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Access to and interest in assistive technology for home-dwelling people with dementia during the COVID-19 pandemic (PAN.DEM)

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ABSTRACT

The COVID-19 restrictions affect daily living in Norway, including home-dwelling people with dementia, and researchers conducting clinical trials in dementia care. In this paper, we 1) describe the development of a pandemic cohort (PAN.DEM) incorporated in the LIVE@Home.Path, an ongoing clinical intervention trial on resource utilisation including home-dwelling people with dementia and their caregivers ($N = 438$ dyads), 2) describe pre-pandemic use of assistive technology and 3) explore the extent to which COVID-19 restrictions increase caregivers interest in innovation in the PAN.DEM cohort ($N = 126$). Our main finding is that assistive technology is available to 71% pre-pandemic; the vast majority utilise traditional stove guards and safety alarms, only a few operate sensor technology, including GPS, fall detectors or communication aids. In response to COVID-19, 17% show increased interest in technology; being less familiar with operating a telephone and having higher cognitive functioning are both associated with increased interest. We conclude that wearable and sensor technology has not yet been fully implemented among people with dementia in Norway, and few caregivers show increased interest under the restrictions.

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Introduction

In response to the COVID-19 pandemic, the Norwegian government on 12 March 2020 announced the most severe and restrictive measures ever implemented in peacetime. In the municipalities, 900 nursing homes were closed to visitors, a restriction that very likely protected many lives (Islam et al., 2020), while healthcare personnel were redirected from dementia teams and homecare services to more care-intensive functions such as nursing home wards. Those still working in homecare were limited to seeing only the most vulnerable patients for the shortest possible time, and caregivers were encouraged to refrain as much as possible from physical contact. At the same time, concerns rose about the deterioration of daily functioning among home-dwelling people with dementia, as the threat of isolation and disruption of day-to-day routines may increase loneliness, depressive symptoms and risk of adverse events (Husebo & Berge, 2020).

At the time of writing (20 September 2020), Norway is approaching the second COVID-19 peak. Stakeholders, clinicians and politicians need tools to minimise the harmful effects of social distancing and isolation at home. A wide array of new technologies may provide solutions (Yang & Kels, 2017). Our current review presents existing research on commercially available and prototype technologies that utilise wearable sensors, nonwearable motion sensor technologies, and assistive technologies/smart housing (Husebo et al., 2019). Different prognostic approaches at home may have the potential to inform clinicians about a range of patient responses, including

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Supplemental data for this article can be accessed here.

alterations in circadian rhythm (Merilahti et al., 2016), changes in gait speed (Channa et al., 2020), falls (Silva de Lima et al., 2017), and monitoring behaviour such as agitation and wandering (Khan et al., 2018; Kernebeck et al., 2019; Bankole et al., 2020). Further, devices for better communication (on behalf of the PD_Manager consortium, 2018; Dorsey et al., 2020), ethical considerations of surveillance technology in dementia (Sorell & Draper, 2012), or the need for real-world, evidence-based solutions to conduct clinical trials (Teipel et al., 2018) are becoming potentially available.

Nevertheless, barriers to the implementation of technology for home-dwelling elderly exist, including governmental engagement, industry resources and competence, home-care services awareness, patients' mental state, and relatives' attitude (Holthe et al., 2020). To learn more about innovation at home, we initiated the LIVE@Home.Path, a 2-year, multicomponent, stepped-wedge intervention trial for people with dementia and their caregivers (Husebo et al., 2020). One important outcome is the implementation of and experience with assistive technology.

In this study, we present a real-time snapshot of access to assistive technology in this population before and during the COVID-19 pandemic. We use data from PAN.DEM (PANdemic in DEMentia) a study of the LIVE@Home.Path trial to a) investigate the pre-pandemic access to assistive technology among home-dwelling people with dementia; b) explore whether COVID-19 restrictions increased caregivers' interest in assistive technology, and possible factors associated with increased interest, and c) discuss safety procedures to adapt the ongoing LIVE@Home.Path trial to the pandemic scenario, in accordance with the principles of responsible research innovation (RRI) (Schuijff & Dijkstra, 2020).

Method

The study protocol of the LIVE@Home.Path describes the multicomponent, randomised controlled design including home-dwelling people with dementia and their informal caregivers, constituting a dyad (Husebo et al., 2020). Participants were eligible for inclusion from May 2019 if they were ≥65 years, diagnosed with dementia according to a standardised protocol, Mini-Mental Status Examination (MMSE) score 15–26 or Functional Assessment Scaling (FAST) score 3–7 (Folstein et al., 1975; Reisberg, 1988). The stepped-wedge randomisation implies that all participants will receive the six-month intervention consisting of Learning; Innovation; Volunteerism, and Empowerment delivered by a municipal coordinator, while the timing is determined by randomisation. The participants waiting for the intervention constitute the control group (Figure 1).

Primary and secondary outcomes

The researchers and coordinators assess data in direct conversation with the person with dementia and the caregivers. According to the mixed method design (John, 2011), core outcomes will be explored using both qualitative and quantitative data. The primary outcome is resource utilisation in terms of formal and informal care time, as measured by the Resource Utilisation in Dementia (RUD) instrument(Wimo et al., 2013; Wimo et al., 2010) and the Relative Stress Scale (RSS) (Greene et al., 1982), while secondary outcomes, amongst others, are successful implementation and utilisation of assistive technology. Other secondary outcomes are shown in Table 1 (Naglie et al., 2006; Whynes & Group, 2008; Hoe et al., 2005; Husebo et al., 2014; Guy, 1976; Rabinowitz et al., 2005; Cummings, 2020; Alexopoulos et al., 1988; Yesavage et al., 1982; Lawton, 1990; Lawton & Brody, 1969; Lyketsos et al., 1999).

Process development of LIVE@Home.Path under the COVID-19 restrictions

By the end of February 2020, the first group of dyads had completed the six-month LIVE-intervention, and the second group was scheduled to receive the intervention from March to August 2020. During the COVID-19 lockdown, the intervention protocol was temporarily halted and replaced with PAN.DEM, a nested cohort study within the LIVE@Home.Path. Data were collected by semi structured telephone interviews with caregivers assessing how the pandemic scenario affected the dyads in terms of resource and service utilisation. The interdisciplinary research group revised the PAN.DEM assessment after 6–8 interviews. The final version is found in the supplementary enclosure, while outcome measures are shown in Table 1. Furthermore, research procedures for the LIVE@Home.Path trial were revised to ensure minimal risk of viral transmission, adapted to periods of both high risk (remote contact via telephone only) and low risk of transmission (possibility of home visits according to the participants' wishes) (Table 2).

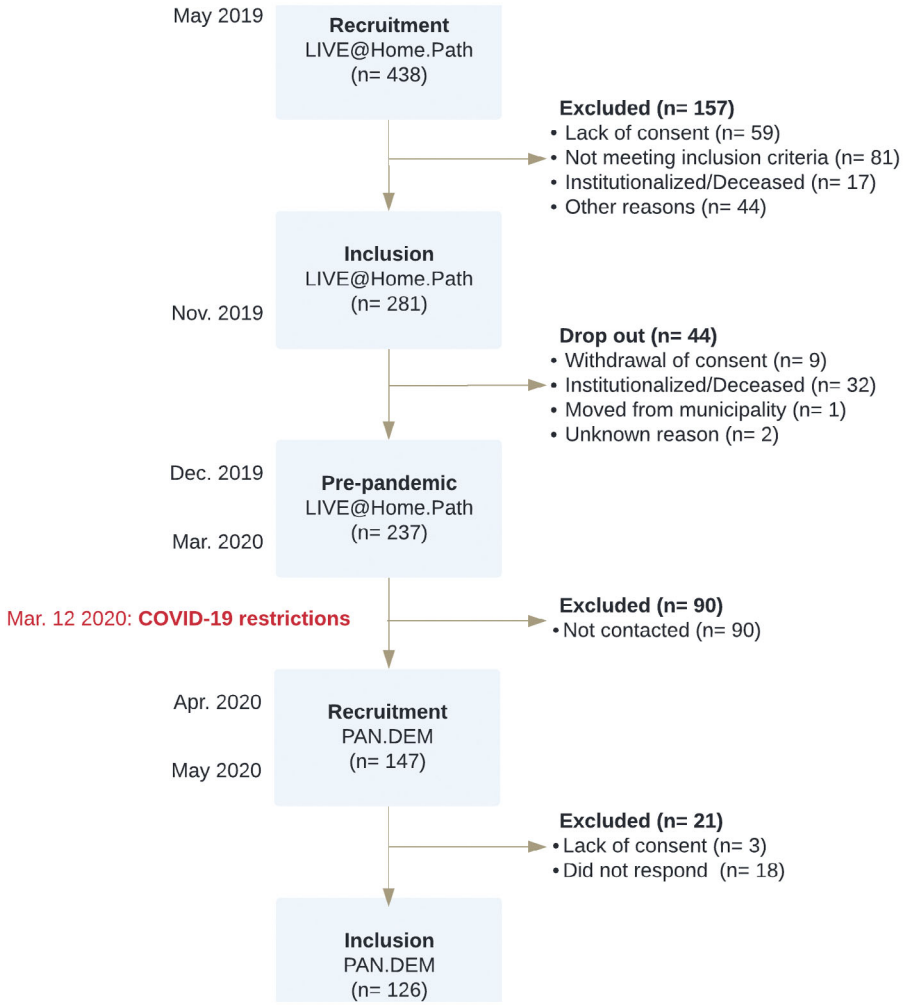

Figure 1. Flow chart of participants in the LIVE@Home.Path trial and the PAN.DEM study.

Table 1. Outcome measures in the LIVE@Home.Path trial and the PAN.DEM study.

	LIVE@Home.Path	*PAN.DEM*
PAN.DEM assessment		x
Resource Utilisation in Dementia (RUD) (Wimo et al., 2013; Wimo et al., 2010)	x	x
Relative Stress Scale (RSS) (Greene et al., 1982)	x	
European Quality of Life-5 Dimensions 5 Levels (EQ-5D-5L) (Naglie et al., 2006)	x	
EQ-5D-VAS Scale (Whynes & Group, 2008)	x	
Quality of Life In Alzheimers Disease Scale (QOL-AD) (Hoe et al., 2005)	x	
Mobilization-Observation-Behaviour-Intensity Dementia Pain Scale (MOBID-2 Pain Scale) (Husebo et al., 2014)	x	
Clinical Global Impression of Change (CGIC) (Guy, 1976)	x	x
Cohen-Mansfield Agitation Inventory (CMAI) (Rabinowitz et al., 2005)	x	
Neuropsychiatric Inventory, 12 Item version (NPI-12) (Cummings, 2020)	x	x
Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1988)	x	x
Geriatric Depression Scale (GDS) (Yesavage et al., 1982)	x	
Activities of Daily Living, Instrumental (I-ADL) (Lawton, 1990; Lawton & Brody, 1969)	x	
Activities of Daily Living, Personal (PSMS) (Lawton, 1990; Lawton & Brody, 1969)	x	
General Medical Health Rating Scale (GMRH) (Lyketsos et al., 1999)	x	

Statistics

We used descriptive statistics to explore the distribution of pre-pandemic characteristics of the person with dementia and their caregiver, in addition to the frequency of access to any assistive technology. Logistic regression was applied to explore factors associated with increased interest in assistive technology under the COVID-19 restrictions, and estimates were presented as odds rations (OR) with 95%

Table 2. Revised procedures for data collection and implementation of the LIVE@Home.Path trial to comply with the COVID-19 restrictions.

- Immediately before study home visits, make a phone call to evaluate participants' physical status, including any respiratory symptoms or fever, contacts with COVID-19 positive individuals, or travel abroad during the last 14 days.
- In the event of symptoms of infections in the respiratory organs, the researchers or other study personnel must not carry out travel activities or home visits.
- Good hand hygiene is a key preventive measure at all risk points, such as travel and home visits. Study personnel must make sure to bring their own hand sanitiser.
- When travelling is required, avoid rush hour, and/or use a taxi or car rental service rather than public transport.

confidence intervals. We applied Akaikes information criterion for model selection; level of significance was set to p Value < 0.05. Stata/IC, release 16 (StataCorp LP, College Station, TX) was used to analyse the data.

Ethics

All participants in the LIVE@Home.Path provided verbal and written informed consent for participation. At inclusion in PAN.DEM, verbal consent was obtained from the caregivers after verbal and written information was provided. If the person with dementia was evaluated as incapable of providing informed consent, the next of kin or legal advocate provided presumed consent based on their determination of whether the person would have agreed to participate when they were capable of providing informed consent. The LIVE@Home.Path trial and the PAN.DEM study were both approved by the Regional Committee for Medical and Health Research Ethics, North Norway prior to data collection, reference 2019/385 and sub reference 10861.

Results

A total of 281 dyads were included to the LIVE@Home.Path trial, 237 dyads were active in the trial at the beginning of March 2020, of which 126 were consecutively included to the PAN.DEM by a phone call invitation (Figure 1). Table 3 presents descriptive statistics on the participating dyads in PAN.DEM. Mean age for the person with dementia was 82 years; 61% were women, and 40% lived alone.

A total of 71% of the participants had access to some assistive technology before the COVID-19 restrictions (Table 4). The majority used traditional appliances such as safety alarms and stove guards, while few had any kind of sensor technology; including GPS, fall detector, and medication adherence

Table 3. Pre-pandemic characteristics for the PAN.DEM dyads ($N = 126$).

	n (%)	mean (SD)
People with dementia		
Age		82 (6.95)
Sex, Female	77 (61)	
Residency		
Living alone	51 (40)	
Co-residing with the reporting caregiver	55 (44)	
Co-residing with someone else	16 (13)	
Dementia aetiology per ICD-10		
Alzheimer's Disease	49 (39)	
Vascular Dementia	6 (5)	
Dementia in other diseases classified elsewhere	11 (9)	
Unspecified Dementia	58 (46)	
GMHR, range 1-4		2.72 (0.70)
MMSE, range 0-30		20.85 (3.91)
FAST, range 1-7		4.08 (0.80)
CSDD total score, range 0-38		6.50 (5.41)
Caregiver		
Age		66 (12.35)
Sex, Female	77 (6)	
Kinship		
Spouse	58 (46)	
Children	66 (52)	
Other	2 (2)	

n: number of participants. SD: standard deviation.
ICD-10: the International Statistical Classification of Diseases and Related Health Problems.
GMHR (Lyketsos et al., 1999): General Medical Health Rating Scale; 1– poor, 2 – moderate; 3 – good, 4 – excellent health.
MMSE (Folstein et al., 1975): Mini-Mental Status Examination; high score indicates high level of cognitive functioning.
FAST (Reisberg, 1988): Functional Assessment Scaling; high score indicates high functional impairment.
CSDD (Alexopoulos et al., 1988): Cornell Scale of Depression in Dementia; higher score indicates depression of increasing severity.

support. According to IADL, 15% were fully independent in using the telephone, including looking up telephone numbers and making calls, while 54% were able to call a few, well-known numbers. Use of social media was rare among persons with dementia; two used Facebook including Messenger; one person communicated with Skype.

During the COVID-19 restrictions, 14% of the caregivers reported more digital contact with the person with dementia compared with pre-pandemic conditions, while 17% reported increased interest in assistive technology (Table 5). Caregivers reported lack of insight to the COVID-19 pandemic in majority of cases; 50% had partial insight and 15% no insight. Caregivers for people with higher scores on the MMSE (OR 1.26, 95% CI 1.03–1.54, $p = 0.032$) and less familiarity with using the telephone assessed by IADL (OR 2.60, 95% CI 1.08–6.23, $p = 0.032$) were more likely to report increased interest in technology under the pandemic. The insight of the person with dementia into the COVID-19 situation, the change in level of contact with caregiver, depressive symptoms during the pandemic, the level of function assessed by FAST, dementia aetiology, health evaluated by

Table 4. Pre-pandemic access to assistive technology and social media for the PAN.DEM dyads ($N = 126$).

	n (%)
Access to assistive technology	88 (71)
Number of assistive technology devices implemented, mean (SD)	1.48 (1.61)
Safety, nonwearables (not exclusive items)	57 (45)
Door sensor	3 (2)
Door camera	1 (1)
Electric door lock	16 (13)
Water sensor	1 (1)
Light sensor	0 (0)
Bed sensor	2 (2)
Timer on electric devices	13 (13)
Stove guard	46 (37)
Safety, wearables (not exclusive items)	48 (38)
Safety alarm without GPS	43 (35)
Safety alarm with GPS	2 (2)
GPS	3 (2)
Fall sensor	0 (0)
Communication devices, e.g. "KOMP"	0 (0)
Orienting devices (not exclusive items)	45 (36)
Calendar to plan or keep track of the time of day, e.g. "MEMOday"	43 (34)
Automatic drug dispensers, e.g. "Pilly" and multi-dose drug dispensing robots	8 (6)
Ability to operate telephone per IADL	
Operates telephone on own initiative, looks up and dials numbers	18 (15)
Dials a few well-known numbers	66 (54)
Answers telephones, but does not dial	24 (20)
Does not use telephone at all	14 (11)
Use of social media (not exclusive items)	
Facebook/Messenger	2 (2)
Instagram	0 (0)
Skype	1 (1)

n: number of participants. SD: standard deviation.
IADL (Lawton, 1990, Lawton, 1969): Activities of daily living, instrumental.

Table 5. Pandemic characteristics for the PAN.DEM dyads ($N = 126$).

	n (%)
Increased interest in assistive technology due to the restrictions	21 (17)
Change in contact between within the dyad due to COVID-19 restrictions (not exclusive items)	
No contact/reduced	34 (27)
More digital contact	18 (14)
Unaltered	61 (48)
Increased	27 (21)
People with dementia's insight into the COVID-19 situation	
Sufficient	44 (35)
Partial	63 (50)
To no degree	19 (15)
CGIC: Caregiver total situation, range −5-5, mean (SD)	−1.85 (1.97)

n: number of participants.
CGIC (Guy, 1976): Clinical Global Impression of Change Scale; negative score – worsening, positive scores – improvement.

GMHR, access to assistive technology, and demographic variables were not associated with increased interest (data not shown). Use of social media was not included in the regression analysis due to the low frequency of use.

Discussion

The PAN.DEM study was developed as a response to the COVID-19 restrictions in Norway, aiming to explore how the lockdown affected home-dwelling people with dementia and their caregivers. Prerequisites for continuing research during the restrictions included changes in procedures for data collection, changes in the types of data that could be obtained, and considerable flexibility of both the participants and the research team to meet each other in the new context. While pausing the LIVE@Home.Path, we were thus able to explore consequences of the ongoing societal changes, a major strength of the study, although limited to a sample of less than half of the dyads still in the trial.

Pre-pandemic access to assistive technology was identified among 71% of people with dementia. However, the vast majority had access to traditional technology such as safety alarms and stove guards,

while only a few could operate more novel sensor technologies. Despite the vast potential for these applications, we found that caregivers' interest in new technology increased among a minority during the pandemic restrictions, suggesting that caregivers might be more likely to consider technology as on obstacle rather than a tool for independence in adapting to the pandemic situation. Our results are of key importance for all levels and actors in the healthcare system and the society in general; although technical solutions are readily available, they are infrequently implemented and accessed. This finding highlights a great potential for initiating technology in dementia care and research for improved resource utilisation.

To investigate the acceptability of technology, Contreras-Somoza et al. (2020) introduce findings from the EhcoButler trial, intended to improve health, independence and quality of life in people with dementia (Contreras-Somoza et al., 2020). Although participants found the platform interesting and ergonomic, researchers concluded that effective implementation depends on bridging digital gaps and requires appropriate investment in product development aimed at people with dementia. In Norway, the Technology Program in Community Health Care (2013–2016) initiated municipal small-scale studies, to kick-start implementation of assistive technology (The Norwegian Directorate of Health 2012). These pilots demonstrate improved economic cost-effectiveness and enhanced quality of services for elderly at home, for relatives and staff (The Norwegian Directorate of Health, 2015). Meanwhile, Holthe et al. (2020) interviewed municipal healthcare professionals on their experiences and current practice, stressing the potential of, but also the barriers to technology implemented for people with dementia (Holthe et al., 2020). This is thought-provoking because other people with neurological diseases, such as Parkinson, have already been utilising wearable and sensory technology as well as communication devices in recent years (Dorsey et al., 2020). Although technology is not a solution to all challenges, advantages may be summarised by the 5 C's: accessible care, increased convenience, enhanced comfort, greater confidentiality for patients and families, and now reduced risk of contagion (Dorsey et al., 2020).

The development of PAN.DEM in the LIVE@Home.Path illustrates the importance of flexible trial management for high risk populations during the period of COVID-19, highlighting our obligation to preserve the integrity of clinical research activities yet minimising risks to vulnerable participants (Brown et al., 2020; Nicol et al., 2020; McDermott & Newman, 2020). Our adaptation and protocol adjustment correspond with the principles of responsible research innovation (Schuijff & Dijkstra, 2020), producing unique data providing information on how the extraordinary pandemic restrictions affected the everyday life of home-dwelling persons with dementia and their informal caregivers in Norway.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

Data can be made available to other researchers on request.

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