

ORIGINAL ARTICLE

Assistive devices among people living at home with advanced cancer: Use, non-use and who have unmet needs for assistive devices?

Marc Sampedro Pilegaard¹  | Karen la Cour¹  | Fjóla Baldursdóttir¹ |
Deidre Morgan²  | Lisa Gregersen Oestergaard^{1,3,4}  | Åse Brandt¹ 

¹The Research Unit for User Perspectives and Community-based Interventions, the Research Group for Occupational Science, Department of Public Health, University of Southern Denmark, Odense, Denmark

²Research Centre for Palliative Care, Death and Dying (RePaDD), Flinders University, Adelaide, South Australia, Australia

³Department of Physiotherapy and Occupational Therapy, Aarhus University Hospital, Aarhus, Denmark

⁴DEFACTUM, Aarhus, Denmark

Correspondence

Marc Sampedro Pilegaard, The Research Unit for User Perspectives and Community-based Interventions, the Research Group for Occupational Science, Department of Public Health, University of Southern Denmark, J.B. Winsløvs Vej 9B, Odense 500, Denmark. Email: mpilegaard@health.sdu.dk

Funding information

Region of Southern Denmark, Grant/Award Number: 15/23775; Danish Association of Occupational Therapists, Grant/Award Number: FF 2 14-3; The TrygFonden and the Danish Cancer Society, Grant/Award Number: R53-A2783; University of Southern Denmark

Abstract

Objective: To investigate which assistive devices people with advanced cancer have and whether they are in use. In addition, to explore the characteristics of people with advanced cancer who have unmet needs for assistive devices.

Methods: This descriptive cross-sectional study used data from a randomised controlled trial evaluating efficacy of an occupational therapy-based intervention. Participants were 237 people with advanced cancer. Data were collected by means of instruments about demography, functioning and assistive devices.

Results: The most frequent assistive devices possessed by the participants were as follows: (1) small aids for dressing (47%), (2) Pillow for positioning (40%) and (3) electrically operated adjustable bed (39%). The prevalence of assistive devices was 92% (95% confidence interval [CI]: 88%–95%) with 14.2% non-use, largest for trolley tables (50%). In all, 27.4% of the participants were found to have unmet needs for assistive devices. These participants had similar characteristics to the other participants except from lower activity of daily living (ADL) ability (p values = <0.001).

Conclusion: The assistive devices possessed by the participants were primarily for positioning and resting, and most were in use. More than a fourth of the participants had unmet needs for assistive devices and were characterised by lower ADL ability.

KEYWORDS

activities of daily living, neoplasms, palliative care, self-help devices

1 | INTRODUCTION

People with advanced cancer may experience difficulties engaging in everyday activities due to cancer symptoms and the side effects of treatment (Johnsen et al., 2009, 2013). Everyday activities represent what people need to do, want to do and are expected to do (WFOT, 2020), for example, activities such as getting around and

doing hobbies and activities of daily living (ADL). A Danish study among people living at home with advanced cancer found most ADL difficulties in shopping and doing laundry and cleaning (Wæhrens et al., 2019). The study also found that nearly all participants had difficulties engaging in everyday activities that they regarded as important, for example, hobbies and craft, gardening, walking, cycling and household activities (Wæhrens et al., 2019). Continued engagement

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *European Journal of Cancer Care* published by John Wiley & Sons Ltd.

in everyday activities is important for people with advanced cancer at the end of life and may ease suffering (Bentz et al., 2021; Svidén et al., 2010; von Post & Wagman, 2019).

Assistive devices, described by the World Health Organization (WHO) as assistive products, may support engagement in everyday activities. These assistive devices “maintain or improve an individual's functioning and independence, thereby promoting their well-being. Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids are all examples of assistive products” (WHO, 2021). A qualitative study on people with advanced cancer suggests that assistive devices may facilitate performance of everyday activities and conserve energy so that other meaningful activities can be pursued (Peoples et al., 2017). Further, assistive devices are recommended to enable everyday activities among people with advanced cancer and to improve their health-related quality of life (HRQoL) (Montagnini et al., 2020; White, 2016). A study among Danish adults with advanced cancer ($N = 169$) showed that 62.9% of all participants had one or more assistive devices (Funch et al., 2019). The most frequent types of assistive devices were ‘daily living’ devices, such as raised toilet seats, reachers, activity chairs or devices for eating and drinking (56.6%), and mobility devices, e.g., rollators or wheelchairs (37.1%) (Funch et al., 2019).

Although research has shown that people with limitations in everyday activities have assistive devices, these are not always used (Sugawara et al., 2018). If the devices are not used, they cannot ease activity limitations, and the societal costs associated with provision of the assistive devices will be wasted (Federici et al., 2016). The extent of non-use of assistive devices varies between types of assistive devices, user groups and countries ranging between no non-use and 30% (Dijcks et al., 2006; Scherer, 2014, 2017). However, no research has examined the non-use of assistive devices among people with advanced cancer. The present study draws on the data from a Danish randomised controlled trial (RCT) evaluating the efficacy of the ‘Cancer Home-Life Intervention’ on everyday activities and HRQoL in people with advanced cancer living at home (Brandt et al., 2016; Pilegaard et al., 2018). The ‘Cancer Home-Life Intervention’ was an occupational therapy-based intervention consisting of six intervention components, including identification of difficulties in everyday activities, needs assessment and provision of assistive devices. It aimed to enable people to perform and participate in the everyday activities at home that they prioritised but had difficulties performing (e.g., ADL, leisure and social activities). On average, a total of 2.6 assistive devices were provided to the participants to solve everyday activity limitations (la Cour et al., 2020). The study showed which types of assistive devices were needed, but characteristics of the participants who had unmet assistive device needs are unknown. Knowledge about use and unmet needs may inform palliative care teams regarding assistive device provision to community dwelling people with advanced cancer.

The objectives of this study were as follows:

- To investigate which assistive devices people with advanced cancer have and whether the assistive devices are in use.

- To explore the characteristics of those who have unmet needs for assistive devices and how they differ from the other participants.

2 | METHODS

2.1 | Design

This substudy has a descriptive cross-sectional design utilising data from the aforementioned rater-blinded, parallel-group, two-armed RCT with a 6- (T2), 12- (T3) and 24-week (T4) follow-up after baseline (T1) (Pilegaard et al., 2018). In total, 242 participants living with advanced cancer were included and randomised to either receive the ‘Cancer Home-Life Intervention’ and usual care (intervention group) or usual care only (control group). Between T1 and T2, the intervention participants received the ‘Cancer Home-Life Intervention’. Assistive devices were provided to 65 (57.5%) of the participants in addition to the ones they already had, indicating unmet needs for assistive devices (la Cour et al., 2020). The provision of the assistive devices was based on a needs assessment conducted by an occupational therapist (OT) using T1 data, an interview with the participants and observation of participants in their homes. Based on this assessment, the OT considered whether assistive devices could resolve the participants' problems with prioritised everyday activities. As 65 participants received assistive devices following OT assessment, these participants were determined to have had unmet needs for assistive devices. The RCT was approved by the Danish Data Protection Agency (FN 215-57-0008) and registered at [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT02356627). The National Danish Ethics Committee noted that no formal ethics approval was required (S-20122000-96). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) was used to report the present study (von Elm et al., 2007).

2.2 | Participants and setting

The participants in the RCT were enrolled from oncology units at Aarhus University Hospital (AUH) and Odense University Hospital in Denmark between February 2015 and October 2016. The inclusion criteria were as follows: age of 18 years or older, a diagnosis of incurable cancer, a functional levels 1–2 on the WHO performance scale (WHO, 1979) (see Appendix A), living in a private home or in sheltered living, living within a radius of maximum 60 km from AUH or on the island of Funen, and sufficient knowledge of the Danish language to complete questionnaires and participate in interviews. The exclusion criteria were as follows: cognitive impairment assessed by an OT, living in a nursing home or hospice, or considered otherwise incapable of complying with the trial. In addition to these inclusion criteria, only participants who had completed a questionnaire about assistive devices were included in the present sub study. All participants received written and oral information about the project procedures and signed written consent forms. All data were deidentified, and only group results were reported.

2.3 | Data collection

The data for the present study was collected by eight trained data collection OTs according to a data collection manual. Prior to the T1 home visit, a study-specific questionnaire on demography and health and the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-30) were sent to the participants to be filled out. The completed questionnaire was collected by the OT at the T1 home visit, and missing answers were checked. Thereafter, a structured checklist about use and non-use of assistive devices was filled out by the OT. Lastly, the Assessment of Motor and Process Skills (AMPS) was conducted by the OT to measure the participants' ADL performance. Registration of the participants' primary tumour site was done by a responsible oncologist at the included hospitals. Data collection for the entire RCT can be found elsewhere (Brandt et al., 2016; Pilegaard et al., 2018).

2.4 | The utilised instruments

2.4.1 | The EORTC QLQ-30

The EORTC QLQ-30 is a 30-item instrument assessing HRQoL (Fayers, 2001). It consists of five multi-item functional scales (physical, role, cognitive, emotional and social); three multi-item symptom scales (fatigue, pain and nausea and vomiting); a global health status/quality of life scale; and six single-symptom scales (dyspnoea, loss of appetite, insomnia, constipation, diarrhoea and financial difficulties) (Aronson et al., 1993). These items are rated using a 4-point Likert-type scale (1 = *not at all*, 2 = *a little*, 3 = *quite a bit* and 4 = *very much*) and subsequently transformed into scores ranging between 0 and 100, with higher scores indicating more symptoms or better function. A study by Johnsen et al. (2009) has suggested the following categorisation of the function scores: ≤ 33.3 corresponds to having severe problems, ≤ 66.7 equals moderate problems, and > 66.7 equals having minor or no problems (Johnsen et al., 2009). The same study categorises symptoms as 'no problem' (≤ 33.2), 'moderate problem' (33.3–66.6) and 'severe problem' (> 66.7) (Johnsen et al., 2009). The EORTC QLQ C-30 has been found to be a responsive, valid and reliable instrument among people with advanced cancer (Groenvold et al., 1997; Kaasa et al., 1995).

2.4.2 | The assistive device checklist

The assistive device checklist included predefined categories: 'mobility', 'self-care', 'household activities', 'communication and recreation' and 'other'. During the T1 home visit, the OT asked the participants which assistive devices they had and whether they used them. In addition, the OT observed which assistive devices were present in the home. The checklist was filled out while the participants and the OT walked about in the participants' homes. Participants could report on the most frequently used assistive devices under each category. The

participants could also report other assistive devices which were not included under each category. Participants could answer in three categories: "Yes and I use it", "Yes but I don't use it" or "No". The checklist is validated based on a former study (Funch et al., 2019) and was pilot tested before use with only one alteration replacing the item 'scissors or special writing pen' with 'pillow for positioning'. The reliability of the checklist was improved as participant self-report was confirmed with observation of the home environment (data triangulation).

2.4.3 | The AMPS

The AMPS is a standardised, observation-based assessment instrument measuring a person's observed overall quality of ADL task performance (Fisher & Jones, 2010). A calibrated OT observes the participant perform two standardised and relevant ADL tasks and scores 16 motor skills and 20 process skills. Each skill is scored on a 4-point ordinal scale. The ordinal scores are converted into two measures of ADL motor and ADL process ability. The ADL motor ability measure identifies the amount of physical effort, clumsiness and/or fatigue a person demonstrates during ADL task performance. The ADL process ability measure determines the overall efficiency of time, space and object use during ADL task performance. Measures on both the ADL motor ability and ADL process ability can be interpreted using independence cut-offs, predicting a need for assistance: (1) low ADL motor ability < 1.0 logits, middle ADL motor ability ≥ 1.0 to < 1.5 logits and high ADL motor ability ≥ 1.5 logits; and (2) ADL process ability measures low ADL process ability < 0.7 logits, middle ADL ability ≥ 0.7 to < 1.0 logits and high ADL process ability ≥ 1.0 logits. Low ADL motor ability and low ADL process ability indicate maximal assistance to live in the community. Studies support that the AMPS can provide valid and reliable measures of function for people with advanced cancer (Gerber et al., 2006; Parks et al., 2009) and have also demonstrated sensitivity to change over time (Fisher & Jones, 2010).

2.5 | Data analysis

Descriptive statistics was used to describe baseline characteristics of the participants, i.e., mean values and standard deviation (SD), median and interquartile range (IQR), or number and percent. The categories from the assistive device questionnaire "Yes and I use it", "Yes but I don't use it" and "No" were dichotomised into Yes/No. To be in the category "Yes", the participants must at least have one assistive device. Prevalence of assistive devices was calculated together with a 95% confidence interval (95% CI). Use and non-use of assistive devices were presented using number and percent. The 65 intervention participants who received assistive devices as part of the intervention were categorised as having unmet needs regarding use of assistive devices. Median and IQR and number and percent were applied to explore the characteristics of people with advanced cancer who have unmet needs regarding assistive device use. Furthermore, participants with unmet needs for assistive devices were compared

TABLE 1 Characteristics of participants and those with unmet needs for assistive devices

	Study population (N = 237)	Participants with unmet needs for AD (n = 65)	Remaining participants (n = 172)	p value
Demography and health				
Age (years), median (IQR)	69 (63–74)	70 (62–75)	69 (63–73)	0.37
Women, n (%)	124 (52%)	30 (46%)	94 (55%)	0.24
Living alone, n (%)	73 (31%)	18 (28%)	55 (32%)	0.52
Type of residence, n (%)				0.70
House	165 (70%)	47 (72%)	118 (69%)	
Apartment	56 (24%)	13 (20%)	43 (25%)	
Other	16 (7%)	5 (8%)	11 (6%)	
Primary tumour site, n (%)				
Gastrointestinal	72 (30%)	19 (29%)	53 (31%)	
Gynaecological	14 (6%)	0 (0%)	14 (8%)	
Lung	46 (19%)	12 (18%)	34 (20%)	
Breast	37 (16%)	11 (17%)	26 (15%)	
Prostate	29 (12%)	11 (17%)	18 (10%)	
Head and neck	17 (7%)	5 (8%)	12 (7%)	
Bladder	15 (6%)	3 (5%)	12 (7%)	
Other	7 (3%)	4 (6%)	3 (2%)	
Comorbidities, n (%)				
Asthma	14 (6%)	5 (8%)	9 (5%)	
Diabetes	25 (11%)	10 (15%)	15 (9%)	
Increased blood pressure	81 (34%)	21 (32%)	60 (35%)	
Heart disease	30 (13%)	9 (14%)	21 (12%)	
Chronic obstructive pulmonary disease	21 (9%)	7 (11%)	14 (8%)	
Arthritis	31 (13%)	13 (20%)	18 (10%)	
Osteoporosis	27 (11%)	7 (11%)	20 (12%)	
Mental illness	7 (3%)	1 (2%)	6 (3%)	
Back disorders	28 (12%)	10 (15%)	18 (10%)	
Eye disease	36 (15%)	9 (14%)	27 (16%)	
Ear disease	12 (5%)	4 (6%)	8 (5%)	
Lower extremity fractures	14 (6%)	5 (8%)	9 (5%)	
Neurological diseases	15 (6%)	6 (9%)	9 (5%)	
Abdomen disease	13 (5%)	3 (5%)	10 (6%)	
Metabolic disorder	14 (6%)	3 (5%)	11 (6%)	
Occupational status, n (%)				
Working	34 (14%)	8 (12%)	26 (15%)	
Retired	192 (81%)	55 (85%)	137 (80%)	
Sick leave	8 (3%)	1 (1%)	7 (4%)	
Unemployed	3 (1%)	1 (1%)	2 (1%)	
Education, n (%)				
≤10 years	63 (27%)	14 (21%)	49 (29%)	0.73
11–12 years	61 (26%)	18 (28%)	43 (25%)	
>13 years	112 (47%)	33 (51%)	79 (46%)	

TABLE 1 (Continued)

	Study population (N = 237)	Participants with unmet needs for AD (n = 65)	Remaining participants (n = 172)	p value
Functioning				
EORTC QLQ C-30, median (IQR) ^a				
Physical function	67 (50–87)	60 (47–80)	73 (53–87)	
Role function ^b	67 (33–83)	67 (33–67)	67 (33–100)	
Emotional function ^b	83 (67–96)	83 (67–92)	83 (67–100)	
Cognitive function ^b	83 (67–100)	83 (67–100)	83 (67–100)	
Social function ^b	83 (50–100)	67 (50–100)	83 (67–100)	
AMPS ^c				
ADL motor ability, median (IQR) ^d	1.2 (0.8–1.6)	1.0 (0.8–1.2)	1.3 (0.9–1.6)	<0.001*
Below age expectations, n (%)	115 (49%)	45 (69%)	70 (41%)	
Independence cut-off, n (%) ^e				
Low	74 (31%)	29 (45%)	45 (26%)	
Middle	91 (39%)	27 (41%)	64 (37%)	
High	71 (30%)	9 (14%)	62 (36%)	
ADL process ability (AMPS), median (IQR) ^d	0.8 (0.6–1.1)	0.8 (0.5–1)	0.8 (0.6–1.2)	0.20
Below age expectations, n (%)	58 (25%)	16 (25%)	42 (25%)	
Independence cut-off, n (%) ^e				
Low	70 (30%)	21 (32%)	49 (29%)	
Middle	69 (29%)	23 (36%)	46 (27%)	
High	97 (41%)	21 (32%)	76 (44%)	
Symptoms				
EORTC QLQ C-30, median (IQR)				
Pain	33 (0–50)	33 (17–50)	17 (0–58)	
Fatigue	44 (33–67)	56 (33–78)	44 (33–67)	
Nausea	0 (0–17)	17 (0–17)	0 (0–17)	
Dyspnoea	33 (0–33)	33 (0–67)	0 (0–33)	
Appetite loss	33 (0–33)	0 (0–67)	33 (0–33)	
Insomnia	33 (0–33)	33 (0–33)	33 (0–50)	
Diarrhoea	0 (0–33)	0 (0–33)	0 (0–33)	
Constipation ^f	0 (0–33)	0 (0–33)	0 (0–33)	
Financial difficulties ^g	0 (0–0)	0 (0–0)	0 (0–0)	

Abbreviations: AD, assistive devices; ADL, activities of daily living; AMPS; Assessment of Motor and Process Skills; EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of life C-30; IQR, interquartile range.

^aThe EORTC QLQ C-30 symptom scores ranges from 0 to 100, with higher scores representing better function or severe symptoms.

^bOne missing; The missing values were in the group of remaining participants, except for a missing value in role function in the group with unmet needs.

^cOne participant has not completed the AMPS and is therefore missing in ADL motor ability and ADL process ability.

^dHigher positive AMPS measures represent a better observed ADL ability.

^eIndependence cut-off AMPS: (1) low ADL motor ability <1.0 logits, middle ADL motor ability ≥1.0 to <1.5 logits, and high ADL motor ability ≥1.5 logit; and (2) low ADL process ability <0.7 logits, middle ADL process ability ≥0.7 to <1.0 logits, and high ADL process ability ≥1.0 logits.

^fTwo missings.

^gFour missings; two in participants with unmet needs and two in the remaining participants.

*p value ≤ 0.05 is considered to be statistically significant.

with the rest of the group in terms of age, gender, whether they lived alone, type of residence, educational level and ADL ability (motor and process). Group selection was informed by a Swedish study, which found that need for assistive devices among Swedish older people was associated with gender, living arrangements (alone or with others), type of residence and ADL ability (Lofqvist et al., 2016) and a Danish register study of patients with cancer, which found that a higher educational level was associated with a higher referral to rehabilitation services (Moustsen et al., 2015). Wilcoxon rank sum test was used in analyses of age and ADL ability since data had a skewed distribution. The chi-square test was used in the remaining analyses. p value ≤ 0.05 was considered to be statistically significant. Data were analysed using the statistical programme STATA/IC 16.1 (StataCorp, 2019).

3 | RESULTS

Of the 242 participants in the RCT, 237 had completed the questionnaire about assistive device use at T1 and were included in the present study. Their median age was 69 years, and the gender distribution was nearly equal. Most participants lived in a house (70%) with someone (69%) and had comorbidity (77%). The most prevalent comorbidities were increased blood pressure (34%), eye disease (15%), arthritis (13%) and heart disease (13%). Most of the participants were retired from the workforce. The site of the primary tumour varied (Table 1). The participants had minor or no problems with physical (median = 67), role (median = 67), emotional (median = 83), cognitive (median = 83) and social function (median = 83). Their ADL motor and ADL process ability were affected (ADL motor = 1.2; ADL

TABLE 2 Assistive devices possessed and used by the participants ($N = 237$)

Assistive device	In possession		Non-use	
	<i>n</i>	%	<i>n</i>	%
Small aids for dressing	112	47.3	20	17.9
Pillow for positioning	110	40.3	2	1.8
Electrically operated adjustable bed	106	38.8	9	8.5
Lounge chair	102	37.4	5	4.9
Handrails	84	30.8	11	13.1
Activity chair	65	23.8	6	9.2
Kitchen aids	62	22.7	10	16.1
Bathing stool	49	17.9	10	20.4
Walking stick and elbow crutches	45	16.5	12	26.7
Rollator	34	12.5	9	26.5
Small aids for bathing	33	12.1	6	18.2
Communication aid	24	8.8	5	20.8
Grab bar	22	8.1	6	27.3
Raised toilet seat	17	6.2	1	5.9
Trolley table	16	5.9	8	50.0
Emergency alarm system	9	3.3	1	NR
Manual wheelchair	8	2.9	3	NR
Shower chair	7	2.6	2	NR
Ramp	4	1.5	0	NR
Small aids for eating ^a	4	1.5	2	NR
Powered scooter	2	0.7	0	NR
Faucet turner	2	0.7	1	NR
Seat cushion to prevent pressure ulcers	1	0.4	0	NR
Shopping trolley	1	0.4	0	NR
Grip rope	1	0.4	1	NR
Printed calendar	1	0.4	0	NR
Leg extenders	1	0.4	1	NR
Robot vacuum cleaner	1	0.4	0	NR
In all	923		131	

Abbreviation: NR, not relevant to calculate due to low prevalence.

^aCovers different types of small devices to be used for the same purpose.

process = 0.8) where 49% of the participants' ability was below age expectation in ADL motor and 25% in ADL process compared to healthy peers of the same age. When looking at the independence cut-off scores, the majority had low or middle independence scores (70% ADL motor and 59% ADL process), indicating that they were likely to need assistance to live in the community (Fisher & Jones, 2010). In fact, a large proportion had low ADL motor (31%) and low ADL process scores (30%) indicating the need for moderate to maximal support. Of the symptom scores, fatigue was the highest (median = 44).

3.1 | Use and non-use of assistive devices

The prevalence of assistive devices was 92% (95% CI: 88%–95%). The most frequently used assistive devices were small aids for dressing (47.3%), including a range of different assistive devices for putting on or removing socks and pantyhose and buttoning devices, followed by pillows for positioning (40.3%), electrically operated adjustable beds (38.8%), lounge chairs (38.8%) and handrails (30.8%). Other types of devices were less prevalent (Table 2).

In all, 14.2% of the assistive devices possessed by the participants were not in use. The assistive devices that had the largest prevalence of non-use were trolley tables (50%), grab bars (27.3%), walking sticks and elbow crutches (26.7%) and rollators (26.5%), while the devices that had the least prevalence of non-use were pillows for positioning (1.8%), lounge chairs (4.9%), raised toilet seats (5.9%), electrically operated adjustable beds (8.5%) and activity chairs (9.2%) (Table 2).

3.2 | Characteristics of participants with unmet needs for assistive devices

Of the participants, 27.4% had unmet needs for assistive devices. The characteristics of these did not differ from the other participants, except that those with unmet needs had a lower ADL motor ability (AMPS 1.0 [IQR 0.8–1.2]) than the remaining participants (AMPS 1.3 [IQR 0.9–1.3]) ($p < 0.001$) (Table 1). The observed difference was clinically relevant (0.3 logits). This is also illustrated in the independence cut-off in the ADL motor ability, where almost twice as many participants with low scores are represented in the unmet group compared to the other participants.

4 | DISCUSSION

The study showed that most people with advanced cancer (92%) had at least one assistive device and that the prevalence of non-use differed substantially, depending on the type of assistive devices, ranging from 1.8% to 50%. Even though nearly all had assistive devices, 27.4% still had unmet needs for assistive devices. The characteristics of participants with unmet needs for assistive devices were similar to

the other participants except that those with unmet needs had lower ADL motor ability (AMPS ADL motor = 1.0 vs. 1.3).

The prevalence of possession of assistive devices was higher than what was found in another Danish study (62.9%) including 164 people with advanced cancer (Funch et al., 2019). The study had nearly identical inclusion criteria and data collection methods and included a population similar to the present study, except that the participants in the study by Funch et al. had worse physical functioning and more fatigue: 58.6 and 55.1, as measured by the EORTC QLQ-C30 (Funch et al., 2019), while the measures for the present study were 67 and 44, respectively. It is not clear why the prevalence of assistive device possession differed between the two studies, especially since people with worse physical functioning and fatigue could be expected to possess more assistive devices. No other studies reporting on the prevalence of assistive devices possession were identified, but a Canadian study on people experiencing activity limitations (mean age 60.9 years) found that 95% had one or more assistive devices (Berardi et al., 2020), i.e., about the same level as found in the present study. Even though the types of assistive devices included in the studies varied and the structure of the assistive technology provision system may differ—the Canadian study included for example glasses and contact lenses, which the present study did not—a high prevalence of assistive devices is evident among people with substantial activity limitations, supporting the statement about the role of assistive devices in maintaining functioning and independence (WHO, 2021). It is therefore not surprising that a high prevalence of assistive devices was found in our study as the participants had reduced ADL ability, with some needing maximal assistance to live in the community (low ADL motor ability = 31%; low ADL process ability = 30%) (Fisher & Jones, 2010). Further, it has been found that people with advanced cancer are more likely to accept use of assistive devices as function deteriorates (Morgan et al., 2017).

Regarding the types of assistive devices that the participants had, it is striking that the purpose of the assistive devices that most participants possessed concerned rest and positioning, i.e., pillows for positioning, electrically adjustable beds and lounge chairs. This probably reflects the fact that the participants had a high degree of fatigue. In addition, it has been shown that people with advanced cancer mainly have a sedentary everyday life, mostly spending their time on self-care activities including resting and sleep, and leisure activities such as reading the newspaper and watching television (la Cour et al., 2009; Wæhrens et al., 2019). Thus, these assistive devices do not seem to aim at maintaining or improving their functioning and independence directly, but rather indirectly by providing them with the opportunity to rest as a prerequisite for better functioning.

The prevalence of non-use of the assistive devices in the home was lower than some of the highest estimates found in other studies (Scherer, 2014; Verza et al., 2006). One explanation may be that assistive devices in Denmark are provided for free based on a needs assessment, mostly done by OTs in the home environment (Indenrigsministeriet, 2017). Even so, the fact that 14.2% of the assistive devices were not used raises concern as the activity limitations

that the assistive devices were intended to compensate for may still be present. Reasons for non-use of assistive devices were not investigated in the present study, but non-use of assistive devices has been studied for other groups of users. Research has shown that non-use of assistive devices is complex and multifactorial, influenced by psychological, contextual and functional factors and that provision of assistive devices should adjust to the changing needs of the user (Tuazon et al., 2019). Thus, non-use may be partially explained by changes in functional abilities experienced by people with advanced cancer over the course of illness progression and treatments (Maersk et al., 2019). The study also found that the participants reported that the assistive devices symbolised their health situation and they preferred not to have to use them in periods with better health (Maersk et al., 2019). However, the reasons for non-use of assistive devices need to be studied further.

Characteristics of those with unmet need for assistive devices did not differ from the other participants, except from lower ADL motor ability. A relationship between lower ADL ability and unmet need for assistive devices has also been found in a study conducted in a Swedish population of older people (Lofqvist et al., 2016). Hence, lower ADL ability could be a characteristic of those who had unmet needs for assistive devices. Inability to access assistive devices they needed may have led to a lower ADL ability. However, very limited research exists about the association between assistive devices and ADL ability in people with advanced cancer. Although a UK study found a positive association between use of walking aids and basic ADL ability, the study did not find any statistically significant association with other types of assistive devices (wheelchair, commode, raiser recliner chair and chair raisers) (Fettes et al., 2020). The reason for the non-significant findings may be due to low statistical power as only 31 participants were included in the analysis of which 17 people had advanced cancer. Furthermore, the aforementioned Danish study found that people with assistive devices had lower ADL ability than people without assistive devices (Funch et al., 2019). The authors suggest that this may be due to the assistive devices users' poorer medical condition and a lower physical functioning rather than possession of assistive devices (Funch et al., 2019). Subsequently, more research is needed regarding the beneficial contribution assistive devices may have for people with advanced cancer.

The present study highlights the importance and prevalence of assistive device use for people with advanced cancer. In addition, the findings also highlight the importance of skilled OT assessment of assistive devices and continued provision for people with advanced cancer. This is further supported by a European survey study investigating OTs palliative care interventions which showed that more than 80% provided assistive devices frequently/very frequently (Eva & Morgan, 2018). Still, reasons for the variations in patterns of assistive device use and unmet need for assistive devices remain unclear and warrant further investigation (Scherer, 2017), which should be examined in further studies of people with advanced cancer. The patterns of assistive device use indicate that this group of people in particular need ongoing assessment of functional ability and ways in which compensatory interventions may optimise function. This includes

examination of which assistive devices can compensate for their progressive loss of functioning.

4.1 | Methodological considerations

The validity of the study findings is supported by the sample size ($N = 237$), which is large considering that the participants had advanced cancer and suffered from fatigue and impaired ADL ability. The setting was Denmark which has an assistive device system that supplies free assistive devices to people who need them after individual assessment (Indenrigsministeriet, 2017). This could affect the representativeness of the study results, but the fact that provision of assistive devices is the intervention most utilised among European OTs (Eva & Morgan, 2018) in spite of different service provision systems indicates that the study findings to a certain degree may be generalisable to other European countries.

Comparing types of assistive devices among people with advanced cancer with those of other groups of people is difficult, because no standardised way to collect data about assistive device use is available and depends on study objectives. The present study employed a questionnaire filled out by the participant and an OT in cooperation as well as a home assessment of the participant. These methods likely enhance the probability of comprehensive recording of all assistive devices compared to participant self-report of a questionnaire. In addition, the questionnaire had been used in a former study (Funch et al., 2019) showing that most relevant assistive devices were included, strengthening the validity of the data. Still, there was a discrepancy between the present and the former study indicating that the reliability of the questionnaire should be investigated (de Vet et al., 2011).

The method to determine unmet need for assistive devices was based on a professional assessment and subsequent provision of assistive devices, which can be regarded as a 'gold standard'. In contrast, in other research studies, unmet need for assistive devices is often established by asking the study participant, who may not know which activity limitations can be compensated for by means of assistive devices and which devices are available (Gramstad et al., 2013).

In conclusion, this study found that the types of devices used the most were aimed at resting and positioning, most likely reflecting a high degree of fatigue and a sedentary lifestyle among the participants. The prevalence of non-use of the assistive devices was 14.2%. Despite nearly all participants (92%) having assistive devices, 27.4% still had unmet needs for assistive devices. Those who had unmet needs in this area had lower ADL motor ability than the other participants but had similar characteristics in other respects. The present study presents new knowledge about assistive devices among people with advanced cancer. However, underlying reasons for the findings have not been investigated and is an area that warrants further research.

ACKNOWLEDGEMENTS

The authors thank the participants and the occupational therapists who were involved in the present study.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

FUNDING INFORMATION

The author(s) disclosed receipt of the following financial support for the research: The TrygFonden and the Danish Cancer Society (R53-A2783), the University of Southern Denmark, the Danish Association of Occupational Therapists (FF 2 14-3) and the Region of Southern Denmark (15/23775) funded the study.

ORCID

Marc Sampedro Pilegaard  <https://orcid.org/0000-0001-6362-410X>

Karen la Cour  <https://orcid.org/0000-0001-7126-0318>

Deidre Morgan  <https://orcid.org/0000-0001-8725-9477>

Lisa Gregersen Oestergaard  <https://orcid.org/0000-0003-2255-1391>

Åse Brandt  <https://orcid.org/0000-0002-1743-8426>

REFERENCES

- Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., & de Haes, J. C. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *JNCI: Journal of the National Cancer Institute*, 85(5), 365–376.
- Bentz, H., Madsen, S. H., Pilegaard, M. S., Brandt, Å., Offersen, S. M. H., Oestergaard, L. G., & la Cour, K. (2021). Occupations contributing to joy for people living with advanced cancer: A qualitative descriptive study. *British Journal of Occupational Therapy*. <https://doi.org/10.1177/03080226211009419>
- Berardi, A., Smith, E. M., & Miller, W. C. (2020). Assistive technology use and unmet need in Canada. *Disability and Rehabilitation. Assistive Technology*, 851–856. <https://doi.org/10.1080/17483107.2020.1741703>
- Brandt, Å., Pilegaard, M., Oestergaard, L., Lindahl-Jacobsen, L., Sørensen, J., Johnsen, A., & la Cour, K. (2016). Effectiveness of the cancer home life intervention on everyday activities and quality of life in people with advanced cancer living at home. A randomised controlled trial and a health economic evaluation. *BMC Palliative Care*, 15(10), 1–11. <https://doi.org/10.1186/s12904-016-0084-9>
- de Vet, H. C. W., Terwee, C. B., Mokkink, L. B., & Knol, D. L. (2011). *Measurement in medicine. A practical guide*. Cambridge University Press.
- Dijcks, B. P. J., de Witte, L., Gelderblom, G. J., Wessels, R. D., & Soede, M. (2006). Non-use of assistive technology in The Netherlands: A non-issue. *Disability and Rehabilitation. Assistive Technology*, 1(1–2), 102, 97–102.
- Eva, G., & Morgan, D. (2018). Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey. *Palliative Medicine*, 32(5), 960–968. <https://doi.org/10.1177/0269216318758928>
- Fayers, P. (2001). *The EORTC QLQ-C30 Scoring Manual* (3rd ed.). QL Coordinator, Quality of Life Unit, EORTC Data Center. Retrieved from <http://www.eortc.be/qol/files/SCManualQLQ-C30.pdf>
- Federici, S., Meloni, F., & Borsci, S. (2016). The abandonment of assistive technology in Italy: A survey of National Health Service users. *European Journal of Physical and Rehabilitation Medicine*, 52(4), 516–526.
- Fettes, L., Bone, A. E., Etkind, S. N., Ashford, S., Higginson, I. J., & Maddocks, M. (2020). Disability in basic activities of daily living is associated with symptom burden in older people with advanced Cancer or chronic obstructive pulmonary disease: A secondary data analysis. *Journal of Pain and Symptom Management*. <https://doi.org/10.1016/j.jpainsymman.2020.10.012>
- Fisher, A. G., & Jones, K. B. (2010). *Assessment of Motor and Process Skills, volume 1: Development, standardization, and administration manual* (7th ed.). Three Star Press.
- Funch, A., Kruse, N. B., la Cour, K., Peoples, H., Waehrens, E. E., & Brandt, Å. (2019). The association between having assistive devices and activities of daily living ability and health-related quality of life: An exploratory cross-sectional study among people with advanced cancer. *Eur J Cancer Care (Engl)*, 28(3), e13002. <https://doi.org/10.1111/ecc.13002>
- Gerber, L. H., Hoffman, K., Chaudhry, U., Augustine, E., Parks, R., Bernad, M., Mackall, C., Steinberg, S., & Mansky, P. (2006). Functional outcomes and life satisfaction in long-term survivors of pediatric sarcomas. *Archives of Physical Medicine and Rehabilitation*, 87(12), 1611–1617.
- Gramstad, A., Storli, S. L., & Hamran, T. (2013). “Do I need it? Do I really need it?” Elderly peoples experiences of unmet assistive technology device needs. *Disability and Rehabilitation. Assistive Technology*, 8(4), 287–293. <https://doi.org/10.3109/17483107.2012.699993>
- Groenvold, M., Klee, M. C., Sprangers, M. A., & Aaronson, N. K. (1997). Validation of the EORTC QLQ-C30 Quality of Life Questionnaire through combined qualitative and quantitative assessment of patient-observer agreement. *Journal of Clinical Epidemiology*, 50(4), 441–450.
- Indenrigsministeriet, *Bekendtgørelse om hjælp til anskaffelse af hjælpemidler og forbrugsgoder efter serviceloven*. BEK nr 1247 af 13/1/2017, (2017). Social- og Indenrigsministeriet.
- Johnsen, A. T., Petersen, M. A., Pedersen, L., & Grønvold, M. (2009). Symptoms and problems in a nationally representative sample of advanced cancer patients. *Palliative Medicine*, 23(6), 491–501.
- Johnsen, A. T., Petersen, M. A., Pedersen, L., Houmann, L. J., & Groenvold, M. (2013). Do advanced cancer patients in Denmark receive the help they need? A nationally representative survey of the need related to 12 frequent symptoms/problems. *Psycho-Oncology*, 22(8), 1724–1730.
- Kaasa, S., Bjordal, K., Aaronson, N., Moum, T., Wist, E., Hagen, S., & Kvikstad, A. (1995). The EORTC Core Quality of Life Questionnaire (QLQ-C30): Validity and reliability when analysed with patients treated with palliative radiotherapy. *European Journal of Cancer*, 31(13–14), 2260–2263.
- la Cour, K., Gregersen Oestergaard, L., Brandt, Å., Offersen, S. M. H., Lindahl-Jacobsen, L., Cutchin, M., & Pilegaard, M. S. (2020). Process evaluation of the cancer home-life intervention: What can we learn from it for future intervention studies? *Palliative Medicine*, 34(10), 1425–1435. <https://doi.org/10.1177/0269216320939227>
- la Cour, K., Nordell, K., & Josepsson, S. (2009). Everyday lives of people with advanced cancer: Activity, time, location, and experience. *OTJR: Occupation, Participation and Health*, 29(4), 154–162.
- Lofqvist, C., Slaug, B., Ekstrom, H., Kylberg, M., & Haak, M. (2016). Use, non-use and perceived unmet needs of assistive technology among Swedish people in the third age. *Disability and Rehabilitation. Assistive Technology*, 11(3), 195–201. <https://doi.org/10.3109/17483107.2014.961180>
- Maersk, J. L., Johannessen, H., & la Cour, K. (2019). Occupation as marker of self: Occupation in relation to self among people with advanced cancer. *Scandinavian Journal of Occupational Therapy*, 26(1), 9–18. <https://doi.org/10.1080/11038128.2017.1378366>
- Montagnini, M., Javier, N. M., & Mitchinson, A. (2020). The role of rehabilitation in patients receiving hospice and palliative care. *Rehabilitation*

- Oncology, 38(1), 9–21. <https://doi.org/10.1097/O1.Reo.000000000000196>
- Morgan, D. D., Currow, D. C., Denehy, L., & Aranda, S. A. (2017). Living actively in the face of impending death: Constantly adjusting to bodily decline at the end-of-life. *BMJ Supportive & Palliative Care*, 7(2), 179–188. <https://doi.org/10.1136/bmjspcare-2014-000744>
- Moustsen, I. R., Larsen, S. B., Vibe-Petersen, J., Trier, K., Bidstrup, P. E., Andersen, K. K., Johansen, C., & Dalton, S. O. (2015). Social position and referral to rehabilitation among cancer patients. *Acta Oncologica*, 54(5), 720–726. <https://doi.org/10.3109/0284186X.2014.997836>
- Parks, R., Rasch, E. K., Mansky, P. J., & Oakley, F. (2009). Differences in activities of daily living performance between long-term pediatric sarcoma survivors and a matched comparison group on standardized testing. *Pediatric Blood & Cancer*, 53(4), 622–628. <https://doi.org/10.1002/pbc.22101> [doi]
- Peoples, H., Brandt, Å., Wæhrens, E. E., & la Cour, K. (2017). Managing occupations in everyday life for people with advanced cancer living at home. *Scandinavian Journal of Occupational Therapy*, 24(1), 57–64.
- Pilegaard, M. S., la Cour, K., Gregersen Oestergaard, L., Johnsen, A. T., Lindahl-Jacobsen, L., Højris, I., & Brandt, Å. (2018). The ‘Cancer Home-Life Intervention’: A randomised controlled trial evaluating the efficacy of an occupational therapy-based intervention in people with advanced cancer. *Palliative Medicine*, 32(4), 744–756. <https://doi.org/10.1177/0269216317747199>
- Scherer, M. J. (2014). From people-centered to person-centered services, and back again. *Disability and Rehabilitation. Assistive Technology*, 9(1), 1–2. <https://doi.org/10.3109/17483107.2013.870239>
- Scherer, M. J. (2017). Technology adoption, acceptance, satisfaction and benefit: Integrating various assistive technology outcomes. *Disability and Rehabilitation. Assistive Technology*, 12(1), 1–2. <https://doi.org/10.1080/17483107.2016.1253939>
- StataCorp, L. (2019). *Stata statistical software: Release 16*. College Station, TX: StataCorp LLC.
- Sugawara, A. T., Ramos, V. D., Alfieri, F. M., & Battistella, L. R. (2018). Abandonment of assistive products: Assessing abandonment levels and factors that impact on it. *Disability and Rehabilitation. Assistive Technology*, 13, 716–723. <https://doi.org/10.1080/17483107.2018.1425748>
- Svidén, G. A., Tham, K., & Borell, L. (2010). Involvement in everyday life for people with a life threatening illness. *Palliative & Supportive Care*, 8(3), 345–352.
- Tuazon, J. R., Jahan, A., & Jutai, J. W. (2019). Understanding adherence to assistive devices among older adults: A conceptual review. *Disability and Rehabilitation. Assistive Technology*, 14(5), 424–433. <https://doi.org/10.1080/17483107.2018.1493753>
- Verza, R., Carvalho, M. L., Battaglia, M. A., & Uccelli, M. M. (2006). An interdisciplinary approach to evaluating the need for assistive technology reduces equipment abandonment. *Multiple Sclerosis*, 12(1), 88–93. <https://doi.org/10.1191/1352458506ms1233oa>
- von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., & Gøtzsche, P. C. (2007). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: Guidelines for reporting observational studies. *PLoS Medicine*, 4(10), e296. <https://doi.org/10.1371/journal.pmed.0040296>
- von Post, H., & Wagman, P. (2019). What is important to patients in palliative care? A scoping review of the patient's perspective. *Scandinavian Journal of Occupational Therapy*, 26(1), 1–8.
- Wæhrens, E., Brandt, Å., Peoples, H., & la Cour, K. (2019). Everyday activities when living at home with advanced cancer: A cross-sectional study. *European Journal of Cancer Care (England)*, 29(5), e13258. <https://doi.org/10.1111/ecc.13258>
- WFOT. (2020). Public statement. Occupational therapy response to the COVID-19 pandemic. Retrieved from <https://www.wfot.org/assets/resources/WFOT-Public-Statement-Occupational-Therapy-Response-to-the-COVID-19-Pandemic.pdf>
- White, K. M. (2016). The role of the occupational therapist in the care of people living with lung cancer. *Translational Lung Cancer Research*, 5(3), 244–246. <https://doi.org/10.21037/tlcr.2016.05.02>
- WHO. (1979). WHO handbook for reporting results of cancer treatment. Geneva: World Health Organization.
- WHO. (2021). *Assistive technology*. World Health Organization. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>

How to cite this article: Pilegaard, M. S., la Cour, K., Baldursdóttir, F., Morgan, D., Oestergaard, L. G., & Brandt, Å. (2022). Assistive devices among people living at home with advanced cancer: Use, non-use and who have unmet needs for assistive devices? *European Journal of Cancer Care*, 31(4), e13572. <https://doi.org/10.1111/ecc.13572>

APPENDIX A: DESCRIPTION OF THE WHO PERFORMANCE STATUS

Grade	Explanation of activity
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Dead