</td>
</tr>
<tr>
<td>Mona</td>
<td>73</td>
<td>Ovarian cancer</td>
<td>Living with her husband in a house in a small town. Retired due to age.</td>
<td>Photographs depicting: Life at home for instance breakfast, baking bread, gardening, walking along a beach, a farmers marked.</td>
</tr>
<tr>
<td>Erik</td>
<td>75</td>
<td>Prostate cancer</td>
<td>Living with his wife in a house in a rural area. Retired due to age.</td>
<td>Photographs depicting: Family celebrations, nature.</td>
</tr>
<tr>
<td>Villy</td>
<td>85</td>
<td>Prostate cancer</td>
<td>Living with his wife in a house in the city. Retired due to age.</td>
<td>Photographs depicting: Participating in family celebrations, travels, maintenance work, playing with grandchildren.</td>
</tr>
</tbody>
</table>
Pilot interview

A semi-structured interview and a photo-elicitation interview were piloted with one participant. As a result, one question about possible changes in understandings of quality of life before and after the cancer diagnosis was added to the first interview. Data from these pilot interviews was included in the study.

Data collection

Data collection was conducted during two visits in the participants’ homes over 14 days from October 2014 to January 2015. All interviews (n=18) were carried out by the first author and ranged from 43 minutes to 2 hours and 15 minutes. The participants provided a total of 77 photographs, with five to thirteen each.

The semi-structured interview that was carried out during the first visit was supported by an interview-guide with open-ended questions, for example: “What does quality of life mean to you?”, “Did your view of quality of life change after your illness?” and “What is important for you in your everyday life?” After this interview, the participants were asked to take photographs that illustrated quality of life for them. Since the intention was to elicit understandings of quality of life throughout the participants’ lives, the participants could take new and/or use pre-existing photographs. The participants were asked to e-mail their photographs to the first author a day before the follow-up interview.

During the second visit, the follow-up interview was conducted through photo-elicitation. To stimulate additional reflections about quality of life the participants were invited to share thoughts and reflections about their photographs and how these reflected quality of life (Rose,
The participants were also asked about possible photographs they would have liked to have taken, but did not, due to lack of opportunity or because they forgot (Fritz & Lysack, 2014).

All interviews were digitally recorded and transcribed verbatim by the first author. Transcripts were imported to QSR NVivo 10 software for data management and coding.

Data analysis

The interviews and photographs were analyzed thematically (Braun & Clarke, 2006; Pink, 2013; Rose, 2012b). As an integral part of the iterative analytical process, the four dimensions of the concept of belonging were actively drawn on in order to investigate how belonging may be associated with quality of life.

Transcripts: To gain a sense of the overall content the first author read and reread the transcripts from both interviews. The entire text was then read again while coding statements that conveyed quality of life. These statements were reread and divided into themes that reflected dimensions of belonging. The themes were then discussed with the co-authors, which resulted in some themes being merged and new ones being added. The complete material was then read again and themes were viewed in relation to the research purpose.

Photographs: Several strategies were used to analyse the photographs. To identify what each photograph depicted, all images were initially viewed systematically using a worksheet for photo analysis (National-Archives, 2017). The preliminary results were presented and discussed with the last author who contributed with reflections and suggestions for further analysis. Then the first, second and last author viewed the entire photo-material (77 photographs) and identified and discussed possible themes.
Transcripts and photographs: The transcripts and the photographs from each participant were analysed in relation to each other, with the aim to unfold each participant’s individual narrative, and the emerging analysis was again discussed with the co-authors. In the final phase the entire data set was considered together in relation to the four dimensions of belonging and the study purpose. This iterative process between parts and whole and between transcripts and photographs ensured coherence.

ETHICS

The first author provided oral and written information about the purpose of the study to the participants and stressed that participation was voluntary and withdrawal possible at any stage of the study. Oral and written consent was obtained. Data was handled confidentially and identifiable data such as names was anonymized. If the participants provided photographs with identifying features such as faces, the written consent specified the future use of these photographs. This was out of respect for possibly bereaved family members who could recognize images of participants who had died after publication. The study complied with the Helsinki Declaration, the Danish Ethics Committee System and was approved by the Danish Data Protection Agency (Project-ID: S-20122000-96-CKH/csf).

FINDINGS

The analysis revealed that being able to develop and maintain a sense of belonging was associated with quality of life for people with advanced cancer, and was described by them as an ongoing process throughout the course of their lives. The four interrelated dimensions of belonging will be used as a structure to present the findings, although sometimes there will be overlap between the dimensions.
**Social belonging**

Several participants expressed quality of life in terms of maintaining emotional connections with people they felt close to, which often represented a lifelong partnership. For example, Erik, a 75 years old man who suffered from advanced prostate cancer and severe chronic obstructive pulmonary disease, selected a photograph (Figure 1) from his recent golden wedding anniversary. When asked about the photograph, Erik talked about his life together with his wife and how he relied on her daily support since his illness:

![Figure 1. Sharing a life together](image)

The most important thing for me, and also what give me quality of life, is the togetherness my wife and I share. The photograph tells about our long life together, and now that there are so many things I cannot do any longer, she helps me in so many ways. And that means a lot, an awful lot. It’s what makes it worthwhile to still be here. (Erik)

Erik’s photograph (Figure 1) and his related comments illustrate his understanding of partnership and belonging, which includes continuous sharing and caring during changing circumstances brought on by severe illness. The extract furthermore describes how advanced cancer may lead to reduced abilities and increased dependency that may impact daily occupations. Like Erik, several participants experienced changing needs for support following their illness, and the possibility of receiving help when needed (or a lack thereof) was particular mentioned as influencing the quality of their lives.
Several participants commented on the importance of being able to contribute to the lives of others despite severe illness, and maintain familiar roles and occupations that involved supporting friends and family when they needed it. Jane, a 59 years old woman with advanced breast cancer, talked about how helping others always had been an important part of her life, for example through volunteering, which she was forced to give up because of her illness. Before being ill with cancer, having lived in a house with a large garden, Jane described how she used to enjoy teaching her grandchildren to plant vegetables and build a playhouse. On becoming ill, Jane moved to an apartment and had to find new ways to be with her grandchildren:

I love the way they (the grandchildren) keep me going. The oldest often comes by himself and stays for dinner, and then I help him with his homework. This is great because it also forces me to learn new things, for example when I have to talk to his teachers about how to do different things, so I’m able to help him. (Jane)

Figure 2. Taking care of the grandchildren

Jane’s example illustrates how advanced cancer may change the way an individual can maintain familiar roles and responsibilities within the family. Nevertheless, Jane longed for her house and the life and the possibilities it used to provide, and struggled to reconstruct her life in new ways that allowed her to still contribute to the life of her family.
Spatial belonging

Many participants struggled with the physical consequences of advanced cancer, such as bodily decline, fatigue and breathlessness. These physical limitations influenced their occupational engagement profoundly, and other ways to maintain valued occupations became significant. Erik’s great interest was bird watching which he had enjoyed throughout his life, and used to involve trips around Denmark. Because of severe breathlessness he was now only able to walk very short distances which confined him to his home most of the time. Reflecting on one of his photographs (Figure 3) Erik said:

I have taken this photograph because I’m very fond of birds, in nature that is. This is why I have two bird feeders; one in front of the house and one in the back yard and as you can see there are a lot of birds. I like watching the birds, and in a way it gives me a better life, because it keeps me active. I’m very fond of birds and nature, because I grew up at a place where I was always close to nature. (Erik)

Eric explained that he took the photograph to illustrate his love of nature, and how the birdfeeders enabled him to continue a lifelong interest. But, with Erik’s comments of having a love for birds in nature in mind, the photograph (Figure 3) can also be viewed as a representation of a life that is primarily lived indoors, where a place such as a window can gain new importance since it enables a sense of belonging with the outside world that may enhance a person’s quality of life.
Occupations in natural surroundings, for example while spending time in the garden enabled some participants to be in the moment and to temporarily shift the focus away from their illness, as Mona shared:

The garden had always been an important place for Mona, but heavy garden work had become difficult since her illness. Since then her garden had become a sanctuary that provided different possibilities for relaxation and tranquillity that that generated existential and spiritual belonging.

The majority of participants spent their time at home and some described how their view of their home had changed since their illness. For some the home had become a place where they could feel safe and relaxed, but for other the home had become a place of confinement that negatively affected their possibilities of social belonging. Annie, who lived with her husband and teenage son, described her experiences in this way:

I spend all day at home alone while my husband is at work. (...) I miss being out and to be with other people. I miss that a lot. (Annie, age 57)
Annie had advanced colon cancer that caused severe pain when she walked, making it impossible for her to leave home by herself. Being at home, she often felt alone and isolated which greatly influenced her quality of life.

_Belonging as existential and spiritual connections_

Living with advanced cancer caused reflections of the transience of life, and several participants described how a sense of belonging with nature generated spiritual and existential thoughts, as was shared by Mona above and Elsa who lived with her husband:

I come from a very Christian home, but turned my back on the church when I was young because of the strictness. I have a more relaxed relationship with the church now, it means something to me. It has to do with the meaning of life, that there is something that is bigger than oneself. Maybe that is why I’m so comfortable in nature. My husband and I often walk along the beach and we love to hike in the Norwegian mountains and to be alone in the magnificent nature (Elsa, age 70).

Like Mona, Elsa associated existential and spiritual belonging with being in and with nature. Existential reflections also evoked memories and enhanced a sense of belonging with deceased family members. For example, Elsa described how preparing Christmas dinner reminded her of her mother since they always cooked Christmas dinner together. On the other hand, special holidays or occasions, such as Christmas or birthdays, could also generate a sense of belonging that evoked profound sadness of having to leave loved ones.

Some participants mentioned how their illness had brought out a new-found interest in family history. For example, engaging in genealogy or beginning to write memoirs were for some
participants ways of preserving their family history for future generations. Handmade paintings or crafts for family or friends were other ways of leaving something for future generations. Marie took a photograph of a pair of baby pants that she had knitted. She used to knit for her entire family and being able to continue to do so despite illness was important for her, since it enabled her to maintain a sense of belonging with her family:

The pants are for my great-grandchild. She is not born yet, but she will be my first great-grandchild. I have been working on the pants for two months now. (Marie, age 68)

Creating intensely personal objects such as the pair of baby pants that could be given as a present can be seen to reflect also an existential hope for the future during a time of suffering and anticipating endings and losses.

**Belonging through artifacts**

Personal artifacts, as indicated above, often hold special meaning since they can contribute to feelings of belonging that may become especially important when living with an approaching death. Some participants described how artifacts provided a sense of connection, for example
with those who had gifted an item for them or to places where it once was purchased, for instance during a vacation. Personal artifacts could however also evoke distress. Elsa described that she removed all her needlework which she produced and accumulated over the years, since it was a painful reminder of her increasing limitations which profoundly impaired her quality of life.

Valued objects handed down through the family, such as special Christmas ornaments or old pictures, contributed to a sense of belonging to a family that included diseased relatives for several of the participants. Mona for example reflects:

Similarly, Villy who described the significance of some family letters that were passed on to him by his parents:

We have this amazing treasure of old letters that goes back to when we were young, which was kept by our parents. When we take car trips my wife reads the letters while I drive. Then we remember our parents and the trips we have been on. We value these moments (Villy, age 85).
Being surrounded by heirlooms prompted some participants to remember and feel close to deceased family providing a strong sense of belonging at this point in their lives, which – in turn – can be seen to enhance their quality of life.

For other participants everyday objects enabled different forms of social belonging in their daily life. Paul lived alone with limited contact to his family and his moped had great significance in maintaining valued connections with his friends:

I get around on my red moped and every day I drive out to my community garden to be with the guys. We have a place out there where we meet and then we have a soda and talk about fixing old mopeds and things like that.

(Paul, age 69)

As several participants experienced increasing difficulties with mobility, other ways of maintaining a sense of belonging, regardless of time and place, gained importance. These ranged from the use of technological devices to the media and the Internet. In these ways feelings of isolation were reduced and a sense of belonging with friends and family, the local community and wider society were enabled, enhancing quality of life.

DISCUSSION

This article sought to provide a deeper understanding of the ways in which different yet complementary dimensions of belonging are perceived as aspects of quality of life by people with advanced cancer who live at home. The findings suggest that most participants
associated quality of life with maintaining a sense of belonging. The underpinning occupations and processes were described by many participants as a complex challenge that involved continuing valued occupations while facing ongoing decline and decreased abilities that affected and limited possibilities for belonging. The findings showed that the individual dimensions of belonging as proposed within occupational science could be ambiguous, in the sense that a home could be experienced as a sanctuary, thus enhancing quality of life, as well as a place of confinement that prevented social belongings and hence reduce quality of life. Moreover, the dimensions of belonging were interrelated, where diverse artefacts could serve as powerful connectors to other people, as well as evoke existential and spiritual feelings.

Belonging through emotional and shared connections was emphasized by most of the participants as essential to quality of life. For people living with an approaching death, the importance of having close and intimate relationships may be particularly significant for ‘a life worth living’ as one participant expressed it. This correspond with Hammell’s (2004b) conceptualization of quality of life in her study investigating quality of life as experienced by people with high spinal cord injury. Further maintaining affirming relationships as well as, contributing and having value in other people’s lives (Saarnio, Boström, Gustafsson, & Öhlén, 2016), are identified as an important dimension of belonging within the occupational science literature across different groups and populations (Hammell, 2004a, 2014; Krigel et al., 2014; Wilcock, 2015). The desire to help others is also identified as an important aspect of quality of life in this study, for example the ability to maintain occupations that involved supporting close relatives. The exchange of giving and receiving is acknowledged as an important way to establish, maintain and build relationships between people (Mauss, 2002).

In the occupational science literature, the significance of social belonging has in particular been explored (Burchett & Matheson, 2010; Hammell, 2014; Hill, 2006; Mills & Payne, 2015; Morgan et
Studies have shown that living with advanced cancer may cause feelings of being excluded and isolated (Davies & Sque, 2002; Willig, 2015). This was also shared by several participants in this study. Some described an everyday life of not belonging as a consequence of illness and continuous decline, which some participants described as a profound loss that greatly impaired the quality in their life.

In our study, participants’ physical problems due to advanced cancer, such as functional decline and pain, resulted in a different dependence on family and friends to maintain ways of social belonging. This was also identified by Håkanson and Öhlen’s (2016) study of connectedness for people with advanced cancer at end of life. This may suggest that people with advanced cancer may not be able to initiate and maintain a sense of belonging or do so in ways they could do previously. Instead, ways of belonging may have to be mediated by others and may be experienced as a threat to a person’s sense of control and autonomy. Hitch et al. (2014a) have addressed a gap of knowledge of proposed risk factors for belonging and have tentatively proposed ‘occupational exclusion’ as a possible risk factor. By suggesting that isolation (e.g. as a consequence of occupational exclusion), may be seen as a negative connotation of belonging, isolation may prevent possibilities of belonging, our study supports Hitch et al.’s (2014a) notion and adds empirical findings to their proposal.

Research has shown that people with advanced cancer spend most of their time at home (Krigel et al., 2014; la Cour, Nordell, et al., 2009), which also was the case for most participants in this study. When functional limitations prevented participants from leaving their home independently, the home became the primary place where valued occupations were maintained. For example, bird watching from a kitchen window can be described as ‘visual participation’ which becomes a means through which a person can experience that he or she still belongs to the life that takes place outside the home (Hasselkus, 2011c; Rowles, 1987) Other studies have shown that being engaged in
occupations without actually performing them can be perceived as an authentic and valued form of occupational engagement for people with advanced cancer (la Cour & Hansen, 2012; la Cour, Johannessen, & Josephsson, 2009; Lyons et al., 2002). This study adds to this growing body of knowledge by suggesting that visual participation, for instance at a window, may contribute to a sense of belonging and quality of life for people with advanced cancer.

Being diagnosed with advanced cancer is known to cause existential and spiritual concerns about an uncertain future (Ellingsen, Roxberg, Kristoffersen, & Rosland, 2013; la Cour, Ledderer, & Hansen, 2016; Marley, Pagana, Velenger, & Humbert, 2016). Being with and in nature may inspire people to reflect on the transience of life through interactions with living non-human objects, such as plants and birds (Hammell, 2014; Unruh, Smith, & Scammell, 2000). Wilcock and Hocking (2015b) describe belonging as an aspect of doing. Findings in this study however indicate that existential and spiritual dimensions of belonging may also be achieved through not doing, for instance by ‘being with nature’. Several participants associated quality of life with existential and spiritual experiences in nature that generated intense feelings of being an integral part of natural life cycles, as well as belonging to family and communities across time and place.

According to Wilcock and Hocking (2015a) belonging is associated with “others, places and things” (p. 136) but the possible link between belonging and ‘things’ is not yet well documented in the occupational science literature. Ilott (2006) and Hocking (Hocking, 1994, 1997, 2000) have particularly emphasized the importance and value of objects in regards to personal, social and cultural dimensions of a person’s life. Maintaining close relationships has been identified as most influential to spiritual experiences (Edwards, Pang, Shiu, & Chang, 2010). Findings in this study showed that various artifacts may gain a new significance for people with advanced cancer in the sense that they may serve as valuable mediators for maintaining social belonging. Artifacts could however also evoke strong feelings of life moving towards its end and having to part with loved
ones. More in-depth knowledge is needed to further understand in which way diverse artifacts, such as everyday objects, crafts and heirlooms, may contribute and support perceptions of belonging.

Methodological considerations

The sample size of nine participants was the result of a convenience sample. The sample size was partly due to working with this particular group of participants (individuals with advanced cancer) and partly due to the prolonged data collection of the preceding cross-sectional study, which prevented us from continued recruitment. Although, the analysis showed recurring themes across the sample, data saturation may not have been reached (Polit & Beck, 2004b).

The combination of semi-structured interviews and photo-elicitation proved to be a useful way to illuminate a deeper understanding of how dimensions of belonging may be linked to quality of life. For example, Mona’s photograph of her red armchairs, prompted her to talk about her diseased in-laws when asked about the drawings on the wall behind the armchairs. This revealed an important dimension of belonging for her that may not have been explored, had it not been for photo-elicitation. Similarly, Erik’s photograph of the bird feeder reflected visual participation as a different kind of belonging. Yet, use of photographs in research may also result in some participants feeling exposed, since photographs may reflect and express personal values in a more direct and permanent way than an interview (Rose, 2012a).

Inviting participants to describe what quality of life meant to them, may have prompted some to focus on the more positive aspects of their life. In light of the seriousness of the participants’ life situation and the predominantly positive experiences they shared, it is likely that important, and possible difficult and exposing, aspect were examined.

Several steps were taken to enhance the trustworthiness of the analysis. An audit trail was kept by recording reflections and decisions made during data collection and analysis. Informal
member checking was carried out during the data-collection and formally after the initial analysis (Polit & Beck, 2004a). Interpretation of the findings was discussed among authors and with other researchers at the University of Southern Denmark.

CONCLUSION

The study highlights that people with advanced cancer living at home associate quality of life with maintaining a sense of belonging. This was identified as a complex and challenging process that entailed sustaining valued occupations while facing continuous decline and decreasing abilities that limit possibilities for diverse ways of belonging.

The findings also indicate that particularly aspects related to dimensions of social belonging may come to the fore when living with advanced cancer, including belonging through artifacts which may enable a sense of belonging, as well as evoke existential and spiritual concerns that may arise with impending death.

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