'What matters most?'

Supporting advance care planning for people with dementia and their families

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*"It is good to have an end to journey toward,
but it is the journey that matters in the end."*

— Ursula K. Le Guin

Contents

List of Abbreviations

ACP	Advance care planning
AI	Artificial intelligence
DNR	Do Not Resuscitate
EAPC	European Association for Palliative Care
EWGPWD	European Working Group of People with Dementia
ICT	Information and communication technologies
ISO	International Organisation for Standardisation
MCI	Mild cognitive impairment
MMAT	Mixed Methods Appraisal Tool
MRC	Medical Research Council
PPI	Patient and public involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
SD	Standard deviation
SUS	System Usability Scale
W3C	World Wide Web Consortium

List of Chapters

The chapters in this dissertation are based on the following publications.

Chapter 2

Monnet, F., Pivodic, L., Dupont, C., Dröes, R. M., & Van den Block, L. (2023). Information on advance care planning on websites of dementia associations in Europe: A content analysis. *Aging & Mental Health*, *27*(9), 1821–1831. https://doi.org/10.1080/13607863.2022.2146051

Chapter 3

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Chapter 4

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Chapter 5

Monnet, F., Dupont, C., Smets, T., Pivodic, L., de Vleminck, A., van Audenhove, C., & Van den Block, L. A user-centred website to support advance care planning for people with dementia and their family caregivers: development and usability study. [submitted]

Chapter 6

Monnet, F., Pivodic, L., Dupont, C., Smets, T., de Vleminck, A., van Audenhove, C., & Van den Block, L. Evaluation of interactive web-based tools to stimulate reflection and communication about advance care planning with people with dementia and their family caregivers. [submitted]

Chapter 7

Monnet, F., Craven, M., Dupont, C., Van den Block, L., & Pivodic, L. Usability of web-based tools designed for communication and decision-making in dementia: systematic review and design brief. [submitted]

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– PART I –

GENERAL INTRODUCTION

CHAPTER 1

Background, research aims, and methods

Background

1. Advance care planning and dementia: Context, barriers, and needs

The process of advance care planning

It is well recognised that people facing life-limiting illnesses stand to benefit from the provision of holistic and person-centred healthcare, thereby improving their overall patient experience as they approach the end of life[1–3]. Advance care planning (ACP) has been advocated as common practice in planning the treatment and care of patients with a life-limiting illness and offers means of eliciting patient and family choice to guide the delivery of such care[4–6]. As part of a European consensus, ACP is defined as:

> *"a process that enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. Advance care planning addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions"*[7].

ACP is centred around several core processes encompassing identifying values, reflecting on care preferences, discussing them with family and professionals, encouraging the selection of a proxy decision-maker, and documenting preferences, with the aim of ensuring that an individual's values and choices guide their healthcare decisions, even when they cannot make decisions themselves[7–11].

Figure 1 presents these core processes based on the extended definition of advance care planning presented above[7]. Firstly, ACP involves individuals reflecting on and identifying their personal values, life goals, and important quality of life domains[12,13]. Ongoing communication and conversations with family, friends, and health professionals are central, as they foster understanding and alignment among all stakeholders involved in the individual's care[7,14]. ACP may also lead to anticipatory decision-making, whereby individuals actively define their healthcare preferences and prepare relevant legal documents to guide potential future healthcare choices (should they opt for such preparations)[7]. This can be accomplished by creating advance directives, which are written documents specifying an individual's preferences for several aspects of their healthcare. These preferences may encompass choices such as opting to withhold or withdraw life-sustaining treatments like cardiopulmonary resuscitation and mechanical ventilation (referred to as do-not-resuscitate or DNR orders) or expressing preferences regarding the withholding or withdrawal of artificial nutrition and hydration for

instance[15]. ACP and advance directives also provide the option to appoint a proxy decision-maker in case the individual becomes incapacitated[16]. This individual is granted legal authority to make medical decisions on the person's behalf if they can no longer do so independently. Importantly, advance directives are a possible outcome of the ACP process. Still, much previous research has stressed the importance of not reducing ACP to filling in advance directives, as the communication process itself is crucial[17–19].

What does ACP entail
- Identifying values
- Reflecting on serious illness scenarios
- Defining goals and preferences of care
- Discussions with family and health professionals
- Encouraging identifying a proxy decision-maker
- Encouraging documenting preferences

When is ACP done
- At any stage in one's life, but ACP can be tailored as an individual's health deteriorates or as they age ACP conversations and documents should be reviewed regularly

Advance care planning process

Why is ACP done
- So that preferences can be taken into account, should one become unable to make one's own decisions

Who is ACP for
- Individuals with decision-making capacity
- Family members
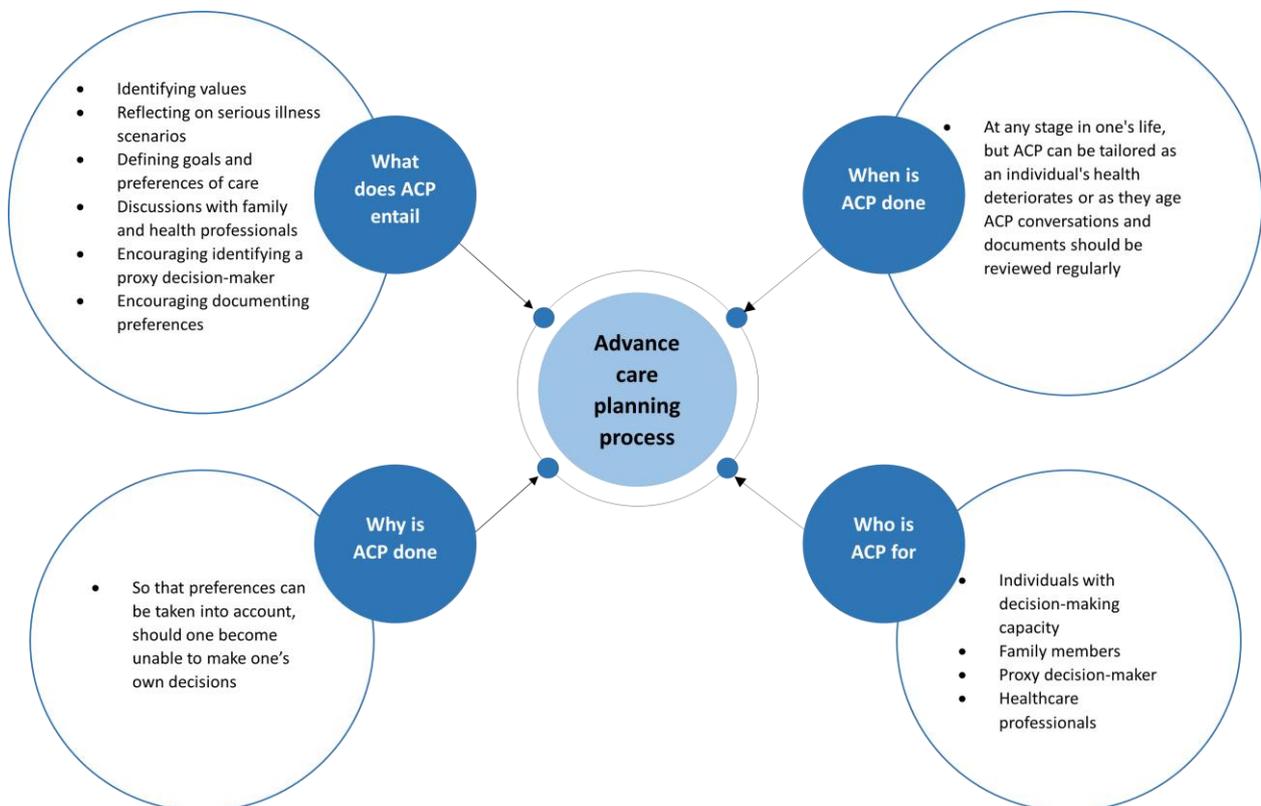- Proxy decision-maker
- Healthcare professionals

Figure 1: Overview of core processes of ACP, derived from the ACP definition by Rietjens et al (2017)

Factors influencing engagement in ACP are multifaceted and intricate, reflecting the diverse needs of all stakeholders involved[1,20]. Patient readiness for ACP conversations varies, and several complex factors hinder its adoption, including lack of awareness, limited knowledge about end-of-life care, and beliefs that ACP is futile[21]. A recent scoping review showed that many members of the public have negative or unclear perceptions of what ACP is and what its purpose is[22]. Another systematic review revealed that ambivalence (i.e. concurrently encountering positive outcomes from ACP along with negative emotions), readiness, and openness of patients with life-limiting illnesses play significant roles in their willingness and ability to participate in ACP[23]. Limited access to suitable information about ACP was found to be an important factor hindering the uptake of ACP in the public[22]. There are also several perceived barriers for health professionals such as time constraints or uncertainty about when

to initiate ACP conversations among others[21]. To enhance ACP uptake and experience, a personalised approach tailored to individual patient needs, concerns, and coping strategies is recommended[23].

Despite these challenges, it has been highlighted that the benefits of engaging in ACP can be substantial. Recent findings from a comprehensive scoping review revealed increased satisfaction among patients and their proxy decision-makers regarding communication and medical care, as well as reduced distress experienced by surrogates and health professionals after engaging in ACP[24]. These outcomes highlight the potential of ACP to impact the quality of patient-centred care and mitigate the emotional burden often associated with complex health-related choices[25]. In essence, ACP aims to provide people with the opportunity to assume a more proactive role in shaping their health and care journeys, facilitating care where their values and preferences remain central.

The evolution of advance care planning: moving towards a public health approach

The concept of ACP has considerably evolved and shifted over the last decades. It initially emerged in the 1960s as a movement to establish advance directives, which served as legal documents for patients to formally decline specific medical treatments[26]. However, since the 1990s, there has been a growing recognition that completing documents alone may not suffice as it needs to give more attention to the complex process of planning care and making decisions[27,28]. The conceptualisation of ACP has thus evolved into a dynamic communication process that involves not only documenting care preferences but also facilitating ongoing communication and shared decision-making[4]. However, the practical application of this conceptualisation of ACP seems challenging, as written documentation and the completion of advance directives often remain the focus of many ACP interventions and evaluations[29,30].

In line with the evolution in the conceptualisation of ACP, the public health approach to ACP emphasises the importance of ongoing communication among patients, families, and health professionals regarding various aspects of future care and treatment planning[31]. Such an approach fits within the 'new public health' approach to palliative care, which focuses on health promotion and empowerment with the aim of enhancing our individual capacities for life and well-being[32]. Focusing on health promotion, interventions adopting such an approach generally aim to enable people to increase control over their health, improve well-being, identify and achieve aspirations, satisfy needs, and adapt to or cope with their environment[33]. Health promotion recognises health as a resource for daily living, emphasising social, personal, and physical capacities. Consequently, it extends beyond promoting healthy lifestyles to encompass overall well-being, indicating that the responsibility for health promotion transcends the health sector alone[34].

Looking at ACP from a public health perspective, several authors have highlighted the need to normalise and reconfigure how health and care decisions are made by reframing ACP as a health-promoting activity through public education and engagement[35,36]. Underlying this approach is the need to move away from the predominant emphasis on end-of-life preferences and medical treatments and towards a more social perspective centred on 'what matters most' to people. This recognises that the support for people with life-limiting conditions extends beyond clinical environments, encompassing broader social dynamics that impact families and communities as a whole[37]. Advocates of the public health approach argue that ACP should be initiated by exploring broader concerns of patients and their family caregivers, focusing on the priorities and values of a person's lived experience, and aligning medical concerns to these broader concerns[36,38,39]. They advocate for expanding ACP conversations within the family context (i.e. outside of the professional setting), which could facilitate a more natural and open dialogue, ultimately enhancing the relevance and uptake of ACP[35,36].

In practice, however, many ACP conversations seem to be restricted to discussions about the end of life between patients, family members, and health professionals in a professional setting or medical environment[35,36]. However, conversations regarding 'what matters most' may not all necessarily require to be conducted by, or with, a health professional. Such 'what matters most' conversations can often be undertaken in the family context and establish a foundation for subsequent conversations with health professionals dealing with considerations such as treatment preferences and preferred locations for death[36]. Importantly, it remains essential for professionals to be aware and be part of these conversations to align care goals with the preferences of patients and their families[36]. Health professionals play a crucial role in discussing preferences with patients and families, reviewing hypothetical future scenarios and uncertainties, identifying potential problems, and setting realistic expectations[40]. Thus, we argue that approaches to ACP in both contexts, i.e. the family context and the professional context, can be complementary, and one does not exclude the other.

Dementia and advance care planning in dementia

Dementia is a progressive neurological disorder characterised by a decline in cognitive function, affecting memory, thinking, behaviour, and the ability to perform everyday tasks[41,42]. It is not a specific disease but rather an umbrella term encompassing various conditions, with Alzheimer's disease being the most common form of dementia[42]. The prevalence of dementia varies across countries and regions, influenced by factors like age, genetic predisposition, and lifestyle[43]. Globally, the prevalence of dementia has been steadily rising[44]. Increased age remains the most recognised risk factor

associated with dementia[45]. But dementia can affect more than just the older population, as evidenced by the 3.9 million people under the age of 65 living with young-onset dementia[46]. In general, in 2021, an estimated 55 million people were living with dementia worldwide, and this number is expected to double by 2030 and triple by 2050[47]. On a global scale, dementia ranks as the seventh leading cause of death and has even emerged as one of the primary causes of death in countries such as Belgium England and Wales[48,49].

Dementia is a highly heterogenous condition, and people with dementia may experience a wide range of symptoms and disease progression rates. After diagnosis, dementia is typically categorised into stages such as mild dementia, moderate dementia, and advanced or severe dementia. However, the specific number and features of these stages vary depending on the assessment tools utilised[50]. Some of the most well-known assessment tools that measure dementia severity are the Global Deterioration Scale (GDS), the Clinical Dementia Rating (CDR), or the Mini Mental Status Examination (MMSE). The GDS, for instance, categorises dementia into seven stages based on the extent of cognitive decline. Stages one through three are the predementia and mild dementia stages (i.e. no cognitive decline to mild cognitive decline characterised by symptoms such as difficulties concentrating, a decrease in work performance or getting lost more frequently), stages four and five are the moderate dementia stages (i.e. moderate cognitive decline with symptoms ranging from difficulties completing tasks and managing finances to not knowing the time or date), and stages six and seven are the severe dementia stages (i.e. severe cognitive decline where people forget recent events, experience incontinence, and need help with most daily activities like eating and personal hygiene)[51].

Currently, there is no cure for dementia, and management focuses on improving the quality of life for people living with the condition. Strategies include early diagnosis to provide appropriate support and interventions, addressing modifiable risk factors like cardiovascular health, and offering pharmacological treatments to alleviate symptoms and slow the disease's progression[52]. Non-pharmacological approaches also play a vital role in dementia care. These include cognitive stimulation therapy, physical exercise, and occupational therapy to enhance cognitive function and maintain independence. Additionally, supportive care for people with dementia often involves caregiver training and education to better cope with the challenges presented by the condition[52,53]. As dementia progresses, people may require specialised care, including assistance with activities of daily living, safety measures to prevent accidents, and interventions to manage behavioural symptoms like agitation or aggression[52]. In the absence of treatments or cure, a palliative care approach is needed and recommended[54]. According to a Delphi study, ACP is one of the central domains of optimal palliative care for people with dementia and one of the highest research priorities related to palliative care in dementia[54].

Due to the natural and gradual deterioration of cognitive and functional capabilities often linked to dementia, ACP can be particularly relevant, although challenging, for people living with dementia. ACP serves the dual purpose of preparing for the unpredictable trajectory of the disease and providing essential support to family caregivers as their role in the decision-making process becomes more important[55]. Indeed, as their condition progresses, people with dementia increasingly rely on others and become more vulnerable throughout the disease trajectory[4,54]. More particularly, people with dementia can gradually lose their ability to make decisions at the later stages, especially major decisions concerning care or medical treatments[56]. Family caregivers often find themselves tasked with making decisions on behalf of their loved ones living with dementia[57]. Therefore, it is recommended that ACP is initiated as early as possible in the context of dementia[58,59]. But even at an early stage of the condition, people with dementia are sometimes excluded from discussions and decision making[60]. It is important to note that having a diagnosis of dementia does not imply an overall lack of decision-making capacity[61]. Decision-making capacity can fluctuate. Thus, diminished capacity for a particular decision should not be assumed, nor should it compromise the person's ability to make other decisions[56].

Research indicates that ACP remains an infrequent practice among people with dementia[62]. Currently, fewer than 40% of people living with dementia have the opportunity to engage in ACP conversations and document their wishes internationally[62–65]. Furthermore, in a systematic review investigating the adoption of ACP across diverse life-limiting illnesses, people with dementia were shown to be notably less likely to have participated in ACP compared to people with other conditions, such as cancer, for example[21].

Barriers to advance care planning in dementia

Despite the recognised importance of ACP, there are specific challenges related to engaging in ACP in the context of dementia[58,59,66]. People with dementia can frequently encounter challenges when discussing topics related to death and dying because they are preparing for an uncertain future[5]. Many people with dementia adopt an attitude of "living in the now" and prefer not to think about the future. Additionally, people with dementia may lack information about the trajectory of the disease and might not be fully aware of what ACP involves[13,58,67]. Cultural factors, including the stigma associated with cognitive decline, can also serve as a barrier to engaging in ACP conversations[67]. Additionally, complex family dynamics can further complicate ACP participation for individuals with dementia[68]. Families of people with dementia can experience similar challenges to people with dementia themselves, such as a limited understanding of dementia and what it entails or limited awareness of ACP. Furthermore, a

lack of knowledge concerning specific life-sustaining treatments or the role of proxy decision-maker can also be experienced as barriers[67,69–71]. Not being close to the person with dementia can also have an impact on families' engagement in ACP[58].

Cognitive problems such as memory loss and communication difficulties, coupled with the unpredictable nature of dementia, can also make ACP challenging[31]. Various studies have shown the uncertainty felt by people with dementia regarding their future and their ability to cope with the more advanced stages of decline[72,73]. Furthermore, navigating the ACP process may become more complicated due to the likelihood of a person's preferences changing as the condition progresses[74], that is the possibility that current wishes of a person living with dementia diverge from wishes previously outlined within ACP conversations or documents. Family caregivers acting as proxy decision-makers may encounter ethical dilemmas when balancing past wishes with a person's current preferences[75]. In these circumstances, family caregivers must often rely on subtle cues from the person's current behaviours and emotions, as well as past conversations, and their knowledge of the individual's values to inform decision-making. Therefore, fostering a collaborative and empathetic approach among all involved parties is essential to ensure that decisions align with the evolving needs and wishes of the person with dementia[13,76].

Facilitators to advance care planning in dementia

People with dementia have a need for a clear understanding of the dementia disease trajectory and a realistic grasp on what ACP entails and what it can accomplish or not[61]. Additionally, as the condition progresses and cognitive abilities decline, the involvement of family or friends becomes essential in facilitating ACP in this population[13]. As dementia advances, many people with dementia may eventually need a proxy decision-maker or legal representative[77]. Thus, having sufficient and relevant information is vital to ensure that people with dementia and their families can discuss and make informed decisions about their future, including decisions about their health and available treatment options[11,78–80].

Moreover, given the gradual evolution of dementia and deterioration of cognitive abilities, early initiation of ACP for people with dementia and their families is particularly crucial[58,59,61,63]. The process of accepting a dementia diagnosis can take time, and it is essential to consider this aspect when engaging in early conversations about future care decisions for people in the initial stages of the disease[81]. Therefore, to optimise ACP for people with dementia and their family caregivers, it is necessary to tailor the approach through personalised conversations according to the level of readiness of the parties involved, recognising the continuous and recurrent nature of ACP

conversations, and adopting communication strategies tailored to the individual's cognitive level and wishes. This approach aims to achieve a balance between discerning the right moment to initiate ACP based on the person with dementia's comprehension of the implications of a dementia diagnosis and their diminishing decision-making capacity[61].

Communication plays a vital role in ACP. An often overlooked yet crucial facilitator in ACP lies in the conversations occurring within families and the home environment[82]. The knowledge derived from conversations at home can provide valuable insights into people's wishes and preferences, forming a foundation to guide the decision-making process[82]. People with dementia and family caregivers have been shown to prefer informal conversations about ACP over formal written ACP documentation due to their flexibility in the face of uncertainties about the future[4]. However, both people with dementia and family caregivers may encounter challenges when engaging in ACP conversations[55], necessitating support to communicate about ACP effectively.

2. Supporting advance care planning for people with dementia: Existing research and potential of digital health interventions

Existing interventions to support advance care planning for people with dementia

ACP interventions, such as trainings for professionals or documentation booklets, have generally aimed to facilitate engagement in ACP conversations by helping patients and family caregivers reflect about and/or make decisions for future care and treatment in coordination with healthcare professionals[63]. However, interventions have primarily been centred on other patient groups than people with dementia or have focused on healthcare professionals. For instance, Houben and colleagues' review on the efficacy of ACP identified just one study out of 55 that focused on people with dementia[83]. Similarly, Fahner and colleagues identified a substantial body of interventions employing conversation guides to guide ACP, however, these were mainly aimed at aiding healthcare professionals, and only a small fraction of them addressed dementia[84]. Additionally, Bryant and colleagues found four studies that aimed to increase ACP for people with dementia. However, most of these studies recruited caregivers of people with advanced dementia, limiting the direct involvement of the person with dementia in the ACP process. Moreover, all these studies involved in-person consultations with health professionals[85]. Indeed, a considerable portion of the current body of literature emphasises the facilitation of ACP within the medical context[85,86], with comparatively very little guidance available for supporting ACP within the family context.

The available research on the effects of ACP interventions for people with dementia is widespread. In an umbrella review, Wendrich-van Dael and colleagues found several reviews and primary studies that reported either positive associations or no significant changes in outcomes following ACP interventions in dementia[61]. However, many different outcomes were reported, with limited consensus on the core outcomes of ACP interventions[61]. A significant challenge in this field is the lack of consensus on a definition of ACP for people living with dementia, as existing definitions do not adequately consider the needs of this population[54]. Very recently, van der Steen and colleagues developed, on behalf of the European Association for Palliative Care, a consensus definition of ACP in dementia, which states:

> *"ACP is a communication process about future care and treatment preferences, values and goals with the person with dementia, family, and the health care team, preferably with ongoing conversations and documentation. This process is continued when the person with dementia becomes unable to make their own decisions."*[87]

It is important to note that the work of van der Steen and colleagues was ongoing at the time this dissertation was written, and part of this dissertation was used to formulate and shape the definition and recommendations presented by the authors of the consensus definition of ACP in dementia.

Another challenge is the lack of theoretical underpinning in ACP interventions for people with dementia[61]. Several systematic reviews have investigated the underlying theories in ACP interventions for the general public. Fahner and colleagues reported that only 6 of the 34 interventions guiding ACP conversations were theory-based[84]. These interventions were based on the representational approach of patient education, which draws on Leventhal's description of illness along five identities (illness identity, cause, timeline, consequences, and cure/control) and the conceptual change model. These two theories were melded to create an approach to psycho-educational interventions that are based on obtaining a clear understanding of the patient's perspective on their illness and then helping to change those representations in ways that facilitate self-management[88]. In their systematic review of web-based ACP programs, Van der Smissen and colleagues found only four theory-based programs out of 24[89]. These were either based on the Multi-Attribute Utility Theory (i.e. weighing competing objectives, when choosing between alternatives, the best choice maximises positive outcomes and minimises negative ones)[90] or on behaviour change theories (e.g. Social Cognitive Theory, the Interpersonal Communication Competence Model, etc.). These behaviour change theories focus on various factors influencing behaviour determinants, including individual factors, factors in groups or relationships, and factors that exist in organisations and communities)[91–93]. However, when looking specifically at interventions for people with dementia, most of the theoretical assumptions were found to be either implicit or not validated for people with dementia[61].

The potential of digital health in dementia care and advance care planning

Digital health care refers to tools and services that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health-related issues and to monitor and manage lifestyle habits that impact health[94]. Web-based interventions are one component of digital health, using internet-based platforms to provide a range of healthcare services and support[95]. One of the key advantages of digital health is the ability for individuals to engage at their own pace, granting them greater autonomy and flexibility in managing their health. These interventions can be tailored to suit each person's unique needs and preferences (e.g. preferred device, level of digital literacy, use of websites vs apps, personalised experience), ensuring that the information and support provided are highly relevant. Moreover, digital health interventions can be accessed at the individual's preferred time and place, eliminating geographical barriers. They can also often be used without constant supervision from health professionals. Additionally, these interventions can reach large audiences simultaneously, making them a cost-effective means of disseminating health information and promoting health on a broader scale[96].

Digital health and particularly web-based tools for people with dementia, have considerably increased over the years and offer promising solutions to several unmet needs[97,98]. These web-based tools encompass a wide range of software, spanning from websites to social media communication, and are all accessible through computer, tablet, or mobile interfaces[99]. Many web-based tools have targeted different needs of people with dementia by, among others, supporting self-care in daily life, facilitating treatment delivery, or ensuring their ability to communicate[100]. For instance, in a recent systematic review, Hoel and colleagues found that technologically driven interventions, including web-based tools, can effectively prompt communication and facilitate social interactions[101]. Additionally, people with dementia have exhibited keen interest and a favourable disposition toward the utilisation of technological innovations to foster their independence[102,103]. Although older people in general and people with dementia particularly might experience more problems with using online tools, research has shown that use of the internet and web-based resources is increasing among older people[104] and the range of experiences with digital technologies in dementia is more extensive than commonly recognised[105]. People with dementia also display eagerness to acquire new skills and acknowledge the significance of embracing digital advancements[106–108]. Considering the potential value of web-based tools and resources, in conjunction with the existing and increasing digital skills and willingness to learn among older people, there is a promising opportunity for dedicated web-based tools to support the ACP process for people with dementia and their family caregivers.

Web-based ACP tools have been proven effective in other medical contexts and may offer a more tailored and accessible option to support ACP for people with dementia and their family caregivers[89,109]. In a recent systematic review, web-based ACP tools were positively evaluated, with end-users (such as patients, healthy individuals, relatives, or health professionals) generally finding that web-based ACP tools were acceptable, easy to navigate, and understandable. These web-based ACP tools addressed topics such as offering information about ACP, exploring goals and values for future treatment and care, considering treatment and care options, designating a health care representative, facilitating the creation of documents, sharing documents with health professionals or relatives, and communicating about preferences with health professionals or relatives[89]. However, out of the 11 existing web-based ACP tools published in international peer-reviewed literature identified by this systematic review, none were designed for people with dementia nor tested with people with dementia[89].

The importance of involving people with dementia in the development and evaluation of web-based advance care planning tools

The loss of cognitive functions associated with dementia can impact individuals' experiences and use of web-based tools[110,111]. For instance, people with dementia can struggle with tasks such as remembering where they are during a task or process within a system or experience increased problems with perception of colour, shape and movement[111]. Because of the dementia-related changes experienced by people living with dementia, many have recognised the importance of designing dementia-inclusive interfaces[111–113]. These results highlight an urgent need for high-quality and user-friendly web-based ACP tools appropriate for use by people with dementia with varying cognitive levels.

In the rapidly evolving field of digital health, user-centred design and patient and public involvement (PPI) have become crucial in ensuring that interventions and technologies meet the needs of their intended users. This holds particularly true for people living with dementia, a group that has unique needs in navigating digital health interventions[102]. User-centred design places the spotlight firmly on the needs, preferences, and experiences of end-users throughout the development process. It entails rigorous research and feedback gathering to gain insights into the target audience. Through iterative design and testing, user-centred design strives to create tools that are intuitive, efficient, and enjoyable for users[114–117]. For people with dementia, this approach is indispensable. It guarantees that digital health interventions align with their real-world needs, enabling a positive user experience and, ultimately, enhancing usability and user satisfaction[118].

Similarly, the concept of PPI highlights the importance of involving people living with dementia in the development and evaluation of digital health solutions. PPI can ensure that interventions are not only technically effective but also acceptable and relevant to the end-users[119]. Consulting with them is essential for gathering valuable input, which can influence design, features, and functionalities of digital health tools[120]. By actively involving people with dementia in the development processes, PPI contributes to the creation of solutions that are in line with their unique needs and preferences[121]. The inclusion of people with dementia in digital health development and evaluation holds promise for future uptake. When end-users feel that their input is valued and that digital health tools cater to their specific requirements, they are more likely to adopt and benefit from these technologies[122]. This engagement not only ensures that digital health interventions are tailored to the lived experiences of people with dementia but also increases the likelihood of their widespread acceptance and use[114,122].

3. Supporting advance care planning in dementia: Research gaps to address

Several research gaps in the way we support ACP for people with dementia and their families warrant attention. People with dementia and their families have specific needs in terms of ACP that differ from those of people facing other conditions[61]. This is in part due to factors such as cognitive decline and the increasingly important role of families in decision-making throughout the dementia trajectory[13]. As of now, research has yet to identify strategies to address the needs of people with dementia and their family caregivers in terms of ACP, such as the provision of more accessible information and support for ACP communication in the family context[82]. Research on supporting ACP for people with dementia and family caregivers in the family context is scarce. Another significant gap lies in the foundations of ACP interventions in dementia, as many existing efforts lack a robust theoretical framework and are based on definitions that exclude people with dementia from the process of ACP.

Digital health interventions have shown effective and acceptable in other domains of dementia care[98], and they show potential in supporting ACP for people with dementia in the family context. However, there is a notable lack of tools that effectively utilise digital platforms for this purpose. Importantly, the involvement of people with dementia in the development and evaluation of ACP web-based interventions has been insufficient, signalling a critical gap in participatory approaches that consider the perspectives and preferences of people with dementia and family caregivers themselves. Addressing these research gaps is crucial for the advancement of effective and inclusive ACP support strategies in the context of dementia care.

Aims of the doctoral dissertation

The overarching aim of this dissertation is to advance our understanding of how to support people with dementia in advance care planning within their family context. To do so, this dissertation comprises three core aims, with each having several objectives:

Aim 1: To explore current definitions of ACP and provide recommendations from the perspectives of people with dementia and their families.

Objective 1: To gain insight into the ACP content provided on dementia associations' websites in Europe (Chapter 2).

Objective 2: To gather the perspectives of the European Working Group of People with Dementia and their supporters on how ACP is defined and develop recommendations for changes to the definition of ACP (Chapter 3).

Aim 2: To develop an ACP support website for people with dementia and their families and evaluate user experiences.

Objective 3: To describe the protocol for a study aiming to develop and simultaneously test the usability of a user-centred ACP support website designed for and with people with dementia and their families (Chapter 4).

Objective 4: To develop and test an evidence- and theory-based website to support people with dementia and their family caregivers when engaging in ACP within the family context (Chapter 5).

Objective 5: To evaluate the use and the experiences of people with dementia and their family caregivers with two interactive web-based tools for reflecting and communicating about ACP (Chapter 6).

Aim 3: To draft recommendations for future web-based tools targeting communication and decision-making for people with dementia.

Objective 6: To identify usability requirements, usability testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care (Chapter 7).

Methods

1. Setting: Advance care planning regulatory context in Belgium

In Belgium, three laws provide a legal framework for ACP since 2002. They focus on patients' rights, the right to palliative care, and euthanasia[123,124]. These legislations grant patients several rights, such as receiving good person-centred quality care, being informed about their health and the potential progression of their conditions, and being able to consent or reject treatment[123,124]. Negative advance directives are documents that hold legal weight and that allow people to refuse medical treatment. Furthermore, under Belgian law, people can use an advance directive to ask for euthanasia in cases involving an irreversible coma. The law also establishes a hierarchy to designate a proxy decision-maker in the case that no legal representative was nominated, with cohabiting partners having precedence, followed by an adult child, a parent, or an adult sibling[123,124]. In the past few years, there has been a push in policy initiatives to encourage ACP and ACP communication. Since 2022, a reimbursement scheme for ACP was introduced. This scheme aims to remunerate general practitioners for the time devoted to ACP activities, facilitating discussions between patients and general practitioners. The goal is not only to engage in ACP conversations but also to disseminate the patient's preferences to other healthcare professionals involved in their care[124].

2. Overview of methods used in the dissertation

To meet the research objectives of this dissertation, different methods were selected, and different types of data collection were conducted. To provide an overview of the current information on ACP provided on dementia associations' website, we used a qualitative content analysis (Chapter 2). In addition, we conducted a qualitative study with the European Working Group of People with Dementia (EWGPWD) using focus groups and individual follow-up interviews to gather their perspectives on the ACP definition (Chapter 3). Following the UK Medical Research Council (MRC) framework for developing and evaluating complex interventions[125]integrated with the process map for the development of web-based decision support interventions[126], we developed and tested the usability of an ACP support website (Chapters 4 and 5). We provided an overview of two innovative web-based reflection and communication tools integrated within an ACP support website and evaluated the use and the experiences of people with dementia and family caregivers using these web-based tools (Chapter 6). We finally conducted a systematic literature review to examine usability requirements, usability testing methods, and design suggestions for future web-based tools targeting communication and decision-making support in dementia care (Chapter 7).

Throughout this dissertation, we recruited people with mild to moderate dementia (both early and late onset) and family caregivers. Overall, we aimed to include diverse groups of people with dementia. That is, we aimed to include participants of different ages, genders, types of dementia (Alzheimer's, Lewy-Body, Vascular, etc.). We also aimed to include people with different relationships between the person with dementia and the family caregiver (e.g. partners, parent-child). Participants had to be both able to and willing to participate in research, to discuss the topic of ACP and to take part in the testing of an ACP support website. All methods are further explained in the following sections.

Methods used to answer research aim 1: To explore current definitions of ACP and provide recommendations from the perspectives of people with dementia and their families.

Content analysis of dementia associations' websites

To meet research objective 1, we conducted a content analysis of information related to ACP on European dementia associations' websites[127]. Eligible websites included those of international and national dementia associations in Europe affiliated with Alzheimer Europe. Websites in multiple languages were considered (i.e. English, French, German, Dutch, Bosnian/Croatian/Serbian, Spanish, Danish, Norwegian, Czech, Swedish, Polish, and Turkish), and the content aimed at a broad audience was analysed, excluding content for healthcare professionals or legal experts. ACP content was identified using specific search terms related to ACP. All dementia associations whose website was included in the study were contacted and asked to forward all ACP content available on their website. All relevant content was downloaded, including webpages and PDF documents. Non-English websites were translated and checked for accuracy[127].

Analysis

The data was analysed using qualitative content analysis[128], involving a reference framework that categorised ACP themes based on two international definitions of ACP[7,8]. The reference framework allowed us to identify ACP content. It included three overarching categories which were: (1) defining ACP, (2) the legal and medical aspects of ACP, and (3) the quality of life, personal, social, and practical aspects of ACP. Two researchers coded the ACP content in NVivo12 using the reference framework and created new themes inductively when necessary. The accessibility and readability of the websites were also assessed based on specific criteria to determine their suitability for people with dementia, based on the DEEP guide on creating websites for people with dementia[113] and the DEEP guide on writing dementia-friendly information[129].

Focus groups and follow-up interviews with the European Working Group of People with Dementia and their supporters

To meet research objective 2, we conducted a qualitative study where focus groups and follow-up interviews were conducted to explore the perspectives on the definition of ACP developed by Rietjens and colleagues (2017)[7], among a multinational group of people with dementia and their caregivers[130]. Participants were members of the European Working Group of People with Dementia (EWGPWD) and their supporters. The EWGPWD is an established group coordinated by Alzheimer Europe. Inclusion criteria were: (1) being a member of the EWGPWD or being the chosen supporter of one of the members of the EWGPWD, and (2) expressing the willingness and consent to engage in discussions related to ACP.

A combination of data collection strategies, online focus groups and online individual follow-up interviews, allowed for in-depth discussions. We used adapted materials and procedures to support people with dementia during the process and facilitate online participation. Supporters also played a double role in the process: (1) they were respondents themselves, and (2) they could be asked to assist people with dementia if necessary. The focus groups involved discussions around the presentation of the definition of ACP and its deconstruction into the 'what', 'why', 'who' and 'when' of ACP. Participants were asked to reflect on the definition of ACP and to what extent it reflected their experiences. Follow-up interviews were conducted based on the themes that emerged from the focus groups[130].

Analysis

The data were transcribed and analysed thematically, following steps recommended by Braun and Clarke, and using NVivo12[131,132]. The coding process involved pre-defined codes based on the existing ACP definition and preliminary open codes that emerged from the data. Researchers iteratively refined and revised the codes, meeting to discuss different opinions on the data and agree on a list of codes. The analysis led to the identification of themes and sub-themes. Based on these findings, a list of recommendations was developed.

Ethical considerations

Participants received an information letter and a link to an online informed consent form. Additionally, participants were asked to give verbal consent to recording. The study received ethical approval from the Ethics Review Board of the Brussels University Hospital of the Vrije Universiteit Brussel (BUN: 1432020000199).

Methods used to answer research aim 2: To develop an ACP support website for people with dementia and their families and evaluate user experiences.

User-centred development and usability testing

To meet objectives 3 and 4, we employed a comprehensive research approach to develop an ACP website for people with dementia and their families. The research followed the process map proposed by Elwyn and colleagues for developing web-based decision support interventions[126] and adhered to the MRC framework for complex interventions[125]. The development process involved multiple stages, including content specification and creative design, incorporating user-centred design principles and continuous stakeholder engagement[133]. Needs assessments (which Chapter 2 and Chapter 3 are part of) and evidence synthesis informed the content specification phase, while iterative prototyping and usability testing were conducted in the creative design phase. User views and input were sought throughout the development process, and meaningful PPI consultation sessions were conducted with an advisory group consisting of people with dementia, family caregivers, experts, and representatives from relevant organisations.

Participants for usability testing of the website were recruited in Flanders through organisations such as the Flemish Alzheimer League and memory clinics. We included participants as people with dementia, family caregivers, or dyads.

- Inclusion criteria for people with dementia were:
    - being aware and informed of their diagnosis,
    - having an interest in and being willing to test an ACP website,
    - speaking and understanding Dutch,
    - being able to understand the information about the study,
    - being able to sign a written informed consent form.
- The inclusion criteria for family caregivers were:
    - being the main or primary caregiver of a person formally diagnosed with dementia,
    - having an interest in and being willing to test an ACP website,
    - being 18 years of age or older,
    - speaking and understanding Dutch.

People with dementia, family caregivers, and dyads evaluated several versions of the prototype of the ACP website using the think-aloud method[134]. Based on their input and feedback from the advisory group, the website was adapted and extended in several iterations (sprints). After three usability sprints (sprints 1 to 3), the final prototype of the ACP website was evaluated by people living with

dementia, their main family caregivers and dyads through semi-structured interviews regarding content, face validity, readability, and lay-out (sprint 4).

Analysis

During sprints 1 to 3, framework analysis was conducted on the notes taken by researchers during the think-aloud sessions[135]. Following sprint 4, framework analysis was also used to analyse the transcripts. The framework analysis approach involved several stages, including data familiarisation, thematic framework development, indexing all study data against the framework, charting to summarise this data, and lastly mapping and interpretation[135]. Based on the interview guide, we developed subcodes which constituted our preliminary framework. Two researchers applied the framework to all the transcripts. Next, all indexed data were charted onto a framework matrix by summarising participants' interviews and arranging them by categories (i.e. subcodes). This facilitated analysis within and between each interview and data preparation for interpretation.

Ethical considerations

This study received approval from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel on 26 June 2021 (BUN: 1432021000437). To determine the ability of people with dementia to give informed consent, we asked them to read the informed consent form out loud. We ask them per line if they understood their rights and whether they understood what was asked of them. One of the researchers (CD) ensured that participants with dementia understood what they signed by discussing the statements formulated in the informed consent form with them. A family caregiver was also present to help the researcher assess the understanding of the person with dementia. They were asked to sign the informed consent form if everything was clear. We also asked the family caregivers to sign the informed consent form of the persons with dementia as witnesses, as recommended by the Alzheimer's Association National Board of Directors[136].

Mixed-method evaluation of interactive web-based reflection and communication tools

To address research objective 5, we evaluated two web-based reflection and communication tools developed within the ACP support website by conducting an eight-week mixed-method evaluation study. We evaluated use by capturing log data (continuous data collection logging user activity on the website) and employed semi-structured qualitative interviews to gather insights into user experience. This study was part of an evaluation study of the ACP support website as a whole[137].

During the eight weeks of the evaluation study, web log data was collected on the ACP support website. This log data was used to record type, frequency, and timeframe of usage of all components and features of the ACP support website. In this study, we focused on the interactions with the web-based reflection and communication tools. We conducted semi-structured interviews with dyads composed of people with dementia and family caregivers or with family caregivers alone after they had used the ACP support website for eight weeks as part of the evaluation study. The study took place in Flanders, the Dutch-speaking part of Belgium. Participants were recruited via organisations involved in dementia care and neurologists working in memory clinics. People with dementia and family caregivers were recruited to the study either as dyads or as individual family caregivers. We used the following eligibility criteria:

- People with dementia and family caregivers:
    o Having an interest in and being willing to test the ACP website
    o Being able to consent to study participation
    o Speaking and understanding Dutch
    o Having a device that can open the website (e.g. laptop, iPad, mobile phone, etc.)
    o Did not participate in the cognitive testing of study materials
- Person living with dementia: is diagnosed with young- or late-onset dementia
- Family caregiver: takes active care (physical, emotional, social, etc.) of the person with dementia
- Dyads: At least one of the participants needs to be able to navigate the website (e.g. the person with dementia and the family caregiver cannot both have disabilities that prevent them from interacting with the ACP support website)

Analysis

Descriptive statistics were used to analyse participants' sociodemographic characteristics, using SPSS. To analyse the log data of the interactions with the web-based tools, we used RStudio. The data was summarised using descriptive analysis. All transcripts from the interviews were transcribed and anonymised. A framework analysis was conducted in this study[135]. Initially, pre-established codes were employed, derived from the interview schedule questions. Subsequently, new codes arising from a thorough examination of the transcripts were introduced to encompass emerging themes. To establish the coding framework, two researchers first examined a subset of the transcripts to gain familiarity with the data. Following this independent coding process, the two researchers compared their coded data, addressing any discrepancies through discussions. The finalised coding framework was then employed to analyse the entire dataset.

Ethical considerations

This study was granted ethical approval by the Ethical Review Board of Brussels University Hospital at Vrije Universiteit Brussel (B.UN 1432022000179). Upon contacting the researchers, individuals expressing interest in the study received an informational letter and a consent form. If their interest persisted after reviewing the study details, the researchers scheduled an appointment with the participants for eligibility screening and obtaining informed consent. Ethical measures were implemented to safeguard the well-being of research participants during the study. As discussions about ACP could be emotionally challenging, participants were monitored during in-person data collection and reassured about their right to discontinue participation at any point. Participants were given the researchers' contact information to facilitate communication and support. These measures were designed to ensure participants' comfort and access to assistance if needed.

Methods used to answer research aim 3: To draft recommendations for future web-based tools targeting communication and decision-making for people with dementia.

Systematic literature review

To meet research objective 6, we conducted a systematic review and narrative synthesis to identify usability requirements, usability testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care. The electronic databases in MEDLINE, Embase, PsychINFO, Web of Science, and Scopus were systematically searched. First, we screened titles and abstracts, then full texts. We extracted data from the included articles, including (1) study information and characteristics, (2) participant demographics, (3) description of the tools (i.e. aims, topic and features), (4) methods used to evaluate usability, (5) usability results (positive, negative, and successful elements/suggestions for improvements). Following data extraction, we conducted a narrative synthesis and reported patterns of findings across the included studies[138].

3. Reflexivity and positionality

Chapters 3, 5 and 6 are based on qualitative or mixed-methods studies. Reflexivity and positionality are two crucial concepts when theorising qualitative research methodology. Reflexivity is an acknowledgment of the role and influence of the researcher on the research project[139] and refers to a continuous process of reflection by which the researcher becomes transparent in reflecting about the possible influence of their attitudes, understandings, and knowledge on the way research is conducted,

analysed and interpreted[140]. Reflexivity is advocated for by qualitative researchers, and is believed to enhance study rigour and trustworthiness[141,142]. A related concept is positionality, i.e. describing one's worldview and the position one adopts about the research and its social and political content[143].

A constructivist epistemology acknowledges that the researcher's prior knowledge and beliefs influence the research process[144]. The author of this dissertation brought to the research her own cultural knowledge and assumptions. Positioning herself in the research process, she is a woman from Switzerland in her mid-twenties, who speaks fluently French and English and with an intermediate to good level of Dutch, and is presently an international researcher in Belgium. With a background in public health and health promotion and having previously worked with people with dementia, she had some prior knowledge of dementia and dementia care. In terms of ACP, the researcher had no prior knowledge before the start of the current project. Over the course of the PhD trajectory, the researcher has delved into the intricate nature of ACP. The researcher acknowledges the value of ACP in promoting person-centred care for people with dementia, but approaches it a nuanced understanding of its challenges and limitations within the broader context of dementia care.

In this dissertation, a number of steps were taken to systematically understand ACP and the use of an ACP support website and related experiences from participants' standpoints, using thematic analysis and framework analysis. This was done through faithful recording of data and continued engagement with transcript data to understand what participants were sharing in all qualitative studies comprised in this dissertation. When reviewing data, attention was given to both the finer detail as well as the overall content and context of what participants described. Moreover, during interviewing, the researcher aimed to foster an attitude of curiosity and tried to elicit participants' views as naturally and openly as possible. In Chapters 5 and 6, given that the studies were done in Flanders, the interviewer was a native Dutch-speaker researcher with a nursing background and experience working with people with dementia. Finally, during interviewing and analysis, interpretations were also regularly discussed with academic supervisors and colleagues. The research team was composed of several researchers with expertise in palliative care and dementia care, and a background in health promotion, nursing, psychology, and implementation sciences.

Dissertation Outline

The dissertation consists of an introduction, main findings, and a discussion. It is divided into five parts with related aims and objectives.

The first part, composed of Chapter 1, describes this dissertation's background, aims and methods.

The second part explores current definitions of ACP and provides recommendations from the perspectives of people with dementia and their families. Chapter 2 examines the ACP content provided on dementia associations' websites in Europe. Chapter 3 presents the perspectives of the European Working Group of People with Dementia and their supporters on how ACP is defined and develops recommendations for changes to the definition of ACP.

The third part outlines the development and testing of an ACP support website for people with dementia and their family caregivers. Chapter 4 outlines the protocol for a study aiming to develop and simultaneously test the usability of an ACP website designed for, and with, people with dementia and their families. Chapter 5 describes how we developed and tested the usability of the ACP support website. Chapter 6 provides an overview of two innovative web-based reflection and communication tools created within the ACP support website and reports on the evaluation of these two web-based tools.

The fourth part of the dissertation focuses on drafting recommendations for future web-based tools targeting communication and decision-making for people with dementia. Chapter 7 identifies usability requirements, usability testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care.

Finally, the fifth part of the dissertation provides an overview of the main findings, a discussion of the findings, discusses the strengths and limitations of the research methods used and implications and recommendations for research and practice in Chapter 8.

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– PART II –

EXPLORING CURRENT DEFINITIONS OF ADVANCE CARE PLANNING AND RECOMMENDATIONS FROM THE PERSPECTIVES OF PEOPLE WITH DEMENTIA AND THEIR FAMILIES

CHAPTER 2

Information on advance care planning on websites of dementia associations in Europe: a content analysis

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Abstract

Objective: To gain insight into the advance care planning (ACP) content provided on dementia associations' websites in Europe.

Methods: We conducted a content analysis of dementia associations' websites in Europe regarding ACP information, using deductive and inductive approaches and a reference framework derived from two ACP definitions.

Results: We included 26 dementia associations' websites from 20 countries and one European association, covering 12 languages. Ten websites did not mention ACP. The information on the remaining 16 varied in terms of themes addressed and amount of information. Four explicitly define ACP. Several websites made multiple references to legal frameworks (n=10, 705 excerpts), choosing legal representatives (n=12, 274 excerpts), and care and treatment preferences (n=14, 89 excerpts); while themes such as communication with family (n=9, 67 excerpts) and professionals (n=9, 49 excerpts) or identifying personal values (n=9, 73 excerpts) were mentioned on fewer websites or addressed in fewer excerpts.

Conclusion: ACP content is non-existent in 10 out of 26 dementia associations' websites. On those that have ACP content, legal and medical themes were prominent. It would be beneficial to include more comprehensive ACP information stressing the importance of communication with families and professionals, in line with current ACP conceptualisations framing ACP as an iterative communication process, rather than a documentation-focused exercise.

Introduction

Advance care planning (ACP) has been defined as an ongoing process that enables individuals to explore and identify their values, reflect upon the meanings and consequences of serious illness scenarios and define goals and preferences for future care and medical treatment. It also involves people discussing these preferences with family and healthcare providers, appointing a proxy decision-maker and recording these preferences and choices[1,2]. Dementia is a progressive neurodegenerative illness that leads to significant cognitive and functional decline. ACP has been described as an essential part of social health for people with dementia as it promotes their capacity to exercise choice and autonomy and fulfil their societal potential[3]. ACP is of great importance for people with dementia and their families as it enables individuals to discuss wishes and goals for health and end-of-life care before they lose decisional capacity[4]. It has also been suggested that ACP can be informed by health behaviour theories[5,6], highlighting the importance of knowledge in ACP engagement. However, lack of knowledge about what ACP involves was found to be a significant barrier to engaging in ACP among people with dementia and their families or those close to them[7,8].

People with dementia and their families have expressed concerns about unmet information needs regarding the trajectory of dementia, advance care planning and available care options[9–11]. Although healthcare professionals are generally regarded as the most useful source of information for healthcare advice[12], a growing number of individuals use the internet when searching for information about health conditions and treatment options[13]. For people with dementia specifically, according to a recent scoping review, the internet has become the most highly utilised source of information and the most preferred source of information for people with dementia and their families[14].

However, potential limitations of information provided on the internet include the risk of it being incomplete and of uncertain quality. The most common type of websites accessed by people with dementia to look for dementia-specific information are those of dementia associations and charities, and government-run websites, as they are seen as trustworthy in terms of quality of information[12]. Several studies have examined the general content of websites providing information for people with dementia and their family carers, investigating among others diagnosis and management of dementia, young-onset dementia, prevention or assessing the whole content of websites[15–18]. Studies and guidelines have also addressed the accessibility and usability of websites for people with dementia, to investigate whether all technological features are dementia-friendly[19,20].

So far there have been no studies of which and how much ACP content is available on dementia associations' websites. Exploring to what extent and ways in which ACP content is addressed (i.e. which subjects are addressed with regards to ACP and to what extent), as well as identifying the

accessibility and readability of the content are important steps within efforts to improve knowledge about ACP for people living with dementia and their families. Therefore, this study aims to gain insight into the ACP content provided on their websites by dementia associations in Europe. We explore the following research questions: [1] what ACP content is available on dementia associations' websites in Europe? and [2] is the ACP content on these websites provided in an readable and accessible way for people with dementia and their families?

Methods

We conducted a content analysis of information related to ACP on European dementia associations' websites. We used the reporting guideline developed by Kable et al. (2012) to structure our paper[21]. As the study uses data freely available in the public domain, ethics approval was not required.

Eligibility

Eligible websites were the official websites of international and national dementia associations in Europe (i.e. northern, southern, eastern, and western Europe) who were affiliated members of Alzheimer Europe. Alzheimer Europe is a non-governmental organisation aimed at raising awareness of all forms of dementia by creating a common European platform through co-ordination and co-operation between Alzheimer organisations throughout Europe. All eligible websites were included. To account for potential differences in the organisation of health and social care competencies between countries, the dementia associations were asked to forward links to regional websites if they deemed that they would offer more information on ACP. This measure aimed to ensure that we did not miss any relevant ACP content during the screening process. We contacted the dementia associations through e-mail and sent one follow-up e-mail in case of non-response within a two-week period.

We included websites available in the following languages: English, French, German, Dutch, Bosnian/Croatian/Serbian, Spanish, Danish, Norwegian, Czech, Swedish, Polish and Turkish. These specific languages were selected based on the languages covered by the authors and members of the DISTINCT network. DISTINCT is a project funded under the European Commission's Horizon 2020 Marie Sklodowska Curie programme, which the present study was part of. Only content aimed at a broad audience was included in the analysis. If reports and documents clearly stated that they were specifically aimed at health and social care professionals or legal experts, they were excluded.

Identification of the ACP content on the websites

We accessed online websites of the dementia associations of the countries mentioned and screened them for ACP content using as reference key terms pertaining to ACP as identified in the ACP definitions of Rietjens and colleagues and Sudore and colleagues[1,2]. Specifically, we searched for content using the following search terms: (1) advance care planning; (2) planning for the future; (3) communicating about the future; (4) personal values and preferences; (4) preferences for future care or treatment; (5) planning for the end of life; (6) proxy or substitute decision-makers; and (7) advance directives.

In addition, all dementia associations whose websites were included in the study were contacted and asked to forward the links to the ACP information published on their websites to ensure we did not miss any information, and to ensure we include information that is considered by the associations themselves to relate to ACP.

Data extraction

We screened all included websites for ACP content in December 2020 and January 2021. All pages on each website were manually searched for the key themes described above, using the find function ("CTRL-F"), and embedded search bars. All ACP related content, which included webpages and available PDF documents (e.g. information sheets, brochures, or reports) to which the website linked directly, was downloaded. .

We extracted the ACP content of all websites, and all non-English websites were translated for analysis using the online translation tools DeepL or Google Translate and then checked by native speakers, either one of the authors or a member of the DISTINCT network, before being approved for analysis. All documents were uploaded into the qualitative analysis software NVivo 12 and the included text files created based on the ACP content extracted from the websites (i.e. webpages and PDFs) were analysed for content by two independent reviewers (FM and CD).

Content analysis of ACP content and coding technique

This study involved a qualitative content analysis of the ACP content, following the method described by Bengtsson[22]. We conducted a directed content analysis, which is involved: (1) identifying important key concepts as initial coding, (2) sorting data in the predetermined categories, (3) highlighting unsorted data that is potentially relevant, and (4) group highlighted data into new categories[23]. Content analysis was chosen for its strengths in systematically categorising large volumes of text-based data, and the ability to assist in interpreting patterns occurring in the text.

We first created a reference framework that outlines criteria for determining that content concerns ACP. The development of such a reference framework has been used previously to identify palliative care content in policy documents concerning healthcare for older people[24]. The reference framework was based on two recognised ACP definitions[1,2], which we broke down into important themes. We created three overarching categories, within which key ACP themes could be classified. The overarching categories were: defining ACP, the legal and medical aspects of ACP, and the quality of life, personal, social and practical aspects of ACP. The final ACP themes included within these categories were: definition of ACP; legal frameworks; legal representatives; care and medical treatment preferences, including end-of-life care; documentation of decisions; personal values and life goals; communication and discussions with family; communication and discussions with health professionals; documentation sharing; timing; meanings and consequences of potential serious illness scenarios; and uncertainties of serious illness scenarios (see Table 1). Appendix 1 gives a more detailed explanation of each theme within our reference framework.

Table 1: Overview of the deductive categories and themes

Defining ACP	Medical and legal aspects of ACP	Quality of life, personal, social, and practical aspect of ACP
• Definition of ACP	• Legal frameworks • Legal representatives • Documentation of decisions • Care and medical treatment preferences	• Personal values and life goals • Communication with family • Communication with health professionals • Documentation sharing • Timing • Meanings and consequences of serious illness scenarios • Uncertainties of serious illness scenarios

Two researchers (FM & CD) each coded the ACP content from each website independently using the reference framework. Where text was determined to represent a theme that was not included in the reference framework, a new theme was created using an inductive approach. The inductive approach of the ACP content was used to allow certain themes to emerge from the data, independently from the reference framework based on the definition of ACP. Inter-coder reliability was then established by discussing disagreements and re-coding content until an agreement was reached. The qualitative analysis software NVivo 12 was used to assign and organise codes, as well as visualising the data through hierarchy charts.

Descriptive analysis of website accessibility and readability

To make an inventory of the different accessibility and readability features of the websites, a descriptive analysis was performed, based on the DEEP guide on creating websites for people with dementia[25] and the DEEP guide on writing dementia-friendly information[26]. First, we assessed the websites based on accessibility, that is, how well the website was able to meet the needs of people with dementia, and whether it included the following items: clear headings, clear home link, clear site map, print option, text to speech option, text size option, contrast option, and clear hyperlinks. In addition, we also assessed the ACP webpages on readability, that is whether the content is presented in a way that is as easy to understand as possible. We only assessed the readability of the ACP content included in the analysis, and not of the associations' websites as a whole. We included the following items: use of simple language, use of pictures, use of videos, use of abbreviations and whether they are defined or not, and use of jargon and whether it is defined or not. Language was evaluated as simple if more than half of the content met the following criteria: (1) short sentences (20 or fewer words), (2) paragraphs constructed with five or fewer sentences, (3) over half of the passages written in active voice, (4) lists used to break up blocks of texts, and (5) jargon was used and explained. These evaluation criteria were based on a previous study conducting descriptive analyses of telehealth websites[27].

Results

Characteristics of the websites included

We included websites from 26 associations, originating from 20 different countries in Europe and one European association. Eight dementia associations answered our request to forward the ACP content of their website, which allowed us to check that we did not miss any content in our extraction process, that the associations themselves considered to address ACP. From the 26 associations identified, all are non-profit organisations and politically and religiously independent. Their mission statements and objectives range from supporting and informing people with dementia and their carers or raising awareness about dementia, to advocating for patients' rights and encouraging research, or even ensuring collaboration between associations. In total, 20 associations mention providing support or information to people with dementia and their families as one of their primary objectives. Of the six remaining associations, five of them (i.e. the National Alzheimer League Belgium, the Malta Dementia Society, the Norwegian Health Association, the Spanish Alzheimer Confederation, and the Turkish Alzheimer Association) focus solely on advocacy and organisational coordination and Alzheimer

Europe is an umbrella organisation of national Alzheimer associations whose focus is on advocacy and research at European level. An overview of mission statements can be found in Appendix 2.
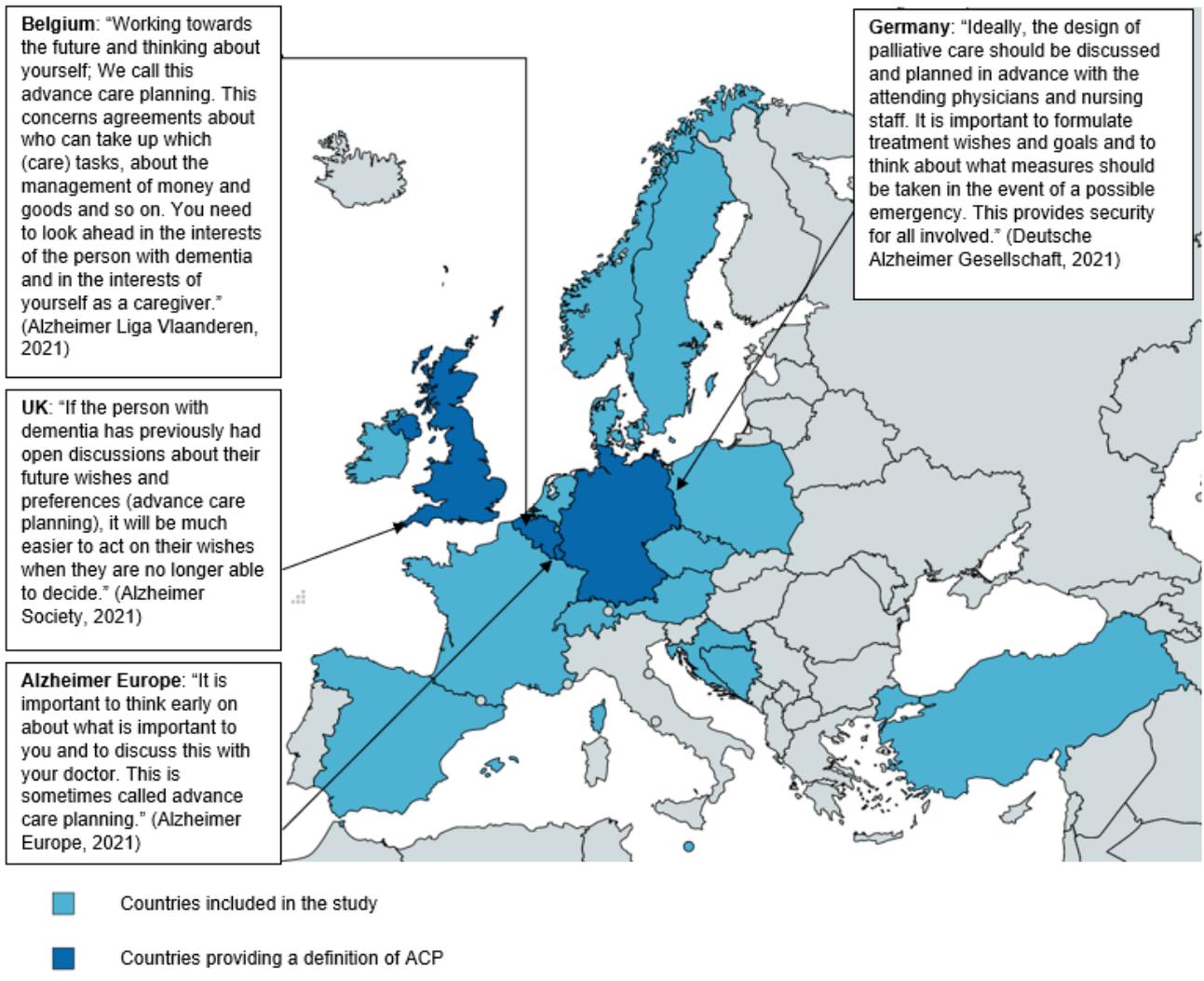
ACP content provided on the websites

Out of the 26 associations' websites included, 10 did not mention anything about ACP. The remaining websites varied widely in the amount of content provided, with some containing a single webpage on ACP (e.g. Alzheimer Austria or Alzheimer's association of Turkey) while others provide a much larger range of content on several webpages (e.g. Alzheimer Europe or Alzheimer Society in the UK) (see Appendix 3).

Across the 16 websites that mentioned ACP, all 12 ACP themes identified in our reference framework were addressed to some extent. We present these themes in three overarching categories: defining ACP, the legal and medical aspects of ACP, and the quality of life, personal, social, and practical aspects of ACP. The analysis also identified four themes that emerged from the data and that were recurring across several websites: (1) reviewing ACP, (2) difficulties of ACP conversations, (3) potential consequences of not doing ACP, and (4) decision-making capacity (Table 2).

Defining ACP

Four websites formulated a definition of ACP (Table 3). Two of these definitions (German and Belgian - Flemish websites) focused on making decisions for future care and medical treatments and the choice of a legal representative, whereas the other two (UK and Alzheimer Europe websites) remained more general and referred to 'preferences' or 'wishes' for the future. Two of four websites with definitions (from Alzheimer Europe and Germany) put forward the importance of discussing ACP with a health care professional. All four emphasised the importance of the ACP process and its potential benefits (Figure 1).

Belgium: "Working towards the future and thinking about yourself; We call this advance care planning. This concerns agreements about who can take up which (care) tasks, about the management of money and goods and so on. You need to look ahead in the interests of the person with dementia and in the interests of yourself as a caregiver." (Alzheimer Liga Vlaanderen, 2021)

UK: "If the person with dementia has previously had open discussions about their future wishes and preferences (advance care planning), it will be much easier to act on their wishes when they are no longer able to decide." (Alzheimer Society, 2021)

Alzheimer Europe: "It is important to think early on about what is important to you and to discuss this with your doctor. This is sometimes called advance care planning." (Alzheimer Europe, 2021)

Germany: "Ideally, the design of palliative care should be discussed and planned in advance with the attending physicians and nursing staff. It is important to formulate treatment wishes and goals and to think about what measures should be taken in the event of a possible emergency. This provides security for all involved." (Deutsche Alzheimer Gesellschaft, 2021)

Countries included in the study

Countries providing a definition of ACP

* All definitions are forward-only translations from the original websites

Figure 1: Definition of ACP per country [28–31]

Table 2: ACP themes identified per dementia associations' website[*]

Dementia Associations (Country)	Defining ACP	Legal and medical aspect of ACP				Quality of life, personal, social, and practical aspect of ACP								Total number of themes identified
	Definition of ACP	Legal frameworks	Legal representatives	Care & medical treatment preferences	Documentation of decisions	Personal values and life goals	Communication with health professionals	Communication with family	Timing	Uncertainties	Meanings & potential consequences	Documentation sharing	
Alzheimer Austria (Austria)		✓	✓	✓	✓					✓			5
Ligue Nationale Alzheimer Liga (Belgium, national umbrella association)													0
Ligue Alzheimer (Belgium, region Wallonia)													0
Alzheimer Liga Vlaanderen (Belgium, region Flanders)	✓					✓	✓						3
Udruženje AiR (Bosnia and Herzegovina)													0
Alzheimer Croatia (Croatia)			✓	✓					✓				3

[*] Several associations from the same country were included if: (1) the national association referred us to additional regional associations, or (2) if two association from this country were affiliated with Alzheimer Europe.

Organisation													Total
Ceská alzheimerovská spolecnost (Czech Republic)			✓	✓	✓					✓	✓	✓	6
Alzheimerforeningen (Denmark)				✓	✓	✓	✓	✓	✓		✓	✓	8
France Alzheimer (France)													0
Deutsche Alzheimer Gesellschaft (Germany)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
Alzheimer Society of Ireland (Ireland)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Jersey Alzheimer's Association (Jersey)													0
Association Luxembourg Alzheimer (Luxembourg)													0
Malta Dementia Society(Malta)													0
Alzheimer Nederland (Netherlands)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Norwegian Health Association (Norway)			✓					✓	✓	✓	✓		5
Polish Alzheimer's Association (Poland)													0
Confederación Española de Alzheimer (Spain)		✓	✓	✓	✓				✓			✓	6

	1	2	3	4	5	6	7	8	9	10	11	12	Total
Fundación Alzheimer España (Spain)													0
Alzheimer Sverige (Sweden)		✓		✓									2
Demensförbundet (Sweden)													0
Alzheimer Suisse (Switzerland)		✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	10
Türkiye Alzheimer Dernegi (Turkey)				✓									1
Alzheimer Scotland (UK)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Alzheimer Society (UK)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
Alzheimer Europe (European)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
Total number of websites addressing theme	4	10	12	14	11	9	9	9	12	9	10	9	

Legal and medical aspects of ACP

The theme *legal frameworks* was assigned to excerpts which included explanations of national laws that govern the ACP process and accounts for more than 60 percent of the total of excerpts, with 705 excerpts across 10 websites. These included laws on advance directives, power of attorney, euthanasia, or protection of vulnerable populations. A further theme is the choice of a *legal representative* (n=12 websites, 274 excerpts). The theme has been defined to represent the exploration and appointment of a legal representative. *Documentation of decisions* and *Care and medical treatment preferences* was also addressed on dementia associations' websites (n=11, 88 excerpts and n=14, 89 excerpts respectively). *Care and medical treatment preferences* included decisions such as 'limiting or stopping treatment and end-of-life care' or 'going into residential care or a nursing home', which were situations often mentioned on the websites, while *documentation of decisions* focused on writing these decisions in living wills or advance directives. These documents are described as ways to plan medical care and legal affairs, as well as financial affairs (Table 3).

Quality of life, personal, social and practical aspects of ACP

The identification of *personal values and life goals* was mentioned on nine websites, although in considerably fewer cases (73 excerpts) than the medical and legal themes. Websites addressed the exploration of wishes based on personal values and life goals, and important quality of life domains for the person. These included for example, 'daily habits and wishes about food, hygiene, dress, physical activities and cultural activities' or 'their likes and dislikes, their background (including ethnicity or religion), what they like to be called, the important people or places in the person's life, what helps them relax, how they take their medication, their normal routines, if they wear glasses or a hearing aid, what they like to do for themselves and what they need help with' (Table 3).

Communication with health professionals and *Communication with family* and *Sharing of documents* were found in the same number of websites (n=9); they were addressed in 67, 49 and 36 excerpts respectively. In several instances, websites encouraged people with dementia to discuss the future with family or trusted individuals (n=9, 67 excerpts), as well as with health professionals (n=9, 49 excerpts). In cases where advance directives were mentioned, some websites (n=9, 36 excerpts) also encouraged people with dementia to share these advance decisions documents, giving the argument that the more people are aware of decisions and wishes, the more they can be respected (Table 3).

Besides references to future wishes and communication, 12 websites mention the *timing* of ACP, advocating for ACP to be done as early as possible (in 58 excerpts). Some websites also address *meanings and potential consequences of future serious illness scenarios* by discussing available

treatment options (and their possible benefits or lack thereof for the patient) (n=10, 58 excerpts). Similarly, some highlight and explore the *uncertainties* associated with a dementia diagnosis and explain their consequences for ACP (n=9, 34 excerpts) (Table 3).

Emerging themes

Regarding the topic of *Reviewing ACP* (n=7, 13 excerpts), some websites emphasise the fact that ACP decisions are not fixed and can be changed. These websites then suggest regularly checking whether decisions still fit with the preferences of people with dementia, for as long as this is possible. The topic of *decision-making capacity* was also recurrent in the ACP content on some dementia associations' websites (n=9, 27 excerpts). These websites highlight the decline in capacity associated with dementia and use it as an argument to promote ACP (Table 3).

Moreover, references to what would happen if people did not do ACP was a recurring theme on different websites. The theme *consequences of not doing ACP* included potential future scenarios where the family does not know the preferences of the person with dementia and must choose on their behalf which treatment they should or should not receive (n=5, 18 excerpts). Finally, several websites pointed to the *difficulties of ACP conversations* (n=6, 15 excerpts) and the emotional impact that they can have on the person with dementia and the family.

Table 3: ACP themes identified on the dementia associations' websites

Themes	Example quotes	Number of websites addressing the theme	Number of excerpts per theme
Defining ACP			
Definition of ACP	'Working towards the future and thinking about yourself. We call this advance care planning. This concerns agreements about who can take up which (care) tasks, about the management of money and goods and so on. You need to look ahead in the interests of the person with dementia and in the interests of yourself as a caregiver.' [31]	4	13
Legal and medical aspects of ACP			
Legal frameworks	'There are several laws which aim to enable decision making and protect the rights of vulnerable adults, including people with dementia. These are the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care & Treatment) (Scotland) Act 2003; and the Adult Support & Protection (Scotland) Act 2007. There is a short description of the main points of each of these laws below.' [32]	10	705

Legal representatives	'If a person is unable to take care of his or her legal matters, to cover their living needs and to assert claims (care allowance, social assistance, benefits, etc.) due to an intellectual disability, they can be represented by a close relative.' [33]	12	274
Documentation of decisions	'You can formulate your wishes for care and nursing in a so-called care will.' [34]	11	88
Care and medical treatment preferences	'Therefore, if the patient is still able to act in a responsible way, he/she should decide on matters related to artificial nutrition and resuscitation.' [35]	14	89
Quality of life, personal, social and practical aspects of ACP			
Personal values and life goals	'[…] getting to know the person's values, wishes and beliefs more generally can help in the future when decisions need to be made on their behalf.' [36]	9	73
Communication with health professionals	'It is usually very difficult for medical laypersons to have an overview of the various treatment situations that can occur and to describe the measures that correspond to their own values for each case. Therefore, consultation with a physician or other competent person or organisation is recommended in order to gain clarity about what is desired and to avoid contradictions between individual definitions.'[37]	9	67
Communication with family	'It can be difficult to discuss these matters with the people you love. You might not want to, and that is understandable. Still, it is important to do it. If you don't, a judge may later determine who can make decisions for you. Postponing is therefore not wise.'[38]	9	49
Documentation sharing	'Once the document has been drafted, there are two ways to ensure that advance directives are taken into account: Register the document. This is the most reliable and safe way. By registering it, it becomes available to the medical centre and its team of professionals. If the document has been signed in front of a notary, the notary will be in charge of registering it. If it has been signed in the presence of witnesses, it can be registered by the person concerned, one of the witnesses or a representative.' [39]	9	36
Timing	'People with dementia are no longer able, at a certain stage of the disease, to make appropriate decisions, in particular regarding medical procedures, care and support. By writing advance directives early enough, they can formulate their decisions and specify their wishes in anticipation.' [40]	12	58

Meanings and potential consequences of serious illness scenarios	'Your doctor and nurse can explain some of the care and treatments that can arise with advanced dementia such as: the use of a ventilator (a machine to breathe for you if you stop breathing); the use of artificial nutrition (tubes which feed you if you can no longer eat or swallow); and the use of Cardiopulmonary Resuscitation, CPR, if your heart stops.' [41]	10	58
Uncertainties of serious illness scenarios	'It is difficult to know how quickly and in what manner the dementia symptoms will develop. All people are different. For some, the symptoms remain stable for a long time. Others have some good days and some bad days.' [42]	9	34
Emerging themes			
Reviewing ACP	'You can change any advance statement that you make at any time. If you have made a written advance statement you must make sure that all copies have been updated.' [43]	7	13
Difficulties of ACP conversations	'Most people have a hard time talking about death. Many thoughts and feelings therefore remain unsaid. But if one does not talk about death, it may come to influence negatively the relationship between the dementia sufferer and the relatives.' [44]	6	15
Consequences of not doing ACP	'In the absence of advance directives. In some cases, the diagnosis is made when the disease is already advanced and the ability to discern significantly reduced. The person with the illness will thus not be able to write his/her advance directives. It also happens that a person refuses such directives. When it comes to making decisions about this person, family and close ones will be consulted.' [40]	5	18
Decision-making capacity	'When a person has a diagnosis of dementia, the solicitor may – and best practice suggests they should – ask for a medical opinion to confirm the person has the capacity to understand what they are signing, at the time of signing it.' [45]	9	27

Descriptive analysis of website features: accessibility and readability of the ACP content

For accessibility and readability, we only assessed the features of the webpages where ACP content was available (16 out of 26 total websites) (Table 3). Overall, all these websites used a consistent style and font size within each one (n= 16). Almost all had an explicit 'home' link (n=11), and seven had a site map (i.e. visible hierarchical listing of webpages). The majority always had clear headings visible (n=14) and only one did not indicate hyperlinks clearly. Seven websites had a print option. Few of the websites allowed for the adjustment of font size (n= 6), adjustment of contrast (n= 2) or had a text to speech option (n=2).

Five readability characteristics were examined on the websites that addressed ACP (16 out of 26 total websites). Six made use of pictures and two of videos. Ten websites had at least half of their ACP content presented in simple language on the webpages addressing ACP specifically. In addition, all these websites avoided the use of abbreviations and acronyms or defined them the first time they were used on the pages (n=16). Jargon (e.g. advance directives, proxy decision maker, power of attorney) was used on most websites to explain advance care planning; jargon was also defined and explained on all websites (n=16).

Table 4: Website features identified per dementia associations' website

Dementia Associations (Country)	Accessibility features								Readability features				
	Clear headings	Clear home link	Clear site map	Print option	Clear hyperlinks	Text to speech option	Text size option	Contrast option	Pictures	Videos	Simple language	Abbreviations are defined	Jargon is defined
Alzheimer Austria (Austria)	✓	✓			✓		✓					✓	✓
Alzheimer Liga Vlaanderen (Belgium)	✓	✓			✓						✓	✓	✓
Alzheimer Croatia (Croatia)	✓	✓		✓	✓				✓		✓	✓	✓
Ceská alzheimerovská spolecnost (Czech Republic)	✓		✓		✓						✓	✓	✓
Alzheimerforeningen (Denmark)	✓				✓				✓		✓	✓	✓
Deutsche Alzheimer Gesellschaft (Germany)	✓		✓		✓		✓		✓			✓	✓
Alzheimer Society of Ireland (Ireland)	✓	✓	✓		✓				✓	✓	✓	✓	✓

Organisation	1	2	3	4	5	6	7	8	9	10	11	12
Alzheimer Nederland (Netherlands)	✓			✓	✓				✓	✓	✓	✓
Norwegian Health Association (Norway)					✓						✓	✓
Confederación Española de Alzheimer (CEAFA) (Spain)	✓				✓			✓			✓	✓
Alzheimer Sverige (Sweden)	✓				✓					✓	✓	✓
Association Alzheimer Suisse (Switzerland)	✓	✓		✓	✓			✓			✓	✓
Türkiye Alzheimer Dernegi (Turkey)					✓					✓	✓	✓
Alzheimer Scotland (UK)	✓			✓	✓					✓	✓	✓
Alzheimer Society (UK)	✓			✓	✓	✓				✓	✓	✓
Alzheimer Europe (European)	✓	✓	✓		✓		✓				✓	✓

Discussion

Our study focused on the extent to and ways in which, dementia associations in Europe address ACP on their websites, as well as the accessibility and readability of this content for people with dementia and their families or those close to them. We found that more than a third of the websites included in the study (10 out of 26) did not address ACP at all. We identified 16 websites providing some content on ACP that people with dementia and their families might turn to. Three websites (i.e. Alzheimer Europe, Alzheimer Society – UK, and the German Alzheimer Society) addressed all ACP themes of our reference framework. The extent to which each ACP theme was addressed on the remaining websites varied greatly. All websites fulfilled some accessibility and readability criteria for people with dementia, although not all characteristics identified by the DEEP guides were accounted for.

Legal and medical themes largely dominated the content on the websites, representing more than two thirds of all excerpts. Most websites that addressed ACP focused primarily on the completion of advance directives, which revolved around three domains: medical care, legal affairs, and financial affairs. Other key ACP themes, such as communication with family, communication with health professionals, sharing of decisions and the identification of personal values and life goals seem largely to be under-addressed. This is an important gap, given that the drafting of advance directives should be preceded by a process of communication between the person with dementia, their family and their healthcare providers. This imbalance may reflect that ACP still has a strong medical and legal focus. Traditionally, ACP has focused heavily on the process of preparing in writing through (i) completing advance care documents, where people can record which treatment they would or would not like to receive at the end of life (such as feeding tube or withholding/withdrawing life support treatments) in the event that they would not be able to take decisions themselves, and (ii) choosing a legal representative, i.e. a formal arrangement whereby a person nominates another person to act in his/her name and make decisions on their behalf[10,46,47]. However, the concept of ACP has considerably evolved over the past decades, going from this documentation-focused process to a broader concept of an iterative communication process between the person with dementia, their family members and health professionals about future care, which is not limited to discussing medical treatment preferences[48–50]. This is also reflected in the current European definition of ACP, which states: "*advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate.*"[1]. A recent umbrella review on ACP for people with dementia also showed that person-centred ACP conversations and communication tailored to the wishes of the person with dementia are of utmost importance in the process of ACP for people with dementia and

their families[51]. However, few of the dementia associations' websites highlight the importance of communication in ACP.

We also identified four themes, that had not been included in our initial reference framework. Our reference framework was based on existing definitions of ACP[1,2], which were not specifically developed for people with dementia. The themes that emerged from the data appeared to be especially important in the context of dementia, i.e. the gradual loss of decisional capacity, the need to regularly review wishes and the implications of not having done ACP prior to loss of capacity, all of which have been described in the literature on ACP for people with dementia[51–53]. Moreover, we also found that six websites addressed the difficulty of having ACP conversations. This is in line with research that has found that people with dementia and their families often face emotionally difficult conversations and experience tensions within the family when discussing ACP[51,52]. Different patient populations can have different ACP needs and face different challenges. While the reference framework based on the ACP definitions addresses the process and subject areas of ACP, these emerging themes illustrate the importance of tailoring content provided on ACP on websites to the needs of different populations by, for example, addressing the specific difficulties faced by people with dementia and their families. This finding may highlight potential gaps in current ACP conceptualisations.

Finally, we analysed the accessibility and readability of the ACP content on dementia associations' websites. Most websites met some of the accessibility and readability criteria set forth by the DEEP guides[25,26]. Most websites had clear formatting, home link, and headings as well as showed a clear sitemap. However, features such as print option, text-to-speech option or font and contrast adjustments were less often offered. Furthermore, although most offered content in a simple language, the use of pictures and videos to support content was less widespread. It can be argued that the target audience of dementia associations' websites are not necessarily people with dementia or their families, but rather policy makers, legal experts or the general public, hence content may not need to meet these accessibility and readability criteria. Looking at mission statements of each respective association shows the variety of objectives and audiences that are targeted. Objectives ranged from supporting people with dementia and their families, to informing the general public (including people with dementia), or advocating for better representation and patient rights. A few associations (such as Alzheimer Europe for example) solely focus on advocacy and research, which may explain the differences in accessibility and readability of the ACP content. However, there is no consistent pattern between the different mission statements of the associations and the accessibility and readability of their ACP content. As most national associations mentioned supporting people with dementia and their families as one of their goals, we argue that they should generally strive for all content to meet these accessibility and readability criteria.

To our knowledge, this is the first study examining the content provided online on the topic of ACP in relation to dementia. This study has a strong international focus and provides a good representation across Europe with countries included from northern, eastern, central, southern, and western Europe. There are some study limitations that need to be considered. First, we cannot exclude that we have missed some relevant content provided on the websites of the dementia associations in the different countries included in the study. Although we used a rigorous method to screen the websites, we relied on the cooperation of dementia associations to flag any missing ACP content or regional associations' websites with additional content. Only eight dementia associations answered our query to check the ACP content we had extracted. Furthermore, given the global access to the internet, we cannot exclude that a European audience could find information on ACP on websites based in other parts of the world, which were not included in this study. We hope that this research will prompt other studies of this type in other world regions. Second, translations of the ACP content on the websites were forward-only translations, meaning that the equivalences of the English translation with the original versions were not verified, and relied solely on the work of one translator per language. Third, although the method selected allowed for a thorough screening of the ACP content on dementia associations' websites, it does not provide any indication of the use of these websites and ACP content by people with dementia and family carers, nor of how they appraise this content.

Overall, our results highlight opportunities for dementia associations in Europe to provide comprehensive ACP information on their websites. Lack of or insufficient knowledge about ACP has been identified as one of the factors hindering ACP in people with dementia[10]. Dementia associations' websites are an ideal place to provide this information to a wide public. We thus recommend that dementia associations adopt a more comprehensive approach to providing ACP content on their website, using the broad ACP framework developed in this paper to screen their content. ACP content should aim to address all categories of the framework, but also take into account disease-specific needs in terms of ACP. Therefore, although this framework can serve as initial guidance for the provision of ACP content, further research is needed to identify how ACP can be made accessible for people with dementia and how they can be best informed about ACP. There is also a need for better ACP tools for people with dementia that dementia associations could refer to. Research should focus on how to promote a broader view of ACP that not only addresses legal and medical information, but combines it with more practical guidance on how to engage in and communicate about ACP. Further research could focus on comparing the ACP content of dementia associations' websites with the content of websites concerned with other conditions such as cancer.

In the future, it would also be important to assess whether the content provided on these websites is deemed to be useful and accessible by people with dementia and their families. We would suggest that dementia associations, researchers, or other entities wanting to provide information about ACP use the DEEP guides on creating websites for people with dementia and on writing dementia-friendly information[25,26] or similar guidelines, and involve people with dementia and their families in content creation to ensure that their voices are heard and that cultural nuances are taken into account.

Conclusion

This study showed that ACP content and its accessibility and readability for people with dementia varied across dementia associations' websites in Europe. Although most websites provide some information on ACP, several key ACP themes have been addressed infrequently, or are not addressed at all. We can therefore conclude that there are several opportunities for improvement of ACP content provision on dementia association websites in Europe. It would be beneficial to include more comprehensive ACP information by stressing the importance of communication processes, in line with recent conceptualisations of ACP.

Supplementary materials

Appendix 1: Reference framework based on ACP definitions

Appendix 2: Overview of mission statements and objectives

Appendix 3: Overview of the webpages accessed

References of Chapter 2

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Supplementary materials of Chapter 2

Appendix 1: Reference framework based on ACP definitions

Codes	Explanation	Example quote
Definition of ACP	The website provides information on ACP: names it and explains what it is, its goals and its limitations.	"[…]It allows you to participate in making decisions that help family and friends know your wishes."
Legal frameworks	The website provides information on relevant legal frameworks in the context of ACP.	"Some states do not recognize DNR orders that were initiated out of state, so check with an elder law attorney or the hospital where you plan on traveling."
Timing	The website addresses readiness and the timing for ACP.	"It's best to express end-of-life care wishes now while you are able to make decisions yourself."
Personal values and life goals	The website addresses the exploration of personal values and life goals and important quality of life domains for the person.	" Discuss your wishes regarding care with your chosen agent early and often to make sure that this person understands your wishes."
Care and medical treatment preferences	The website addresses the exploration of preferences for future care and (non)treatment, including end-of-life care.	"Do I want all available treatment measures to be taken? Are there any treatments I do not want?"
Meanings and consequences of serious illness scenarios	The website addresses meanings and potential consequences of future serious illness scenarios, i.e. how the illness can affect the patient, and the illness trajectory.	A diagnosis of Alzheimer's disease is life-changing. You can take an empowering first step by learning more about the changes you may experience, and what to do next to move forward with your life.
Uncertainties of serious illness scenarios	The website addresses the exploration of uncertainties of dementia diagnostic, in terms of effect on the body, the mind, relations, as well as in timing.	Things you once did easily will become increasingly difficult, such as maintaining a schedule or managing money. Some people may try to cover up their difficulties to protect themselves and their family from embarrassment.
Legal representatives	The website addresses the exploration and appointment of a legal representative.	"The power of attorney document allows you (the principal) to name another individual (called an attorney-in-fact or agent) to make financial and other decisions when you are no longer able."

Communication with family	The website encourages to discuss with family or trusted individuals.	"Have conversations with your care partner or family members about the legal plans you would like in place."
Communication with healthcare professionals	The website encourages to discuss with healthcare professionals.	"Once you have expressed your end-of-life wishes with your spouse or care partner, it's important to discuss your wishes with your doctor."
Documentation of decisions	The website encourages to make advance directives, gives information on how to do it, or provides advance directives templates.	" The sooner you establish your legal plans, the better prepared you and your family will be."
Documentation sharing	The website encourages to share advance decisions documents, and gives information on how to do so.	"Once legal documents are filled out, distribute copies to your care team, including your care partner, spouse, attorney and physicians."

Appendix 2: Overview of mission statements and objectives

Dementia association	Main target areas	Examples/quotes of mission statements and objectives
Alzheimer Austria (Austria)	Provide information and support Awareness-raising Advocacy	"Improving the quality of life for the sick person and their relatives has top priority. Through personal discussions, we create a basis of trust and offer information, training, encouragement and support. In addition, we are committed to a society in which people live with one another as equals. We are committed to a better understanding of the disease among the general public and act as a proxy for our target group in the socio-political environment."
Ligue Nationale Alzheimer Liga (Belgium)	Inter-organisational coordination	"The Ligue Nationale Alzheimer Liga ASBL/vzw/VoG is a national association that is active in the field of Alzheimer's disease and related dementias. It brings together three regional associations in Belgium."
Ligue Alzheimer ASBL (Belgium)	Provide information and support Research	"The Alzheimer League is a non-profit organisation providing information and support to patients, relatives and professionals confronted with Alzheimer's disease and other forms of dementia. It constitutes a network of self-help and information groups in Wallonia and Brussels. Our actions are specific and empathetic towards families, professional caregivers and any person in need. We are also involved in scientific research."
Alzheimer Liga Vlaanderen (Belgium)	Provide support	"Alzheimer's League Flanders is the point of contact for people with dementia, their family caregivers and anyone affected by dementia. We aim to support people with all forms of dementia, their caregivers and family members in Flanders in dealing with dementia in a dignified way in order to make dementia bearable together."
Udruženje AiR (Bosnia and Herzegovina)	Provide information and support Advocacy Research	"The main task of the Center for Dementia are : (1) assistance to people living with dementia (2) assistance to family caregivers (3) assistance to family doctors, (4) educational-advisory assistance, (5) development of guidelines, (6) publishing literature on dementia, (7) conducting scientific research, (8) organisation of conferences and seminars."
Alzheimer Croatia (Croatia)	Provide support Education	"The Croatian Alzheimer's Association (HUAB) is an association of experts and persons involved in promoting, developing and improving care for people with dementia, providing psychosocial assistance to their families and educating all people involved in the care and nursing of the sick."

Ceská alzheimerovská spolecnost (Czech Republic)	Provide support	"Our goal has been to help and support people with dementia since our inception, which includes both the sick and their families, because dementia affects both groups equally."
Alzheimerforeningen (Denmark)	Provide support and information Research	"The Alzheimer's Association is an independent patient and relative organisation for people with dementia, that aims to ensure better conditions for people with dementia and their relatives. We advise, inform and support research into dementia diseases."
France Alzheimer (France)	Provide support and information Education	"Educating, informing, accompanying, guiding, supporting... To help people with Alzheimer's disease and their family caregivers, France Alzheimer focuses its action on these different missions"
Deutsche Alzheimer Gesellschaft (Germany)	Provide support and information Awareness-raising Research	"The German Alzheimer Society is committed to a better life with dementia. We support and advise people with dementia and their families. We inform the public about the disease and we are an independent contact for the media, professional associations and research."
Alzheimer Society of Ireland (Ireland)	Provide support Advocacy	"The Alzheimer Society of Ireland works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers."
Jersey Alzheimer's Association (Jersey)	Provide support	"Previously an arm of the UK Alzheimer's Society, Dementia Jersey (previously Jersey Alzheimer's Association) was formed in 2010 to support everyone in the island affected by dementia in whatever way."
Association Luxembourg Alzheimer (Luxembourg)	Provide support and information Awareness-raising	"The primary goal of ala is to improve the quality of life of people with dementia and their families. Our efforts are supported by our targeted counselling, support and care services on the one hand, and our education and awareness-raising offers on the other."
Malta Dementia Society (Malta)	Advocacy	"The aims and objectives for which the society is established are to encourage and promote the best methods of care, education and treatment of persons with dementia and related disorders generally throughout the Maltese islands and elsewhere. […]"

Alzheimer Nederland (Netherlands)	Provide support and information Research Advocacy Awareness-raising	"Alzheimer Nederland is working on a future without dementia and on a better life for people with dementia and their loved ones. We do this on the basis of our five spearheads: research, support, advocacy, dementia-friendly society, education and information."
Norwegian Health Association (Norway)	Advocacy	"The organisation works with public health, research on cardiovascular disease and dementia, and is an interest organisation for people with dementia and their relatives."
Polish Alzheimer's Association (Poland)	Provide support and information Advocacy	"Our goals are: (1) Organising various forms of help for families and carers of patients. (2) Exchange of information and education of people caring for the sick. (3) Influencing politicians and decision-makers in social life to help the sick and their families more effectively. […]"
Confederación Española de Alzheimer (Spain)	Advocacy	"The Spanish Alzheimer's Confederation (CEAFA) aims to work to put Alzheimer's on the political agenda, seeking the necessary social commitment and valuing knowledge to be able to represent and defend the interests, needs and rights of all people living with Alzheimer's."
Fundación Alzheimer España (Spain)	Provide support and information Research	"The statutory objectives of the Foundation are: (1) Provide information and guidance to people who suffer from symptoms of Alzheimer's disease or who want preventive assistance from it, as well as their families and relatives, (2) Provide and procure technical and health assistance to people who are affected by the so-called Alzheimer's disease or dementias with similar symptoms (3) Promote and encourage research […]"
Alzheimer Sverige (Sweden)	Provide support and information Awareness-raising	"Alzheimer Sweden is a nationwide patient and relative organisation for people living with Alzheimer's or other cognitive illness and their relatives. Alzheimer Sweden works with knowledge dissemination, information, counseling and opinion formation to make cognitive diseases visible in society."
Demensförbundet (Sweden)	Provide support Advocacy	"The Dementia Association is today Sweden's largest relatives' organization for dementia patients and their relatives. We work to improve conditions for people with dementia and their relatives and have a unique support activity in our 110 dementia associations that work voluntarily around the country."

Association Alzheimer Suisse (Switzerland)	Provide support and information Awareness-raising Advocacy	Alzheimer Switzerland works to: (1) reduce prejudice, combat stigmatization and break down taboos related to dementia; (2) to develop information and knowledge about dementia and to disseminate this knowledge in a form that is accessible to all target groups (people with dementia, family caregivers, professionals and the general public […]"
Türkiye Alzheimer Dernegi (Turkey)	Awareness-raising Advocacy	"The highest priority in the activities of the association is given to raising awareness and education of our people on Alzheimer's disease and its care, and increasing the quality of life of people and families suffering from this disease."
Alzheimer Scotland (UK)	Provide support and information Advocacy	"Our aim is to make sure nobody faces dementia alone. We provide support and information to people with dementia, their carers and families, we campaign for the rights of people with dementia and fund vital dementia research."
Alzheimer Society (UK)	Provide support Advocacy Research	"Alzheimer's Society is the UK's leading dementia charity. We campaign for change, fund research to find a cure and support people living with dementia today."
Alzheimer Europe (International)	Advocacy Research	"Our mission is to change perceptions, policy and practice in order to improve the lives of people affected by dementia. We are a non-profit non-governmental organisation (NGO) and will achieve our mission by providing a voice to people with dementia and their carers, making dementia a European priority, changing perceptions and combating stigma, raising awareness of brain health and prevention, strengthening the European dementia movement and supporting dementia research."

Appendix 3: Overview of the webpages accessed

Country	Alzheimer Association	URL and date accessed	ACP webpages/ publications included in the analysis
Austria	Alzheimer Austria	https://www.alzheimer-selbsthilfe.at/ Accessed December 14, 2020	• https://www.alzheimer-selbsthilfe.at/leben-mit-demenz/rechtliches-finanzielle-fragen/
Belgium	Ligue Nationale Alzheimer Liga	https://alzheimer-belgium.be/ Accessed December 14, 2020	
Belgium	Ligue Alzheimer ASBL	https://alzheimer.be/ Accessed December 14, 2020	
Belgium	Alzheimer Liga Vlaanderen	https://www.alzheimerliga.be/nl Accessed December 14, 2020	• https://www.alzheimerliga.be/nl/over-dementie/dementie/beginnende-dementie/werken-aan-de-toekomst-denken-aan-jezelf
Bosnia and Herzegovina	Udruženje AiR	https://www.demencija.org/o-nama/ Accessed December 14, 2020	
Croatia	Alzheimer Croatia	https://alzheimer.hr/ Accessed December 15, 2020	• https://alzheimer.hr/files/8615/1957/0610/Letak_aCROsSLO_HR-web.pdf
Czech Republic	Ceská alzheimerovská spolecnost	http://www.alzheimer.cz/ Accessed December 15, 2020	• http://www.alzheimer.cz/pro-rodinne-pecujici/tipy-pro-pecujici/jak-pecovat-o-nemocneho-v-pokrocilem-stadiu-demence/ • http://www.alzheimer.cz/pro-rodinne-pecujici/pecujte-take-o-sebe/stres-a-co-s-nim/

Denmark	Alzheimerforeningen	https://www.alzheimer.dk/ Accessed December 15, 2020	• https://www.alzheimer.dk/viden-om-demens/behandling-pleje-og-omsorg/pleje-og-omsorg/ • https://www.alzheimer.dk/er-du-paaroerende/den-sidste-fase/
France	France Alzheimer	https://www.francealzheimer.org/ Accessed December 15, 2020	
Germany	Deutsche Alzheimer Gesellschaft	https://www.deutsche-alzheimer.de/ Accessed December 15, 2020	• https://www.deutsche-alzheimer.de/menschen-mit-demenz/rechtliche-fragen.html • https://www.deutsche-alzheimer.de/fileadmin/alz/pdf/empfehlungen/empfehlungen_sterbephase.pdf • https://www.deutsche-alzheimer.de/fileadmin/alz/pdf/factsheets/infoblatt10_vorsorgeverfuegungen_dalzg.pdf • https://www.deutsche-alzheimer.de/fileadmin/alz/pdf/empfehlungen/empfehlungen_medizinische-Behandlung.pdf • https://www.deutsche-alzheimer.de/fileadmin/alz/pdf/factsheets/infoblatt24_palliative_versorgung_dalzg.pdf • https://www.deutsche-alzheimer.de/unser-service/archiv-alzheimer-info/selbstbestimmung-bis-zum-lebensende.html
Ireland	Alzheimer Society of Ireland	https://alzheimer.ie/ Accessed December 16, 2020	• https://alzheimer.ie/wp-content/uploads/2018/11/18055-ASI-PlanForFuture-2018-web_low-res.pdf • https://alzheimer.ie/living-with-dementia/i-am-a-carer-family-member/planning-for-the-future/ • https://alzheimer.ie/living-with-dementia/i-have-dementia/planning-for-the-future/
Jersey	Jersey Alzheimer's Association	https://jerseyalzheimers.com/ Accessed December 16, 2020	

Luxembourg	Association Luxembourg Alzheimer	http://ala.lu/fr/home/ Accessed December 16, 2020	
Malta	Malta Dementia Society	https://sites.google.com/site/maltademenia society/ Accessed December 16, 2020	
Netherlands	Alzheimer Nederland	https://www.alzheimer-nederland.nl/ *All links redirect to https://www.dementie.nl/* platforms belongs to Alzheimer Nederland* Accessed December 17, 2020	• https://www.dementie.nl/een-volmacht-of-levenstestament-regelen • https://www.dementie.nl/wilsbekwaamheid-bij-dementie • https://www.dementie.nl/regeltips-voor-iemand-met-dementie • https://www.dementie.nl/zorgbeslissingen-en-mentorschap-bij-dementie • https://www.dementie.nl/belangrijke-beslissingen-voor-later • https://www.dementie.nl/keuzes-rond-het-levenseinde • https://www.dementie.nl/zorg-rond-het-levenseinde • https://www.dementie.nl/checklist-weet-wat-je-wanneer-moet-regelen-bij-dementie
Norway	Norwegian Health Association	https://nasjonalforeningen.no/ Accessed December 18, 2020	• https://nasjonalforeningen.no/demens/etter-diagnosen/apenhet-og-kunnskap/
Poland	Polish Alzheimer's Association	https://alzheimer-waw.pl/ Accessed December 18, 2020	
Spain	Confederación Española de Alzheimer (CEAFA)	https://www.ceafa.es/es Accessed December 18, 2020	• https://www.ceafa.es/es/el-alzheimer/la-planificacion-en-el-alzheimer-consejos-vitales-legales-y-economicos • https://www.ceafa.es/es/que-comunicamos/publicaciones/estudio-juridico-frl-marco-normativo-integral-para-la-garantia-de-derechos-de-las-personas-afectadas-por-alzheimer-y-otras-demencias%20sent%20did%20not%20match%20the%20inclusion%20criteria

Spain	Fundación Alzheimer España	http://www.alzfae.org/ Accessed December 18, 2020	
Sweden	Alzheimer Sverige	https://www.alzheimersverige.se/ Accessed January 11, 2021	• https://www.alzheimersverige.se/stod-radgivning/lagar-och-rattigheter/framtidsfullmakt/
Sweden	Demensförbundet	https://www.demensforbundet.se/ Accessed January 11, 2021	
Switzerland	Association Alzheimer Suisse	https://www.alzheimer-schweiz.ch/ Accessed January 11, 2021	• https://www.alzheimer-schweiz.ch/fr/les-demences/article/planifier-lavenir/ • https://www.alzheimer-schweiz.ch/fileadmin/dam/Alzheimer_Schweiz/Dokumente/Publikationen-Produkte/IB_163_F_33_Directives_anticipees_2020.pdf • https://www.alzheimer-schweiz.ch/fr/les-demences/article/faire-ses-directives-anticipees-1 • https://www.alzheimer-schweiz.ch/fileadmin/dam/Alzheimer_Schweiz/Dokumente/Publikationen-Produkte/les-droits-et-les-devoirs.pdf
Turkey	Türkiye Alzheimer Dernegi	https://www.alzheimerdernegi.org.tr/ Accessed January 11, 2021	• https://www.alzheimerdernegi.org.tr/adan-zye-alzheimer/#1597602770544-7d9fb609-8017
UK	Alzheimer Scotland	https://www.alzscot.org/ Accessed January 14, 2021	• https://www.alzscot.org/living-with-dementia/end-of-life-care • https://www.alzscot.org/sites/default/files/2020-09/Dementia%20and%20law%20in%20Scotland_January%202020.pdf • https://www.alzscot.org/our-work/dementia-support/information-sheets/getting-to-know-me • https://www.alzscot.org/our-work/dementia-support/information-sheets/powers-of-attorney

			• https://www.alzscot.org/our-work/dementia-support/information-sheets/making-decisions-about-future-treatment
UK	Alzheimer Society	https://www.alzheimers.org.uk/

Accessed January 15, 2021 | • https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-making-decisions#content-start
• https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-psychological-cultural-religious-spiritual-needs#content-start
• https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-place-death#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/dementia-advance-decisions-statements#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/advance-decisions-dementia#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/how-to-make-advance-decision#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/making-sure-people-know-about-advance-decision#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/reviewing-changing-advance-decision#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/advance-decisions-lasting-power-attorney-lpa#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/download-free-template-advance-decision-form#content-start
• https://www.alzheimers.org.uk/get-support/legal-financial/advance-statements-dementia#content-start
• https://www.alzheimers.org.uk/dementia-together-magazine-aprmay-20/something-contribute-feeling-excluded-care-decisions-made
• https://www.alzheimers.org.uk/get-support/daily-living/making-decisions-artificial-feeding
• https://www.alzheimers.org.uk/get-support/daily-living/making-decisions-around-residential-or-nursing-care |

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CHAPTER 3

The perspectives of people with dementia and their supporters on advance care planning: A qualitative study with the European Working Group of People with Dementia

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Abstract

Background: Advance care planning has been defined in an international consensus paper, supported by the European Association for Palliative Care. There are concerns that this definition may not apply to dementia. Moreover, it is not informed by input from people with dementia.

Aim: To gather the perspective of the European Working Group of People with Dementia and their supporters on how advance care planning is defined and develop recommendations for changes to the definition.

Design: An in-depth qualitative study was conducted, analysing online focus groups and interviews using thematic analysis.

Setting/Participants: We included 12 people with dementia and 9 supporters.

Results: Participants suggested several changes to the current advance care planning definition: mentioning people with decreasing decisional capacity; better reflecting the role of family and/or trust-based relationships; reducing focus on end-of-life/medical decisions; strengthening focus on social aspects of care. Elements of the current definition that participants suggested keeping and highlighting include the framing of advance care planning as a continuous process, that is also optional; mention of communication next to documentation of decisions; and the importance of proxy decision makers. Based on this input, we developed three overarching and 16 specific recommendations for a modified definition of advance care planning that is inclusive of people with dementia.

Conclusions: The perspectives of the European Working Group of People with Dementia and their supporters highlighted the need for a person-centred and dementia-inclusive advance care planning definition. We provide tangible recommendations for future adaptations of the definition that reflect these perspectives.

Keywords: Advance care planning, dementia, family caregivers, qualitative study

Key statements

What is already known

- Advance care planning has been defined in an international consensus paper.

- Advance care planning is particularly relevant for people with dementia, however, the definition of advance care planning may not be applicable to them.

- People with the dementia were not involved in the development of current definitions of advance care planning.

What this paper adds

- The existing definition of advance care planning should be adapted to be more inclusive and applicable to people with dementia.

- A more person-centred approach to advance care planning should be highlighted in the definition, which would emphasise discussions of social aspects of care and what matters most in the future.

- The definition of advance care planning should better reflect the role of families or trust-based relationships.

Implications for practice, theory, and policy

- Using a dementia-inclusive and person-centred definition of advance care planning can lead to interventions and policies that better reflect the needs of people with dementia and their supporters.

Introduction

Advance care planning has been advocated as a process that enables individuals to make plans about their future health care[1]. Over the past decades, advance care planning has been increasingly studied and has been defined in multiple ways[1–3]. Originally seen as a documentation-focused process encouraging the completion of advance directive documents, the concept of advance care planning has shifted towards to a broader concept of communication about several aspects of future care and treatment planning[3,4]. Advocates of advance care planning argue that it should be common practice in planning the treatment of patients with all life-limiting illnesses[5].

In a recent international consensus paper, supported by the European Association for Palliative Care, advance care planning was defined as a process that:

> "e*nables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. advance care planning addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions"[2].*

Recommendations for the application of this definition were developed, which deal with aspects such as the readiness of the individual to engage in advance care planning, as well as the content of advance care planning and how to target it depending on the condition[2].

There are several shortcomings in this definition. It requires people to have decisional capacity to engage in the process and can thus not be applied to people who lack decisional capacity[6] such as many people with dementia. The process of advance care planning is however particularly relevant for people with dementia and people close to them, as many people with dementia gradually lose their ability to make informed decisions, verbal communication becomes more difficult, and people close to them play an increasing important role in decision-making[6,7]. Although loss of capacity may occur in many different conditions, especially when nearing end of life, people with dementia are particularly affected due to the extended duration over which capacity can gradually decrease[8]. Several advance care planning interventions for people with dementia have been developed to tackle this, however there is no consensus about what advance care planning for people with dementia should include[9].

The inclusion of people with dementia and people close to them in research is essential to ensure that their needs and perspectives are fully understood and considered in the development of interventions[10]. The definition of advance care planning has been developed mainly based on professional expert recommendations and a small number of patients' relatives with experience of terminal illness and acting as patient representatives. However, people with dementia and their family members were excluded as experts by experience[2]. People with dementia have not been part of the process of describing advance care planning for their group, and more generally, their voices are missing in the scientific developments in this field. Therefore, this research addresses the gap in patient involvement in the work leading to the definition of advance care planning. We aimed to (1) obtain the perspective of a multinational group of people with dementia on how advance care planning is defined, and (2) develop recommendations for changes to the definition of advance care planning based on these perspectives.

Methods

Study design

We conducted an in-depth qualitative study (focus groups and interviews) with a multinational group of people with dementia and people close to them. We used reflexive thematic analysis to explore their perspectives on the definition of advance care planning and to formulate recommendations for the definition of advance care planning.

Participants

Our participants were members of the European Working Group of People with Dementia and their supporters. Members of this group are usually accompanied by a relative, friend, or a member of staff from their national Alzheimer Association, and these individuals are referred to as supporters[11]. This European group is coordinated by Alzheimer Europe and composed of people with dementia who are nominated by their national associations[11]. The working language of the group is English. In the case that members are not English-speaking, their supporter can act as interpreter.

All members of the group and their supporters were invited to participate in the study by email. AD and DG, who are familiar with the working group, were the main point of contact with the participants. The main inclusion criteria were (1) membership of the European Working Group of People with Dementia or being the chosen supporter of one of the members, and (2) participants' expressed willingness and consent to engage in discussions related to advance care planning. All members of the European Working Group of People with Dementia are in the mild to moderate stages of dementia,

and thus should have the capacity to understand what is being asked of them. Participants could have any age, dementia type, length of illness, and comorbidity or could be from any country.

Our study population was limited to the size of the working group. However, we aimed to include this specific group to ensure diversity of perspectives. The European Working Group of People with Dementia is a multinational group with members from varying backgrounds, experiences, and cultural contexts. Furthermore, we used a combination of data collection strategies, i.e. focus groups and follow-up interviews, which allowed us to engage in detailed discussions with all participants. This depth of engagement allowed us to explore the topic thoroughly, ensuring that we obtained rich and nuanced insights.

Data collection

We conducted online focus groups and interviews in English. To support people with dementia during the process and facilitate online participation, we used adapted materials and procedures, which are summarised in Table 1. Supporters played a double role in the process, as they were respondents in both focus groups and interviews, but could also be asked to provide assistance to people with dementia if needed or act as interpreter for not English-speaking participants.

Table 1: Measures to facilitate online participation

Measures	Description of measures
Availability of preparation materials	• Preparation materials, i.e. information sheets presenting the definition of advance care planning and questions that would be addressed during the study, were sent two weeks before the focus group or interview. • All materials were developed considering guidance on how to present materials to people with dementia such as: use of colour, clear wording, page layout, and font size[12,13].
Focus group or interview procedures	• Limitations in terms of time and number of participants: six to eight participants were included per focus groups and focus groups and interviews were limited to 1 hour. • Clear and structured interview-guides with carefully prepared questions and prompts in case people with dementia needed help understanding the questions. • People with dementia could always be accompanied by a supporter to help them if needed. • Time allocated during the focus group/interview to enable participants to reflect on the questions and prepare their answers.

Focus Groups

We conducted three online focus groups in November 2020, which were led by two moderators (LP and LVdB) and an observer (FM), who assisted with technical problems, moderated the chat and took notes. AD and DG were also present as they are familiar with the members of group. We used a semi-structured topic guide and PowerPoint slides to give an overview of the extended definition of advance care planning and present the questions to participants. Specifically, the researchers presented a deconstruction of the definition into the 'what', 'why', 'who', and 'when' of advance care planning (Figure 1), which was used as visual prompt. Participants were asked to reflect on the definition of advance care planning and to what extent it reflected their experiences. They shared their ideas one after the other to ensure fair participation and then discussed their ideas as a group.

What does advance care planning entail?	Why is advance care planning done?	Who is advance care planning for?	When is advance care planning done?
Advance care planning is a process, rather than a one-time event.	So that preferences can be taken into account, should one, at some point, be unable to make one's own decisions	Individuals with decisional capacity	At any stage of life, but advance care planning content can be more targeted as individuals' health conditions worsen or as they age
Identifying values / Discussing with family		Family members	
Reflecting on meanings and consequences of serious illness scenarios / Discussing with healthcare providers		Personal representative (if present)	Advance care planning conversations and documents should be updated regularly as values and preferences might change over time
Defining goals and preferences for future medical treatment and care / Encouraging identification of a personal representative		Healthcare providers	
Addressing concerns in physical, psychological, social, and spiritual domains / Encouraging recording (documenting) preferences / Encouraging regular review of preferences			

Figure 1: Deconstruction of the extended definition of advance care planning

Follow-up interviews

At the end of each focus group, participants were invited to follow-up interviews. The semi-structured interview schedule was guided by the findings of the focus groups. Interviews commenced with a reminder of the definition of advance care planning using Figure 1. The interviewer (FM) invited participants to elaborate on the main three themes that emerged from the focus groups. Interviews were conducted on Zoom between June and July 2021.

Analysis

Audio-recorded focus groups and interviews were transcribed verbatim. De-identified transcripts were coded using thematic analysis, following steps recommended by Braun and Clarke[14], and using NVivo12. Two researchers (FM and CD) first read each transcript thoroughly. The main constructs derived from the existing definition of advance care planning were used as a framework. Next to this, we also used open codes that did not fall within these pre-existing concepts but were reflective of the content resulting from the focus groups and interviews. Both researchers individually coded the data. First, they assigned pre-defined codes and then iteratively assigned preliminary open codes[14,15]. This underwent several rounds of refinement, which included iterative processes of shifting between transcripts and codes while continuously revising the codes. Between these iterations, the researchers met to explore different opinions on the data and finally to agree on a list of codes. Subsequently, our attention turned towards comprehensively interpreting the content as a whole. FM organised the codes into candidate themes and subthemes, reinspected the codes within each theme, and identified recurring topics within the content. Finally, FM named and presented the themes and sub-themes. Following the analysis of the focus groups and interviews, the authors developed a list of recommendations based on these findings.

Ethics

Participants received an information letter and link to an online informed consent form. This process required some adaptations in terms of formulation to make the materials as accessible as possible. Additionally, participants were asked to give verbal consent to recording. The study received ethical approval from the Ethics Review Board of the Brussels University Hospital of the Vrije Universiteit Brussel (BUN: 1432020000199).

Results

The focus groups involved 21 participants, of which 12 were people with dementia and 9 supporters, and were from Ireland, United Kingdom, Germany, Slovenia, Iceland, Sweden, Austria, Belgium and Portugal. Interviews were conducted with 9 people with dementia and 7 supporters. Four people with dementia needed their supporter to act as interpreter. Supporters were partners (n=4), children (n=2), siblings (n=1), or friends/members of a national dementia association (n=3). We identified two themes and nine sub-themes (Figure 2).
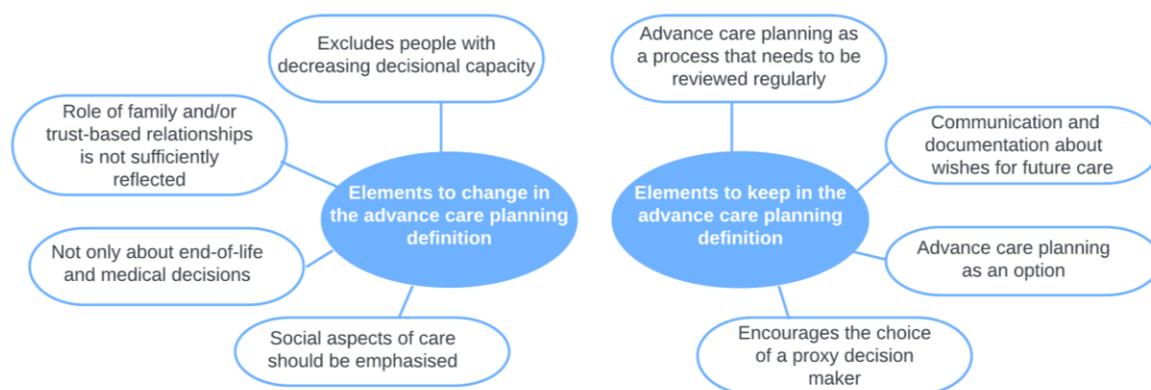
Figure 2: Thematic map of the findings

Elements to change in the advance care planning definition

Several aspects of the definition of advance care planning were highlighted as either missing or not emphasised enough. Participants reflected on elements which they thought should be improved in the definition to better reflect their experiences with advance care planning. This related to who is involved in advance care planning and what advance care planning entails.

Excludes people with decreasing decisional capacity

Participants highlighted that the focus of the current advance care planning definition on individuals with decisional capacity excluded many people with dementia from the process of advance care planning. They noted that decisional capacity is a gradual process and may be dependent on the situation or the person with whom advance care planning conversations are taking place.

> *"I have a friend who lost his communication skills. He stopped talking quite early on in his*
> *dementia. And everybody assumed that because he couldn't talk that he didn't have capacity.*
> *And he still did. He could still read, he could listen, he could think. So you know, you have to*
> *take it all into consideration."*
> *(Person with dementia #1)*

Furthermore, participants discussed strategies to support decisional capacity and involve the person with dementia in advance care planning as long as possible. Decisional capacity was seen as knowing what one wants, knowing what one does, or as understanding questions and consequences of different decisions. Some participants also reflected on the way that decisional capacity is assessed in practice, and advocated for a triangular process to this assessment, involving the person with dementia, a family caregiver, and a health professional.

Role of family and/or trust-based relationships is not sufficiently reflected

Participants reflected on the fact that the definition did not show the importance of families or other trust-based relationships (e.g. friend, neighbour, family of choice) in advance care planning. Many noted that family dynamics may differ among people and that the decision of whom to involve in advance care planning concerned trust-based relationships in general rather than family ties only. Participants found that families or people whom they trust should be involved in advance care planning because of their extensive personal knowledge of the person with dementia.

> *"So it's really important as the disease progresses that the loved ones are involved in their advance care decisions. Because they know their loved ones, they know the person, they know their personality and they know what that person would prefer."*
> *(Supporter #5)*

Participants highlighted that for the sake of clarity, it is of utmost importance that families and people whom they trust are up-to-date concerning the wishes of the person with dementia. Additionally, they also commented on the importance of discussing the potential role of family and people they trust in advance care planning, both in the present and as the condition evolves in the future. People with dementia particularly noted that considering the importance of families or trust-based relationships in the process, support systems are needed to conduct advance care planning conversations and to deal with any potential negative consequences of these conversations, such as emotional burden.

Advance care planning is not only about end-of-life and medical decisions

The members of the group and their supporters perceived an emphasis on medical decisions and end-of-life care within the definition of advance care planning. Although the definition mentions other aspects within advance care planning such as psychological, social or spiritual needs, they noted a stronger emphasis on preferences for medical treatments. Participants also found that emphasis on medical decisions was reflected in their experiences in practice, where the focus was solely on medical treatment decisions and end-of-life care preferences. They emphasised the importance of considering advance care planning as a process that enables them to identify what matters most to them in the future, including but not limited to medical decisions and end-of-life care preferences.

> *"Well, I think when we talk about advance care planning there's a concentration on how we are going to leave this world. Advance care planning to me is how we're going to live in the world as well."*
> *(Person with dementia #3)*

Social aspects of care should be emphasised

Participants found that social aspects of care were of utmost importance within advance care planning, and should be emphasised in the definition. They described social aspects of care as: (1) future daily activities, (2) future psychosocial interventions, (3) place of residence, (4) place of death.

> "When I think about social aspects of care, it could be for example that: my husband is a very social person and he wants to be among people even if he can't contribute in the way somebody without dementia can. You know those types of social aspects. To do all the things he always loved doing. If he was still able to walk, he's always gone walking. It could be seen in a care setting that he is wandering. No he's not wandering, he's always gone out for walks."
> (Supporter #2)

Participants also reflected on the fact that social aspects of care can be difficult to discuss, particularly with health professionals. They noted issues with recording their preferences for these aspects of care, as most advance directives may not provide this option.

Elements to keep in the advance care planning definition

Several aspects of the definition of advance care planning were positively perceived by the participants. Overall, they found that the definition was comprehensive in terms of what the process involved and when it should be done.

Advance care planning as a process that needs to be reviewed regularly

Participants supported the notion that advance care planning should be a process, rather than a one-off event. All emphasised the need to give people with dementia the opportunity to regularly review their advance care planning decisions.

> "It says advance care planning is a process rather than a one-time event. And I agree with that it's extremely important that it is a process and that it is revised regularly."
> (Person with dementia #8)

Some people with dementia also mentioned that in many cases people may not know that they can change their wishes if they want to, and that more effort to raise awareness about the process itself should be made.

Encourages the choice of a proxy decision maker

All participants agreed with the part of the definition dealing with the choice of a proxy decision maker. They mentioned that the proxy decision maker should be a person they trust, and someone who understands the wishes of the person with dementia. Furthermore, they reflected on the difficult role of the proxy decision maker, which includes advocating for the person with dementia and advocating for his/her wishes, as well as coordinating care with families and health professionals according to what is considered in the best interest of the person with dementia.

> " The role of the proxy decision maker is to implement as far as possible the wishes of the person who has made that decision. And it has to be as far as possible. Because you can't always do it. But at least you have an idea, some parameters to go by. You know what they want and you do your best to do that."
> (Supporter #7)

Communication and documentation about wishes for future care

Participants highlighted the importance of: (1) communicating about advance care planning with both families or people they trust, and health professionals; and (2) documenting preferences in advance directives. They reflected that communicating about and documenting advance care planning decisions could give a sense of control to the person with dementia, less burden for the family and people they trust in moments when decisions have to be made, and finally a sense of relief for both parties.

> "[In the context of moving to a care facility] That's going to be a tough day for me and that's going to be a tough day for them. But they will know, if it's done early enough, that this is what I've asked for and this is what I want."
> (Person with dementia #1)

Advance care planning as an option

Both people with dementia and supporters highlighted that advance care planning should remain optional, and that if the person with dementia did not wish to discuss it, they should be free not to. Furthermore, many noted that the advance care planning process should be conducted at the pace of the person with dementia, and that they should be able to stop whenever they wish to. Some also mentioned that ideally, advance care planning should be conducted as early as possible after, if not before, diagnosis.

"As family, you can encourage, gently encourage and use some gentle persuasion to say it is for your best to discuss it. But some people with dementia are hard nuts to crack and so stubborn. So if they won't, you cannot force them."
(Supporter #3)

Recommendations

Table 2 summarises recommendations for the definition of advance care planning derived from the input of the European Working Group of People with Dementia and their supporters. They range from the need for a dementia-inclusive definition, elements from the current definition that should remain, to elements that should be adapted or stressed.

Table 2: Recommendations for the advance care planning definition, comparison to the current extended definition, example quotes

Recommendations	Comparison to the extended definition[2]	Example quotes
1. The current definition of advance care planning should be adapted in a way that is dementia-inclusive. A separate definition for people with dementia is not needed, but the current one should be adapted to be inclusive. More specifically:	The European Working Group of People with Dementia noted that currently the definition of advance care planning excludes many people with dementia, as its focus is solely on "individuals who have decisional capacity".	
Advance care planning should be accessible and inclusive to all, including people with diminishing decisional capacity.		"So I think that that needs to be taken into consideration, but to be honest with you, I think a generic definition with smaller changes for our needs is all that is required because we're no different." (person with dementia #2)
Loss of decisional capacity is a gradual process and may be situation- or task-specific, and should therefore not be seen as a 'black and white' event that excludes people from taking part in advance care planning.		"Well we think that yes somebody can become very advanced in their dementia, but they still may be able to make an informed decision with the correct support of somebody who knows them well, or the health care practitioner. So just because somebody has reached a certain stage, we mustn't forget that they may still be able this kind of… If they can't make

		the decision, at least give us some hmm input as to how they feel about it." (dyad – person with dementia #4 and supporter #4)
Clear strategies to assess the level of capacity of a person should be put into place, adopting a triangular process involving the person, the family caregiver, and health professionals.		"We have to invite them every time there is a decision made. We have to invite them for their opinions and their thoughts. The fact that they may not be able to articulate to our level, then that's our fault. We need to facilitate as best we can that they understand the question being asked and that they elicit the answer that they want to give us. Not the answer that we want it to be." (supporter #6)
2. Several elements of the current extended definition of advance care planning have been identified and stressed by the European Working Group of People with Dementia as important for advance care planning in the context of dementia, and therefore should remain and be highlighted in a dementia-inclusive definition. They relate to the goals, content, and timing of advance care planning:	These elements are currently already present in the extended definition of advance care planning or its accompanying recommendations and were stressed as particularly important. Excerpts from the extended definition that relate to the recommendations made by the EWPWD:	

a. Advance care planning should encourage communication and documentation of decisions about preferences for future care and treatment, but should not be limited to the completion of advance directives.	"[…] to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers […] and to record and regularly review."	"For her it is important that this topic is sufficiently talked about in the family. And whether the family knows the person, in this case her, well enough. And she is aware that this depends on her, that she has to talk about it now with her family and the people who support her." (person with dementia #12)
b. Advance care planning can involve the identification and appointment of a proxy decision maker, whose role is to advocate for the person with dementia, implement their preferences for future care, and be involved in the coordination of their care in the event that the person with dementia cannot do so themselves.	"[…] It encourages individuals to identify a personal representative […]"	"But there may be the odd one or two who may have motives of their own. And that's the point of the proxy. It's always important to appoint a strong advocate. Because the job is so difficult." (supporter #1)
c. People with dementia should be given the opportunity and be encouraged to regularly review previous choices and wishes stated as part of the advance care planning process.	"[…]and regularly review any preferences."	"advance care planning lifts a weight from your shoulders, because I'm not afraid to die. I don't want to but I'm not afraid to. It's the manner in which you die that concerns me. I'm terrified absolutely that I'll end up on the sidewalk somewhere and of just fading away. And so I've got advance directives in place. I've

		got a proxy to make sure that these happen and we review them regularly, yearly almost" (person with dementia #3)
d. Advance care planning should ideally be initiated early; at a time where the person is healthy or at least as soon as possible after a dementia diagnosis.	Recommendation 19: "Individuals can engage in advance care planning in any stage of life but its content can be more targeted as their health condition worsens or as they age."	"The problem with the whole thing around advance care planning and the whole thing about capacity is that usually these questions are asked too late." (supporter #2)
e. The advance care planning process should be conducted at the pace of the person with dementia, according to their readiness to discuss and engage in advance care planning.	Recommendation 2: "Advance care planning should be adapted to the individual's readiness to engage in the advance care planning process".	"But if you don't want to talk about it, then that's fine! Absolutely fine. Nobody should be forced to put advance directives in place." (person with dementia #10)
3. Several elements of the current extended definition of advance care planning should be adapted to better reflect the experiences and perspectives of people with dementia and their family caregivers in the context of advance care planning. They relate to the content of advance	These elements are currently either missing from the extended definition of advance care planning or its accompanying recommendations, or are part of the definition/ recommendations but are not stressed or elaborate enough. Excerpts that are concerned:	

care planning, as well as the people involved in the advance care planning process and their roles:

a. Advance care planning should be a communication process about what matters most to the person with dementia in addition to their values and preferences for their future care and medical treatment.	"identify their values, […], to define goals and preferences for future medical treatment and care, and to discuss these." The notion of what matters most to the individual is lacking from the definition.	"She wants to go out in the fresh air, also if she cannot walk anymore. Then somebody should bring her out in the garden. And she can hear the birds twittering and feel the sun on her body or her face and she can smell the flowers and… yeah it is very important for her to be close to the nature and in the fresh air. And sometimes she says she wants to have her cake every day. Also, if the parameters in her blood speak for it, she still wants it. And she would like that somebody comes and takes her hand and gives her a hand massage, and things like that." (person with dementia #8)
b. Advance care planning should focus on preferences for how people with dementia want to live with dementia, including but not limited to medical treatments or end-of-life care.	"identify their values, […], to define goals and preferences for future medical treatment and care, and to discuss these." The notion of preferences for the future life is missing from the definition.	"I think that these are such important issues but the difficulty is that people recognise advance care planning as a death contract, but it's not. It's how you want to be treated from the day of diagnosis. What pathways you want to go through, what steps you want to take." (person with dementia #1)

c. While eliciting preferences for future care and medical treatment is important, a stronger emphasis is needed on social aspects of care such as wishes for meaningful future daily activities, choice of place of residence/care and place of death, and wishes for future psychosocial interventions.

"[…]. Advance care planning addresses individuals' concerns across the physical, psychological, social, and spiritual domains." The social aspects of care were found to be particularly important and should be further highlighted in the definition.

"So I mean I am more for the natural things. You know I'm at peace when I'm at home. I'm at peace when I am surrounded in nature and I want to die peacefully." (person with dementia #6)

d. People with dementia should be able to discuss their wishes and preferences concerning social aspects of care with families and health professionals as part of advance care planning. Measures should be put in place to ensure that arrangements for social aspects of care are put in place for as long as possible in the dementia trajectory.

"[…]. Advance care planning addresses individuals' concerns across the physical, psychological, social, and spiritual domains." The social aspects of care were found to be particularly important and should be further highlighted in the definition.

"So if there is really a cut, like it is necessary to go into a nursing home, then we have already decided for one which is really next to our apartment that we have currently and then there should be a good possibility to still communicate and so we have foreseen some things like that. So it's not far away from where we live right now and so there is also the benefit that I know the region and maybe I don't get so easily lost in the case that I walk alone and things like that." (person with dementia #7)

e.	Advance care planning should be embedded within a broader person-centred care planning approach to enable people with dementia to discuss social aspects of care with their health professionals and document related wishes.	"[…] Advance care planning addresses individuals' concerns across the physical, psychological, social, and spiritual domains." The social aspects of care were found to be particularly important and should be further highlighted in the definition.	"these medical things you can write down in a directive. But the social things are very difficult to include, they are necessary of course, but it is difficult the way it is now." (supporter #1)
f.	The role of family in advance care planning may depend on family dynamics, hence the involvement of families in advance care planning should be flexible and in line with the wishes of the person with dementia. Families might be involved from the start of the advance care planning or asked to step in later in the process when capacity starts to decline. Roles might vary and range from being involved in the decision-making process, supporting the person with dementia in their decisions, or ensuring that the decisions of the person with dementia can be implemented.	"[…] discuss these with family and health-care providers." Family involvement and the role of family should be more explicit and elaborated on in the definition.	"Well you know my family knows me better than anybody else. And they also know the old me. And I think that's really important. Hopefully they can support me in my decisions. There is always the more unscrupulous members of some families, but you've got to put your trust in someone you know." (person with dementia #5)

g.	The essential role of trust-based relationships in advance care planning and the choice of a proxy decision-maker in the context of dementia should be emphasised. This implies that people of trust have personal knowledge of the person with dementia and can be relied upon to respect their wishes. Trust-based relationships may include family members such as partners, children, parents, or relatives, but also other people close to them such as friends.	"[…] discuss these with family and health-care providers." More than familial ties, trust-based relationships were valued in the advance care planning process and the choice of proxy decision-maker, and thus should be added to the definition.	"the most important persons are family. But also people who know me well and who accompanied me for a longer time before. It is very important that there is trust." (person with dementia #1)
h.	Support systems should be put in place for people with dementia and their families or people close to them to have advance care planning conversations and deal with any issues that may arise such as: emotional difficulties with the topic, difficulties to understand the wishes of the person with dementia, unwillingness of one of the parties to discuss advance care planning, or familial conflicts.	"[…] to discuss these with family and health-care providers." In addition to discussing advance care planning with family and health-care providers, people may need additional support in engaging in advance care planning.	"But it should be something that is offered. I like the idea of maybe somebody coming independently in and negotiating with the family. Because sometimes it can be very difficult for a wife or a son or daughter or husband to hear: please, if something happens, don't resuscitate me." (supporter #7)

Discussion

Main findings

Our study reports the perspectives of the European Working Group of People with Dementia and their supporters on the extended definition of advance care planning and makes recommendations based on their input. They expressed support for several aspects of the current definition that they considered essential, such as advance care planning being a *process* that is reviewed regularly and that is optional. Participants also agreed that advance care planning should encourage communication and documentation of decisions about future care, and should not be limited to the completion of advance directives. The European Working Group of People with Dementia also made important and tangible suggestions for changes to the current definition of advance care planning. They highlighted the need for the definition to include people with declining decisional capacity, better reflect the role of families or trust-based relationships, and better address social aspects of care.

A central point raised by the group is the need for a dementia-inclusive definition of advance care planning. Dementia introduces specific challenges compared to other serious illnesses, such as the gradual - although fluctuating - loss of decisional capacity. However, advance care planning should be applicable to all regardless of their condition. Our participants highlighted that the main aspect excluding them in the current definition was the clear focus on people with decisional capacity only. At the same time, they emphasised that there is no need for a separate definition for people with dementia. Instead, the existing definition of advance care planning should be adapted to be more inclusive of people with dementia and applicable to people with or without conditions that influence cognitive capacities. This is consistent with the work of Alzheimer Europe calling for inclusive research and the ethical involvement of people with dementia[16]. Other approaches have also advocated for dementia-inclusive research, such as dementia-friendly communities, which aim to ensure that people with dementia are entitled to equal opportunities in all aspects of life as well as equal access to care[17].

Participants strongly emphasised the role of families and trust-based relationships in the advance care planning process, which they found to be under-addressed in the definition of advance care planning. Families or others one trusts are generally considered to have personal knowledge of the person with dementia, and they are often an important point of contact in communication and decision-making in the later stages of dementia. Our study suggests that the involvement of others should be flexible in terms of timing and extent of involvement. The importance of families and trust-based relationships contrasts with traditional conceptualisations of advance care planning or decision-making that are framed in highly individualised terms[18]. Our findings highlight the need for a more relational approach

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to advance care planning, but also emphasises that the person with dementia should be able to choose how others get involved.

Another clear point made by our participants was the importance of social aspects of care within advance care planning. Participants felt that the definition of advance care planning currently focuses too much on medical care, while it should include broader conversations on what matters to people in the future, on social care, and on future meaningful daily life activities. These perspectives reflect current debates about conceptualisations of advance care planning. In past conceptualisations of advance care planning, significant emphasis was placed on the written preparation process, which involves creating documents to specify end-of-life treatment preferences, as well as designating a proxy decision maker[19]. Under the impulse of public health approaches to care in the last phase of life, advance care planning has evolved to a broader concept of an iterative communication process between the person concerned, people close to him/her and health professionals, about future care and what matters most[3,4,19,20]. However, our participants highlighted that this evolution is not reflected enough in the definition nor in practice. Our study provides further support for discussion about what matters most for the future as part of advance care planning. It calls for a more person-centred care planning approach to advance care planning and for the corresponding changes in its definition.

Strengths and limitations

This study filled an important gap in the involvement of people with dementia and their supporters in the work leading to the definition of advance care planning. This inclusive approach helps to ensure that the perspectives of people with dementia and their supporters are considered in the definition of advance care planning. Our study enriches the palliative care practice by shedding light on the specific needs and perspectives of people with dementia and their supporters in the context of defining advance care planning. We advocate for a more inclusive, holistic, and person-centred approach that is sensitive to the unique challenges presented by dementia and provide practical guidance for adapting the definition of advance care planning. The use of a dementia-inclusive definition of advance care planning in practice could lead to interventions and policies that better reflect the needs of people with dementia and their supporters and that are more acceptable to them. Our study is also a successful example of meaningful involvement of people with dementia as participants in qualitative research. It demonstrates that this group can meaningfully participate in online focus groups and interviews. Furthermore, while interviews and focus groups were not conducted in the mother tongue of most participants, our approach allowed individuals who were not fluent in English or who felt more confident expressing themselves in their native language to actively contribute. This was made possible through the presence of their supporters who were fluent in both the native language and

English and acted as trusted interpreters. This approach enhanced the quality and richness of the data collected, ensuring that the perspectives of participants who might have otherwise been excluded due to language barriers were effectively captured in our study. This study also has several limitations. The participants are members of an European advisory group, and tend to be rather politically and socially active, which may not reflect the whole of the population of people with dementia. Our study should be replicated in other populations to increase the diversity of the perspectives presented in this paper. Furthermore, it should be noted that not all participants in the focus groups took part in the follow-up interviews, which also may limit the diversity of perspectives in our study.

Conclusion

The perspectives of the European Working Group of People with Dementia emerging from our study contribute to the understanding of advance care planning in dementia and highlight the need for a dementia-inclusive advance care planning definition. Participants stressed important aspects of the current definition of advance care planning such as the description of advance care planning as an optional process that focuses on both communication and documentation and that needs to be reviewed regularly. Our participants highlight several aspects of the definition of advance care planning which should be changed or addressed in more depth, among which are the issues of decisional capacity, family involvement and social aspects of care. We provide tangible recommendations for an adapted definition of advance care planning in line with the perspectives of people with dementia and their supporters.

Supplementary materials

Appendix 1: Focus group topic guide

Appendix 2: Interview topic guide

Author contributions

Study concept and design: Monnet, Pivodic, Diaz, Gove, Van den Block. Recruitment of respondents: Diaz, Gove. Acquisition of data: Monnet, Pivodic, Van den Block. Transcribing: Monnet. Analysis and interpretation of data: Monnet, Dupont. Drafting the manuscript: Monnet. Critical revision of the manuscript: Diaz, Gove, Dupont, Pivodic, Van den Block.

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Supplementary materials of Chapter 3

Appendix 1: Focus group topic guide

Welcome
Ask permission to record
Introduction to the study and instructions for the session
1st question *Show the definition on a slide, and go through it slowly with the participants.* *Show the figure and go through the WHAT, WHY, WHO, and WHEN.* Based on this definition, please consider the following question: • From your own perspective (person with dementia or significant other), does this definition reflect your own experiences or needs for ACP? ○ Would you change anything? Please consider the different categories (WHAT, WHY, WHO and WHEN) when thinking about your answer. ○ Are there any important elements missing? ○ What would you stress/emphasise in the definition? ○ What would you say is particularly important for dementia?
Silent generation of ideas and rounds of answer
Discussion *If the moderator notices that overlapping ideas are mentioned: repeat, reformulate the idea and ask for confirmation* *If the moderator notices that a unique idea is mentioned: ask whether others agree* *In this discussion round, the moderator should really focus on things that haven't been said before. Using the boxes of the visual representations, check that all categories (WHAT, WHY, WHO, WHEN) and all topics have been addressed by the participants.*
2nd question • From your own perspective (as a person with dementia or as a significant other), what do you think about the wording and format? Would you change any of the wording/terms used?
Silent generation of ideas, followed by rounds of answer
Discussion *If the moderator notices that overlapping ideas are mentioned: repeat, reformulate the idea and ask for confirmation and if needed to extend on the idea.* *If the moderator notices that a unique idea is mentioned: ask whether others agree, why or why not*
Conclusion

Appendix 2: Interview topic guide

Welcome
Ask permission to record
Introduction to the study
Decision-making capacity • What does decision-making capacity mean to you in the context of having dementia and thinking about current and future care? • How can we involve people with different levels of decision-making capacity in advance care planning? • What is the role of family members in supporting decision-making in the context of advance care planning?

Family
• General question: In your opinion, what can the role of family be in advance care planning? Who could be involved, when, and how much?
    o Personal prompt: Who would you ideally involve in advance care planning? Who would you not involve?
• General question: What are the main benefits and the main challenges of involving family members in advance care planning?
    o Personal prompt: What difficulties did you encounter when talking with family about advance care planning?
    o Personal prompt: What did you find easy when talking with family about advance care planning?
• What should be taken into account when choosing a legal representative (or proxy decision maker)? What would you say is his/her role in advance care planning?
    o How would you choose a legal representative (or proxy decision maker)?

Content and context: social aspects of advance care planning
• General question: What are the social aspects of advance care planning that should be considered?
    o Personal prompt: What social aspects of advance care planning would be important to you? (give examples)
• General question: Should a person who discusses advance care planning with their health professional also discuss social aspects? If yes, how could this be done?
    o Personal prompt: If you were to discuss advance care planning with a health professional, would you wish to discuss social aspects? If yes, how would you do this?

Conclusion

– PART III –

DEVELOPMENT AND TESTING OF AN ADVANCE CARE PLANNING SUPPORT WEBSITE FOR PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

CHAPTER 4

An advance care planning website for people with dementia and their family caregivers: Protocol for a development and usability study

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Abstract

Background: Web-based tools for people with dementia and their family caregivers have considerably increased over the years and offer promising solutions to several unmet needs. The use of web-based tools in the field of advance care planning (ACP) for people with dementia and their family caregivers has yet to be explored and requires careful consideration given the sensitive topic and the specific needs of people with dementia and their families. This paper reports the protocol for a study aiming to develop and simultaneously test the usability of an ACP website designed for, and with, people with dementia and their families.

Methods: The development of the website is based on a process map for the development of web-based decision support interventions and on the Medical Research Council (MRC) framework for complex intervention development and evaluation. We apply a user-centred approach in combination with patient and public involvement (PPI) throughout the development process. Participants and a PPI group give feedback on four prototypes of the ACP website. For each iteration, we aim to include 12 participants (3 people with dementia, 3 family caregivers and 3 dyads) in usability testing. In the first three iterations, usability testing includes: (i) a think-aloud exercise; (ii) researcher observations and (iii) the System Usability Scale (SUS) questionnaire. The last iteration of usability testing is composed of a semi-structured interview assessing layout, content, face validity and readability. Qualitative data from the think-aloud exercises and interviews is analysed using thematic analysis. Mean scores are calculated for the SUS questionnaire.

Results: This study received approval from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel. Recruitment began in October 2021.

Conclusions: This protocol describes a feasible and inclusive approach to the development of an ACP website together with people with dementia, their family caregivers and other stakeholders. We provide a clear overview of how to combine of PPI input and user-centred development methods, leading to a transparent and reliable development process. This protocol might stimulate active participation of people with dementia, their caregivers, and regional stakeholders in future studies on web-based technologies. The results of this study will be used to refine the design and create a relevant and user-friendly ACP website that is ready to be tested in a larger evaluation study.

Keywords: Advance care planning, people with dementia, technology, development, usability testing

Introduction

Background

Web-based tools for people with dementia have considerably increased over the years and offer promising solutions to several unmet needs[1,2]. Many web-based tools have targeted different needs of people with dementia by, among others, supporting self-care in daily life, facilitating treatment delivery, or facilitating communication[3]. Further, many people with dementia are enthusiastic and positive about using technologies to facilitate their independence[4]. However, the use of web-based tools in the field of advance care planning (ACP) for people with dementia has yet to be explored. To the best of our knowledge, no web-based ACP tool has been developed for people with dementia.

ACP has been defined as an ongoing process that enables individuals to explore and identify their values, reflect upon the meanings and consequences of serious illness scenarios, and define goals and preferences for future care and medical treatment[5,6]. ACP encourages people to discuss these preferences with family and healthcare providers, to appoint a proxy decision-maker and to record these preferences and choices[5,6]. We adopt a public health approach to ACP. This approach originated from an ongoing shift in the ACP concept; going from a clinician-led and documentation-focused process that highlights the need of advance directives, to a broader concept of ongoing communication between patients, family, and health care providers about several aspects of future care and treatment planning[7,8]. The public health approach to ACP highlights the need to normalise and reconfigure the way decisions are made by reframing ACP as a health promoting activity through public education and engagement. Underlying this approach is the need to have conversations about end-of-life preferences, death, and dying not only within a medical context (between patients and healthcare providers) but also within the family context.

Considering the progressive decline in cognitive and functional abilities associated with dementia, ACP can be particularly relevant for people living with dementia, as they become more vulnerable and more dependent on others throughout the disease trajectory[9,10]. Yet, research has shown that ACP is not a widespread practice among people with dementia[11]. People living with dementia and their families are often not well informed about ACP, as they might not be aware of ACP at all or there might be many uncertainties concerning this complex topic which can be due to a lack of familiarity with the process or with the specific content of ACP[12–14]. Talking about ACP has been found to be complicated as people with dementia and their families experience tensions and perceive this as emotionally difficult conversations[15]. Moreover, people with dementia have quite specific needs in terms of ACP compared to other illnesses. They have a need for a clear understanding of the dementia disease trajectory and what ACP can achieve or not[14]. Furthermore, the more the disease advances and

cognition declines (in a non-linear gradual way), the more family plays a crucial role in ACP in this population[16]. As their condition evolves, many people with dementia may require a surrogate decision-maker or legal representative[17].

In other patient groups than dementia, many ACP tools have been developed that are not web-based, such as trainings for professionals or documentation booklets. These have generally aimed to facilitate engagement in ACP discussions by helping patients and family caregivers in reflecting about and/or making decisions for future care and treatment in coordination with healthcare professionals[18]. However, web-based tools can have many advantages over paper-and-pencil or face-to-face tools. Web-based ACP tools can be accessed online at any preferred time and place, can be used at everyone's on pace, with or without the presence of a healthcare professional or family caregiver, and can reach a larger audience[19]. Additionally, one of the most important features of web-based tools is the use of interactive elements allowing tailoring to the specific needs and preferences of individuals, which seems particularly relevant for dementia[20]. A recent systematic review identified 10 existing web-based ACP tools published in international peer-reviewed literature. However, they were mostly developed in and limited to the United States[21]. None were designed for people with dementia or tested with people with dementia, despite the specific needs of this population.

Objectives

In this paper, we describe the protocol of a study that aims to develop and test the usability of an ACP website especially designed for, and with, people with dementia and their families. Furthermore, the website should be user-friendly, interactive, and accessible at any preferred time, so that people with dementia and family caregivers can use the ACP website at their own pace and within the family context.

Study design and methods

Development overview

The methods for the development of the ACP website are based on a process map for the development of web-based decision support interventions for a specific audience proposed by Elwyn and colleagues[22], and follows the Medical Research Council (MRC) framework for the development of complex interventions[23]. Given the complexity of the intervention, combining these approaches is warranted for the development of a website that is both evidence- and theory-informed.

This study focuses on the development stage of the MRC framework for the development of complex interventions[24]. Within the development stage of the MRC framework, we use the process map for the development of web-based decision support interventions, which provides a clear development approach for digital interventions especially. It is composed of main steps such as (1) content specification, with an emphasis on considering patients' perspectives in addition to synthesising the current scientific evidence; and (2) creative design, including storyboarding and field and usability testing[22]. Furthermore, as recommended in the MRC framework, we build in theory and integrate continuous stakeholder engagement. Thus, in a first content specification phase, we specify the information that should be included in the ACP website by identifying relevant existing evidence, and conducting needs assessments among people with dementia, family caregivers and dementia experts. In a second creative design phase, prototypes of the ACP website are developed and revised in several iterations.

User-centred design and Public and Patient Involvement (PPI)

In all phases of the development process, we incorporate user views as recommended in recent literature reviews on development of technological interventions[4,25]. We adopt a user-centred approach throughout the development of the ACP website. User-centred design is a recognised method for complex intervention development[23] and is an evidence-based approach that emphasises the importance of the needs of end-users during the development[26]. Additionally, as advocated by Alzheimer Europe, we integrate meaningful PPI consultation sessions at different stages of the development process to enhance the quality and relevance of the ACP website[27]. PPI sessions are conducted with an advisory group composed of people with dementia, family caregivers, representatives from local dementia associations, and palliative care experts (nurse and consultant for ACP). This group is consulted throughout the development process, in parallel to user-testing with study participants, through online meetings and emails.

Stakeholder groups involved in the development process

The development of the ACP website is supported by four groups as suggested by Elwyn and colleagues[22]: a project management group (composed of: FM, CD, LVdB, LP, TS), a project group (composed of all authors of this paper), an advisory group (a PPI group composed of representatives of regional dementia and palliative care organisations and experts in Flanders, people with dementia, and family caregivers) and a technical production group (contracted IT partner). Figure 1 gives an overview of each groups' responsibilities.
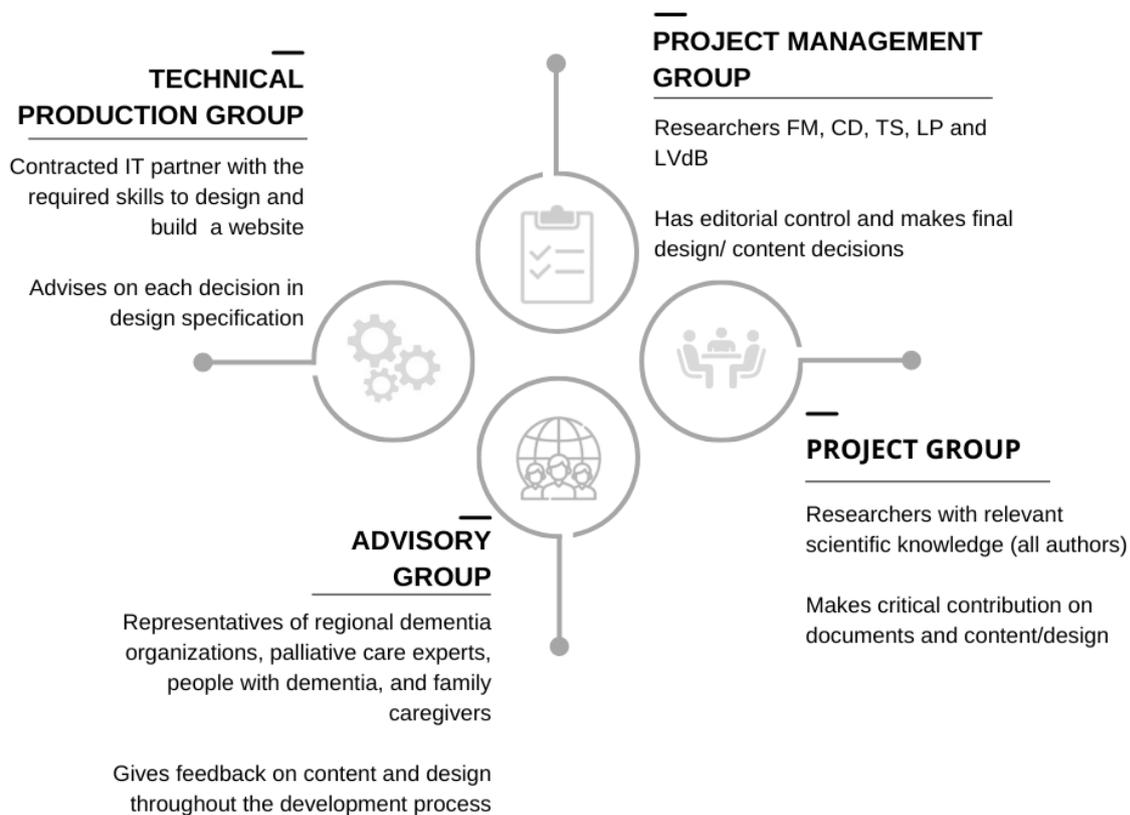
TECHNICAL PRODUCTION GROUP

Contracted IT partner with the required skills to design and build a website

Advises on each decision in design specification

PROJECT MANAGEMENT GROUP

Researchers FM, CD, TS, LP and LVdB

Has editorial control and makes final design/ content decisions

ADVISORY GROUP

Representatives of regional dementia organizations, palliative care experts, people with dementia, and family caregivers

Gives feedback on content and design throughout the development process

PROJECT GROUP

Researchers with relevant scientific knowledge (all authors)

Makes critical contribution on documents and content/design

Figure 1: Overview of the stakeholder groups involved in the development process

Content specification phase of the ACP website

In this phase, we specify the information that should be included in the ACP website by identifying relevant existing evidence, and conducting needs assessments among people with dementia, family caregivers and dementia experts. An overview of the activities conducted in this phase and their main output is presented in Figure 2. Results from the research activities in the content specification phase are reported separately[28–30]. In this content specification phase, we summarise the evidence from these activities to ensure the content and structure of the website is in line with previous research on web-based ACP tool, the information already provided online by dementia associations, and the needs expressed by people with dementia and their families for ACP and an ACP website, as well as with the opinion of experts in the field.

Creative design phase of the ACP website

Results from the content specification phase inform the design phase of the ACP website. The findings from the evidence base and the user needs assessment are used to build a first concept of the website. An overview of the study, its aims, and all involved groups is shown in Figure 2.
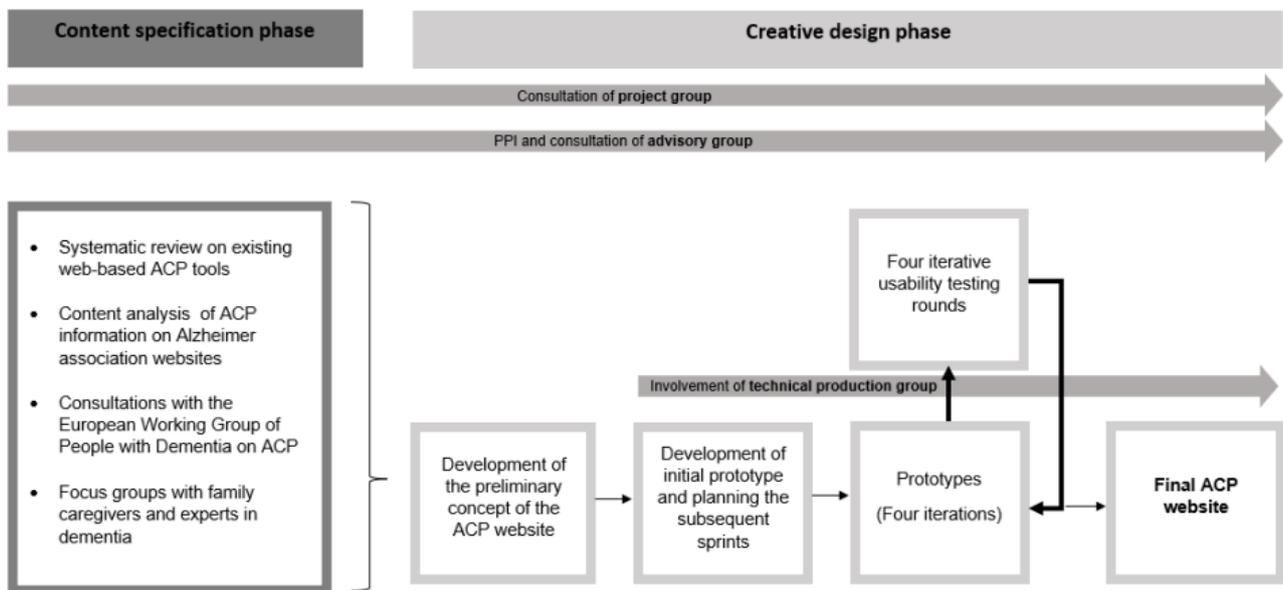

Figure 2: Overview of the development process and usability testing of the ACP website

We adopt an agile development approach to build the ACP website. This approach is characterised by an iterative and dynamic development process while collaborating with several groups of stakeholders. It is based on the principles of continuous design improvement and testing based on rapid feedback and change and allows for a high-quality adaptive software[31,32]. Such an approach is thus in line with a user-centred approach. Within the agile development approach, we use the Scrum method, as it particularly emphasises the role of feedback loops. The core characteristic of the Scrum method is the sprint, which is a short development timeframe of approximately four weeks[33]. Each sprint requires careful preparation from recruitment of participants to meetings with the advisory group and the technical production group. Based on the complexity of website development and previous work using a Scrum in the development of health-related interventions[34], we estimate that the development of the ACP website will be conducted in five successive stages, including four sprints. An overview of the sprints is shown in Table 1.

Table 1: Overview of the sprints executed during the iterative development process

Sprints	Objective	Content	User-testing	
			Data collection	Participants (N)
Pre-sprint	Development of the first prototype	- Development of initial prototype - Planning of the subsequent sprints	Feedback from advisory group and project group	N/A
Sprint 1	Evaluate the usability of the first three features	Usability testing of the homepage, structure of the website	Think aloud method Survey Feedback from advisory group.	12 participants (3 people with dementia, 3 family caregivers and 3 dyads)
Sprint 2	Evaluate usability of the following three features	Usability testing of the informational part of the website	Think aloud method Survey Feedback from advisory group and project group	12 participants (3 people with dementia, 3 family caregivers and 3 dyads)
Sprint 3	Evaluate usability of the remaining features	Usability testing of the communication part of the website and the interactive tools	Think aloud method Survey Feedback from advisory group and project group	12 participants (3 people with dementia, 3 family caregivers and 3 dyads)
Sprint 4	Test the content, face validity and readability of the tool, its lay-out and ease-of-use	Content, face validity and readability of whole website	Semi-structured interviews Feedback from advisory group and project group	12 participants (3 people with dementia, 3 family caregivers and 3 dyads)

In the pre-sprint, the project management group summarises and synthetises the evidence found in the content specification phase. Then, the preliminary concept of the ACP website is discussed in a meeting with the advisory group. The project management group drafts a specification document based on the evidence synthesis and the discussions of the advisory group. Based on this specification document, the technical production group develops the first prototype of the ACP website.

Usability testing

We follow the definition of the International Organisation for Standardisation (ISO) of usability (ISO 9241-11) i.e. "how well users can learn and use a product to achieve their goals and how satisfied they are with that process"[35]. This includes the evaluation of the ease of learning, efficiency of use, memorability, error frequency, and satisfaction[36].

People with dementia, family caregivers, and dyads evaluate several versions of the prototype of the ACP website. Based on their input as well as feedback from the advisory group, the technical production group adapts and extends the tool in several iterations (sprints). After three usability sprints (sprints 1 to 3), the latest prototype of the ACP website is evaluated by people living with dementia, their main family caregivers and dyads in terms of content, face validity, readability, and its lay-out (sprint 4). The findings are used to develop the final prototype of the ACP website. An overview of the usability testing is provided in Table 2. The following sections explain the procedure in more details.

Participants

We aim to include 48 participants in total. We organise the testing with people with dementia, family caregivers, and dyads. For each iteration (sprint) we aim to include 12 participants (3 people with dementia, 3 family caregivers and 3 dyads), who are asked to test the prototype and fill in the SUS questionnaire. For every sprint, we seek to enrol new participants. For people with dementia, the inclusion criteria were:

- Being aware and informed of their diagnosis;
- Having an interest in and being willing to test an ACP website (including using a computer and internet)
- Speaking and understanding Dutch
- Being able to understand the information about the study;
- Being able to sign a written informed consent form

For family caregivers, the inclusion criteria were as follows:

- Being the main or primary caregiver of a person formally diagnosed with dementia;
- Having an interest in and being willing to test a web-based ACP tool;
- Being 18 years of age or older
- Speaking and understanding Dutch

Recruitment

We ask participants to use a computer and the internet, which can be challenging as one needs to have a certain level of computer-literacy. The topic of ACP can also be sensitive and can evoke emotional reactions. Therefore, we use a process of active volunteering in our recruitment, i.e. potential participants have to indicate themselves if they want to participate in the study. Thus, it is a self-assessment of willingness to participate and interest in the topic.

We recruit participants through different organisations such as the Flemish Alzheimer Liga, memory clinics, or Belgian sickness funds. Individuals who are interested in participating are asked to contact one of the researchers, who in turn sends an information letter and an informed consent form about the study through email. Potential participants are asked to reply to the email or send back the forms if they still want to participate in the study after reading the study information letter and informed consent.

Data collection

Sprints 1 to 3

The usability tests are conducted in individual sessions with people with dementia, family caregivers and dyads. Each session is conducted according to a pretested protocol, in the following order: (i) a think-aloud exercise on a set of predefined tasks[37]; (ii) researcher observations and (iii) a usability questionnaire. The aim of combining these methods is to gather more diverse data. The same type of sessions are performed with the participants in the sprints 1 to 3. The sessions are conducted in a familiar setting, for instance the location where they are recruited or in the homes of the participants.

First, we ask the participants to fill in a demographics' questionnaire. We give them tasks and oral instructions on how to go through the features of the ACP website prototype. People with dementia, their family caregivers, and the dyads are asked to navigate through each prototype version using a "think aloud" method. This involves asking participants to verbalise their thoughts, impressions and feelings whilst engaging with the tool. A researcher is present to observe and note the participants' physical cues, successes in tasks, mistakes, difficulties, or comments[37]. Guidance or interference from the researcher is kept to a minimum to investigate whether the ACP website prototype is intuitive. However, if the participants fall silent for too long (e.g. if the researcher notices that a participant has silently moved on to a new task or is experiencing difficulties without expressing them), the researcher reminds them to keep thinking aloud using prompts[37].

In addition, participants' perspectives on usability are further assessed through the System Usability Scale (SUS) questionnaire[38]. The SUS is a widely used and a simple, reliable and validated 10-item scale that measures subjective usability, and that has already been used by people with dementia (37,38). The SUS score measures users' perception of the usability of the prototype in terms of effectiveness, efficiency, and satisfaction. Each item is scored on a 5-point Likert scale (strongly disagree = 1, strongly agree = 5). Higher scores (range = 0-100) represent better usability[38].

Sprint 4

We ask all participants to fill in a demographics' questionnaire. Then, we ask people with dementia, family caregivers and dyads to navigate the ACP website and answer questions in a semi-structured interview about the content, face validity and readability of the website, as well as about its lay-out.

Data analysis

The data from the think-aloud sessions and interviews is audio-recorded and transcribed verbatim. The field notes from the observations serve to further support the data collected during the think-aloud exercise. From sprint 1 to 3, the think-aloud sessions are analysed through thematic analysis of the notes taken by the researchers and, if the notes were not sufficient, we listen back to the audiotapes to complete the notes. After sprint 4, the data from the transcript is analysed using thematic analysis[39]. The data is coded by two researchers to identify key themes. The researchers meet and discuss the preliminary codes before agreeing on a final list of codes. Disagreements are resolved through discussion.

The data from the SUS questionnaire complements the findings from the think-aloud sessions and interviews. Data is analysed with SPSS (SPSS Inc), v25. The SUS score is calculated by summing the score contributions of each item. For items 1,3,5,7 and 9 the score contribution is the scale position minus 1. For items 2,4,6,8 and 10 the score contribution is five minus the scale position. To obtain the overall value of the SUS score the sum of the scores must be multiplied by 2.5. Mean scores are calculated and comparisons between types of participants are considered. A score of 68 or above will be deemed acceptable[40]. Descriptive statistics are used to describe participant demographic characteristics.

Ethical considerations

This study received approval from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel on 26 June 2021 (BUN: 1432021000437). To determine the ability of people with dementia to give informed consent, we ask them to read the informed consent form out loud. We ask them per line if they understand their rights and whether they understand what is asked from them.

One of the researchers (CD) ensures participants with dementia understand what they sign by discussing the statements formulated in the informed consent form with them. A family caregiver is also present to help the researcher assess the understanding of the person with dementia. If everything is clear, they are asked to sign the informed consent. We also ask the family caregivers to sign the informed consent form of the persons with dementia as witnesses, as recommended by the Alzheimer's Association National Board of Directors[41]. All data is coded anonymously, and pseudonyms are used when quoting participants.

Results

We began recruitment of participants in October 2021 and participant enrolment has been completed. A total of 48 participants took part in the usability testing across four prototypes of the ACP website and we conducted a total of six advisory group meetings. Data analysis has not started.

Dissemination of the results will be led by the authors and will include presentations at international conferences and publications in scientific peer-reviewed journals; and creation of best practice guidance for the development of technology for people with dementia. Results from the development and usability study will be published during 2023. A larger evaluation study will also be conducted. After evaluation and further adaptation where needed, the ACP website will be made freely available as a resource for people with dementia and their family caregivers, if it is evaluated as acceptable and useful by users, and no negative effects are noticed. The website will be disseminated via the dementia organisations which were involved in our advisory group and is expected to be publicly launched in 2024.

Discussion

User-involvement and PPI are recognised as critical components in the development of eHealth and digital solutions, as they can help ensure that interventions meet user needs[42,43]. Involving users in technology development has been suggested as an important component for improving technology acceptance, especially for older people[44]. The involvement of people living with dementia in particular has been highly advocated for in the development of technology both in research and by groups such as Alzheimer Europe[25,27,45]. Yet, studies providing a detailed description of user involvement in technology development are scarce. A particular strength of this protocol relates to the step-by-step description of our development process and how we approached the involvement of multiple key stakeholders in all phases of the website development. We particularly emphasise on the combination

of PPI input and user-centred development methods, leading to a transparent and reliable development process. In the case of the ACP website, the development process brings together researchers, regional stakeholders in the fields of dementia and palliative care, as well as people living with dementia and family caregivers, to support people with dementia and their families in engaging in ACP.

Furthermore, this protocol describes in detail a unique combination of approaches consisting of the MRC framework for the development of complex interventions[23], the process map for the development of web-based decision support interventions[22], and an agile development approach rooted in user-centred design. The findings of the content specification phase, which are based on rich and extensive input from people with dementia, family caregivers, dementia experts, as well as up-to-date research evidence on ACP in the field of dementia, have informed the design and content of the ACP website. The iterative development process adopted in the creative design phase facilitated the provision of feedback from the end-users. This combination of methods can support researchers and designers in the development of web-based technologies, as well as understanding and considering user needs early on and throughout the development process. We hope that our efforts to describe this research approach will inspire researchers to integrate PPI and user-centred approaches in their own studies. We strongly encourage the active participation of people with dementia, their caregivers, and regional stakeholders in research on the development of web-based technologies for dementia care.

One of the challenges anticipated in the study described in this protocol is that our sample may not be very heterogeneous. In particular, one of the inclusion criteria was to have an interest in testing a website regarding ACP, thus our sample may be composed of people with generally higher computer skills and who are already familiar with the topic of ACP. Therefore, we may lack different types of perspectives which could influence the content and design of the ACP website. This study is the first step before a larger evaluation study, which will involve a larger sample and where we will aim for variability in the sample in terms of age, gender, type of dementia and dyad composition (e.g. partners or a parent and child). Additionally, continuous technical support should be organised to encourage the participation of people with lower computer skills.

Conclusion

The methods put forth in this protocol describe a feasible and inclusive approach to the development of an ACP website. The results from this study will be used to refine the design of the ACP website for a future larger evaluation study to assess the ACP website's acceptability by people living with dementia and their family caregivers and the effects on people with dementia and family caregivers' knowledge of ACP, attitudes towards ACP, and intention to engage in ACP. We hope that the findings of the development and usability of the ACP website for people with dementia and their family caregivers will contribute to the design and development of future studies involving the development of web-based technologies for people with dementia.

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We would like to thank all study participants who took part in the usability testing of the different prototypes. We also thank the members of our advisory group, as well as the team at Mindbytes for their efforts to develop, build, and refine the ACP website.

Data availability

Data sharing is not applicable to this paper as no datasets were analysed for the creation of this study protocol.

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Conflict of interest

The authors declare that they have no competing interests

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CHAPTER 5

A user-centred advance care planning website for people with dementia and their family caregivers: development and usability study

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Abstract

Objective: Advance care planning (ACP) is a dynamic communication process about future care preferences. We aimed to develop and test an ACP support website for people with dementia and their family caregivers.

Methods: We adopted a user-centred design process to develop and test the ACP support website. A content specification phase included needs assessment, evidence synthesis, and translation into preliminary content. A creative design phase included storyboarding, iterative prototyping, and usability testing. People with dementia and family caregivers engaged in usability testing across four iterations, using System Usability Scale questionnaires, and think-aloud and semi-structured interviews. An advisory group with people with dementia, family caregivers, and diverse regional stakeholders was involved. Descriptive statistics and qualitative framework analysis were applied.

Results: Website goals were: providing ACP information and facilitating ACP conversations. A 'what matters most' approach (i.e. enabling users to reflect on 'what matters most' in the present and in the future) and non-linear navigation were favoured. We tested the website with 17 people with dementia and 26 family caregivers. Feedback addressed design, navigation, and content. Usability scores of 76.4 for family caregivers and 81.3 for people with dementia were achieved. Participants highlighted the value of information and interactive ACP tools, the need for language simplification and harmonised layout. People with dementia experienced challenges in using interactive tools.

Conclusion: The user-centred development process, involving diverse stakeholders, led to the development of an ACP support website deemed usable and useful. Future evaluation should focus on acceptability, feasibility, and effectiveness of the ACP support website.

Keywords: Advance care planning, people with dementia, family caregivers, web-based tool, development, usability testing

Introduction

Background

Advance care planning (ACP) has recently been defined as a process that enables individuals to identify values, reflect upon the meanings and consequences of serious illness scenarios, and define goals and preferences for future care and medical treatment[1,2]. Over the past decades, ACP shifted from being a doctor-led, medical process focused on the end of life to a more comprehensive approach involving continuous communication among patients, families, and health professionals about preferences for future care and treatment including at the end of life[3]. Box 1 provides an overview of the characteristics of ACP, as defined by the European Association for Palliative Care[1].

Box 1: Advance care planning (ACP) characteristics

- ACP is an ongoing process involving: (a) reflection and identification of values, preferences, and goals for future care and medical treatment, (b) communication and conversations among patients, family members, and health professionals about these preferences.

- ACP may involve, but is not limited to, the documentation of preferences through an advance directive, a written document in which a person can specify preferences for care such as consenting or refusing treatment and care measures.

- ACP also provides the option to appoint a proxy decision maker (also known as surrogate decision maker or legal representative). This individual may make medical decision on behalf of the person in case he/she becomes incapacitated.

- ACP conversations and any documents resulting from them should be reviewed regularly.

Given the progressive nature of dementia and the decline in cognitive and functional abilities of those affected by dementia, ACP has been advocated to be particularly important for people with dementia and their family caregivers[4]. Within the context of dementia, several studies have found that people commonly discuss ACP within the family context (i.e. outside of professional consultations), and in some cases even engage in more ACP conversations with family than with health care professional[5]. Furthermore, it was found that some people with dementia and family caregivers prefer to discuss values and preferences in a flexible manner with family[6]. This is in line with a public health approach in palliative care highlighting the strength of having conversations about future care and preferences

within the family context, to supplement conversations in a professional context[7]. The public health approach argues that initiating ACP by exploring values and broader life aspects within the family context can establish a foundation for important considerations like treatment preferences and preferred places of death within the professional context. However, until now, there has been little development of tools which could support people with dementia and their family caregivers in this process.

Web-based tools can provide accessible platforms in this regard[8]. Technology, and especially web-based tools, have been advocated as a good way to support ACP and have shown significant potential in meeting the unique needs of people with dementia[9,10]. Web-based tools offer flexibility, allowing users to access them at their convenience, at any location, and at their own pace. They can be used independently, with or without the involvement of health professionals or family caregivers, making them accessible to a broader audience[11].

Importantly, previous research has shown that adopting a user-centred approach is paramount when developing web-based tools for people with dementia. This approach prioritises the needs, preferences, and abilities of the end-users throughout the development process, ensuring that objectives and content align closely with their specific requirements[12–14]. Furthermore, the user-centred approach promotes usability, accessibility, and acceptance of technology, resulting in enhanced user experiences and outcomes[15–17]. In line with the user-centred approach, the growing recognition of the importance of patient and public involvement (PPI) in dementia research highlights that the expertise and lived experiences of people with dementia and their family caregivers need to be considered[18–20]. PPI in dementia research encourages the co-design and evaluation of interventions, including web-based tools, to ensure they are user-friendly, acceptable, and effective[20–22].

Despite the potential benefits, there are currently no rigorous and comprehensive web-based tools that specifically consider the unique needs of people with dementia in the context of ACP. Existing web-based ACP tools are not developed for or tested with people with dementia, and are rarely based on theory[23]. Yet, people with dementia can have quite specific needs in terms of ACP compared to other illnesses. For instance, the role of family becomes increasingly important in the ACP process as the disease progresses and cognitive abilities gradually decline[24,25]. People with dementia and their family caregivers may also face barriers such as a lack of awareness or knowledge about ACP or difficulties initiating and engaging in such sensitive conversations[4,6,26,27]. To bridge this gap, there is a need for research that focuses on the rigorous and user-centred development and evaluation of a web-based ACP tool targeted for people with dementia and their family caregivers. Such a web-based tool is not intended to replace all aspects of the ACP process, as for some parts (i.e. when medical end-of-

life scenarios or decisions are discussed) health professionals will need to be involved. It is intended to provide the support needed to reflect and initiate conversations, including those with professionals.

Objectives

In this study, we aimed to develop and test an evidence- and theory-based website to support people with dementia and their family caregivers when engaging in ACP within the family context. To maintain clarity and consistency throughout our study, we use the term 'ACP support website'.

Methods

Overall design of the study

This study followed the process map proposed by Elwyn and colleagues for developing web-based decision-support interventions[28] and adhered to the development phase of the Medical Research Council (MRC) framework for complex interventions[29]. An overview of our development approach and timeline is provided in Figure 1. It involved two main phases, i.e. content specification and creative design, in which we adopted user-centred design principles and continuous stakeholder engagement. A comprehensive outline of the research methodology can be found in the published study protocol[30].

The **content specification phase** consisted of a needs assessment, evidence synthesis, and translating evidence into preliminary content for the website. The **creative design phase** consisted of storyboarding, iterative prototyping and usability testing. We adopted an agile development approach, specifically the Scrum method, to create the ACP support website prototypes[31,32]. This approach involved iterative and dynamic development, collaborating with various stakeholders, and continuously improving the design through rapid feedback and testing. The Scrum method, known for its emphasis on feedback loops, involves short development timeframes called sprints, typically lasting around four weeks. This led to the development of 4 prototypes over 5 stages, encompassing 4 sprints. User views and input were sought throughout the development process. Furthermore, meaningful PPI consultation sessions were conducted with an advisory group set up for the purpose of this study.
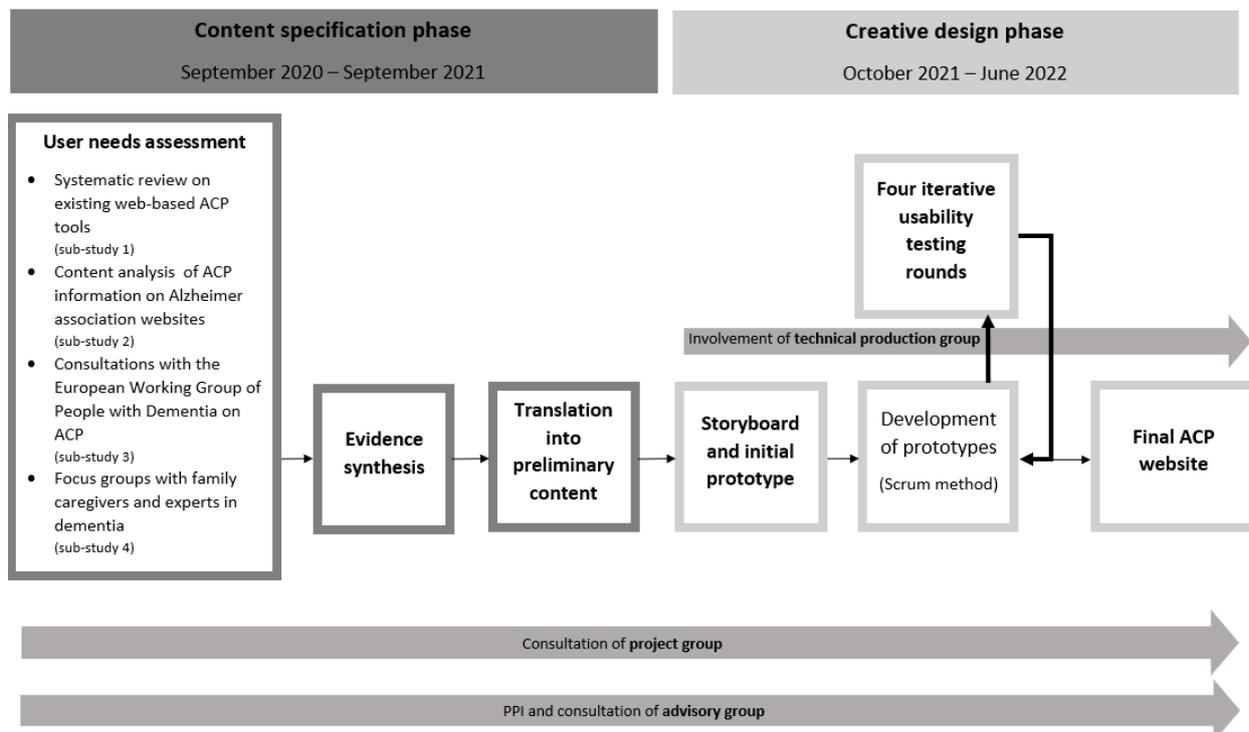
Figure 1: Overview of the development process and usability testing of the ACP support website

Stakeholder engagement throughout website development and testing

Following the process map for developing web-based decision-support interventions[28], four distinct stakeholder groups were involved throughout the development process. These groups encompass a project management team, consisting of FM, CD, LVdB, LP, and TS; a project group comprising all the authors of this paper; a technical production group consisting of a contracted IT partner; and an advisory group created for the purpose of this study, which was composed of people with dementia, family caregivers, representatives from regional dementia associations, and palliative care experts. This advisory group was consulted in the context of PPI throughout the development process through online meetings and email correspondence.

Content specification phase

Needs assessment

We used four data sources to explore and specify the content of the ACP support website: (1) a systematic review of publicly available, interactive web-based tools to support ACP (sub-study 1)[33], (2) a content analysis of information on ACP on websites of dementia associations (sub-study 2)[34], (3) focus groups and interviews with the European Working Group of People with Dementia (EWGPWD) on their perspectives of ACP (sub-study 3)[35] and (4) focus groups with family caregivers and health professionals to define the content of an ACP support website for people with dementia and their family caregivers (sub-study 4)[36].

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Appendix 1 provides an overview of the objectives and methods utilised in each sub-study conducted as part of the needs assessment. The results of these sub-studies are reported in previous publications[33–36].

Evidence synthesis

The findings of the needs assessment were integrated to draw out core elements for the website. A comprehensive summary table was generated, presenting the main findings from each individual data source. Subsequently, an analysis was conducted to identify points of convergence, instances of complementary information, or areas of divergence among the findings from each sub-study.

Translation of evidence into preliminary content of the website

Based on the results of the evidence synthesis, we used Intervention mapping principles to create the first content of the ACP support website[37,38]. More specifically, we identified theoretical methods and practical applications to translate the synthesised evidence into preliminary website content. This means that we used broad methodologies designed to change factors determining behaviour (i.e. theoretical methods)[37] and tailored them to suit the characteristics of our target population and our specific context (i.e. practical applications)[38]. This allowed us to identify core elements that the website should contain. To transform theoretical methods into a practical applications, we required a thorough understanding of the underlying theories associated with the methods[37,39]. We identified theoretical methods and practical applications via the Intervention Mapping handbook to find theoretical methods that influence specific determinants[37]; and our focus groups with family caregivers and health professionals (sub-study 4) to inquire about what the target group believed were effective strategies[36].

Creative design phase

The results obtained during the content specification phase informed the creative design phase of the ACP support website. We created an initial structure of the website and related materials in the form of a storyboard. We then developed a first working prototype of the website and proceeded to conduct usability testing with participants using an iterative process.

Storyboard

The project group, in consultation with the advisory group, created a storyboard that considered various crucial factors, encompassing the website's structure, navigation pathways, and the design of materials. This involved decisions on how information would be presented, the incorporation of interactive elements, and the integration of features such as accessibility features or media. The

storyboard phase was approached as a dynamic process, remaining open to significant alterations based on insights gained from usability testing.

Iterative usability testing

Setting and participants

Participants for usability testing of the website were recruited in Brussels and Flanders through organisations such as the Flemish Alzheimer League and memory clinics. Participants included people with dementia, family caregivers, or dyads of both.

Inclusion criteria for people with dementia were: (1) being aware and informed of their diagnosis, (2) having an interest in and being willing to test an ACP support website, (3) speaking and understanding Dutch, (4) being able to understand the information about the study, (5) being able to sign a written informed consent form.

The inclusion criteria for family caregivers were: (1) being the main or primary caregiver of person formally diagnosed with dementia, (2) having an interest in and being willing to test an ACP support website, (3) being 18 years of age or older, (4) speaking and understanding Dutch. We sought to include 12 participants per sprint, of which 3 people with dementia, 3 family caregivers, and 3 dyads. For every testing iteration (i.e. sprint), new participants were recruited.

Patient and public involvement

We conducted continuous PPI with the advisory group. The pre-sprint solely consisted of a PPI consultation with the advisory group. A brief presentation was given about the ACP support website and the aims of the research projects, followed by a short discussion. Topics included different possibilities for layout and structure of the website, as well as the evaluation of potential mood boards (e.g. colour schemes, fonts). The content of the following sprints and prototypes was determined. The storyboard and notes from the meeting were the base for developing the first prototype of the ACP support website.

We also conducted PPI consultations at the end of each sprint. Meetings started with a brief presentation of the findings from usability testing with participants, followed by a discussion. Topics included the structure, layout, and content of the prototypes.

Data collection procedures

We conducted usability testing from sprint 1 through 4. In sprint 1 to 3, we tested the usability of the ACP support website with people with dementia, family caregivers, and dyads. Each testing session started with a questionnaire covering sociodemographic characteristics, followed by a think-aloud

interview on predefined tasks to be conducted on the website[40]. Participants were given tasks and verbal instructions to navigate through the ACP support website prototype, using the think-aloud method to express their thoughts, impressions, and feelings. A researcher (CD) observed and took note of the participants' physical cues, successes in tasks, mistakes, difficulties, or comments[40]. The researcher minimised interference so the prototypes' intuitiveness could be captured, intervening only when participants remained silent for too long. Participants' perspectives on usability were further evaluated using a usability survey. In sprint 4, all participants were requested to complete a sociodemographic questionnaire. Subsequently, people with dementia, family caregivers, and dyads were asked to explore the ACP support website and provide feedback through a semi-structured interview.

Data collection measures

Quantitative measures: The sociodemographic characteristics questionnaire distributed to participants of each sprint covered age, gender, and dementia type. Participants were also asked to rate their computer skills on a scale from 1 to 10, with 1 being no skills and 10 being excellent skills. In each sprint, participants rated system usability of the ACP support website prototype on the 10-item System Usability Scale (SUS)[41]. The SUS can measure subjective usability of a website in terms of effectiveness, efficiency, and satisfaction. Responses were recorded on a 5-point Likert-type scale[42]. Total SUS scores were converted to a 0 to 100 scale, with higher scores indicating better usability[42]. A SUS score above 68 is considered above average[43], indicating acceptable experienced usability.

Qualitative assessments: The think-aloud interviews in sprint 1 to 3 were conducted following a predefined set of tasks to be completed on the different website prototypes. Participants were asked to share their perspectives on design, clarity of content, ease of navigation, and interaction with the prototypes. The semi-structured interviews in sprint 4 were conducted using an interview guide (see Appendix 1) which covered participants' perspectives on topics such as the website's content, face validity, readability, and layout.

Data analysis

The think-aloud and semi-structured interviews were audio-recorded and transcribed verbatim. All transcripts were pseudonymised. The field notes from the observations were utilised to supplement the data obtained during the think-aloud interviews. During sprints 1 to 3, framework analysis was conducted on the notes taken by researchers during the think-aloud interviews[44,45]. When necessary, the audiotapes were reviewed to enhance the completeness of the notes. Framework analysis is a form of thematic analysis which involves several stages, including data familiarisation, thematic

framework development, indexing all data against the framework, charting to summarise this data, and lastly mapping and interpretation[44,45]. Following sprint 4, framework analysis was also used to analyse the transcripts of the semi-structured interviews. FM and CD familiarised themselves with the data by listening and immersing themselves in the interview transcripts and audio-recordings. Based on the interview guide, we developed subcodes which constituted our preliminary framework. FM and CD applied the framework to all the transcripts. Next, all indexed data were charted onto a framework matrix by summarising participants' interviews and arranging them by categories (i.e. subcodes). This facilitated analysis within and between each interview, and the preparation of data for interpretation.

The data obtained from the SUS questionnaire complemented the insights from the think-aloud sessions and interviews. The data were analysed using SPSS (SPSS Inc), v25. Mean scores and standard deviations (SD) were calculated for people with dementia and for family caregivers. We used descriptive statistics to describe sociodemographic characteristics of the participants.

Ethics statement

This study received approval from the medical ethics committee of Brussels University Hospital of the Vrije Universiteit Brussel on 26 June 2021 (BUN: 1432021000437), and all participants provided written informed consent.

Results

Content specification phase

Based on the ***needs assessment and subsequent evidence synthesis***, we could draw several key lessons regarding the aims and content of the ACP support website. A full account of these findings is described in Appendix 2; here we provide a summary.

First, we identified two distinct aims for the ACP support website i.e. to provide information about ACP and to support communication about ACP. Participants in our focus groups on the content of the ACP support website (sub-study 4) highlighted that information about ACP (e.g. what it is and why it is done) and guidance on how to start and conduct ACP conversations throughout the dementia trajectory, should be the main aims of the website[36]. Regarding specific elements of the website, our participants expressed a desire for testimonials from peers and from health professionals who have already experienced ACP. They wished for an ACP support website that would enable them to discuss ACP within the family context, before engaging in discussions with health professionals[36].

Second, a 'what matters most' approach to ACP seemed most appropriate for a website to support ACP within the family context. Insights gathered from the EWGPWD (sub-study 3) stressed the importance of adopting a holistic approach of ACP that prioritises what matters most to people with dementia and their family caregivers[35]. The EWGPWD found that while medical aspects of care are an important part of ACP, social aspects of care, conversations about what matters to people in the present and in the future, and future meaningful daily activities should be included in the ACP process[35]. Our literature review of web-based ACP tools (sub-study 1) and our content analysis of dementia associations' websites (sub-study 2) showed that this 'what matters most' approach is not commonly adopted[33,34]. A significant portion of web-based ACP tools included in sub-study 1 did not comprehensively cover every aspect of the ACP process (i.e. definition of ACP; legal frameworks; legal representatives; care and medical treatment preferences; documentation; personal values and life goals; communication with family; communication with health professionals; documentation sharing; timing; meanings and consequences of potential serious illness scenarios; and uncertainties of serious illness scenarios)[33]. This finding was corroborated by our content analysis of the ACP information on dementia associations' websites (sub-study 2), which revealed that only a limited number of websites addressed all aspects of ACP[34]. Notably, the emphasis was on medical and legal aspects of ACP.

Third, navigation should not be linear and forced upon the users. We found that most ACP tools generally adopted a linear approach to ACP, where users are guided through a predetermined sequence of steps (sub-study 1)[33]. However, it is important to note that ACP should ideally be a flexible process involving exploration, discussions, and the documentation of preferences and decisions. The appropriateness of predefined steps can vary depending on people's readiness, personal barriers, and preferences towards ACP. Some people may seek to explore options without immediately engaging in ACP discussions, while others may prefer to prioritise decision-making. Our focus groups (sub-study 4) also identified the need to account for users' varying readiness levels to engage in ACP in the structure of the website[36].

Next, the lessons learned from the evidence synthesis were discussed within the project group to **translate the evidence synthesis into aims, methods and specific content of the ACP support website**. An overview is shown in Table 3. The identified aims of the website were: (1) users are informed about ACP and (2) users engage in ACP conversations, measured via several outcomes, including knowledge, attitudes, self-efficacy, perceived barriers, and skills. Then, we identified several theories (e.g. protection motivation theory, social cognitive theory, etc.) that could be applied to the outcomes targeted by the ACP support website. Based on these different theories, we selected methods of behaviour change to achieve the website's aims and subsequently translated this to the content needed for the website itself.

Table 3: Website aims, outcomes targeted, methods used and corresponding theoretical basis, and website content

Website aims and outcomes targeted		Methods used and their theoretical basis			Website content
Aims	Outcomes	Methods	Theory basis	Description of methods	What the website should contain
1. Users are informed about ACP	Knowledge of what ACP is	Arguments	Elaboration Likelihood Model[46]	Using a set of one or more meaningful premises and a conclusion.	Information about what ACP involves, its goals and its limitations.
		Elaboration	Theories of Information Processing[47], Elaboration Likelihood Model[46]	Stimulating the learner to add meaning to the information that is processed	Description of different scenarios by asking questions: is ACP something for me?
	Attitudes towards ACP	Positive Framing	Protection motivation theory[48,49]	Messages emphasising the advantages of performing a behaviour	Information about how ACP can benefit all parties involved in the process.
2. Users engage in ACP conversations	Self-efficacy for participating in ACP conversations	Verbal persuasion	Social cognitive theory[50]; theories of self-regulation[50]	Using messages that suggest that the participant possesses certain capabilities	People with dementia and families are given tips for successfully discussing ACP.
		Modelling	Social cognitive theory[50], theories of learning[51]	Providing an appropriate model, being reinforced for the desired action	Testimonial of dyads talking about ACP and how they started doing ACP.
	Perceived barriers to having ACP conversations	Modelling	Social cognitive theory[50], theories of learning[51]	Providing an appropriate model, being reinforced for the desired action	Role model stories of how dyads have previously started ACP conversations and how to tackled issues.
	Skills to engage in ACP conversations	Active learning	Elaboration Likelihood model[46], social cognitive theory[50]	Encouraging learning from goal-driven and activity-based experience	Tips on how to communicate with family, person with dementia, health professionals

Creative design phase

Storyboard and pre-sprint

Based on the work in the content specification phase, the project group and the advisory group jointly developed an initial website structure, resulting in the structure of the website presented in Figure 2 . A few important accessibility features were also selected such as a text-to-speech option, a contrast option, and a font size option. We also determined that it would be important to ensure that content could easily be printed.
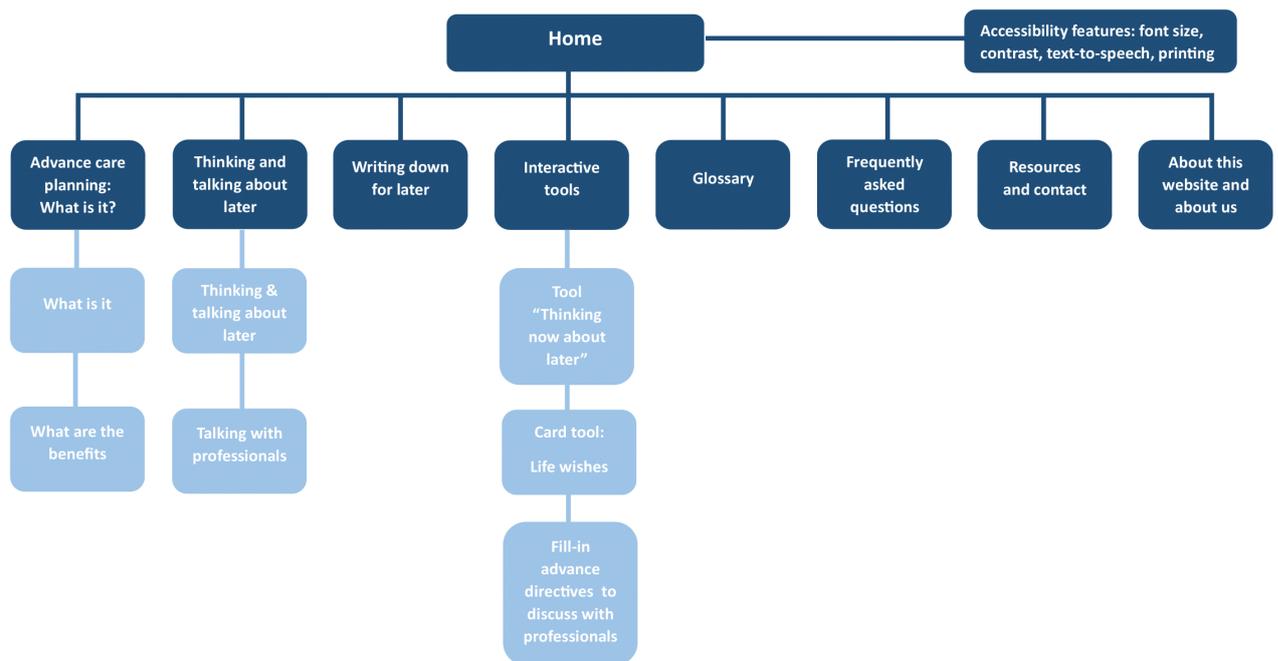

Figure 2: Initial website structure diagram

Additionally, the project group developed the materials for the ACP support website, drawing upon their collective expertise. First, to provide comprehensive information, we presented a complete overview of the ACP process, as identified in our content specification phase. We built the information on the website around the following core ACP processes, as identified in our content specification phase[33]: (1) information, (2) reflection and communication, and (3) decision-making and documentation.

To inform users about ACP, a part of the website is dedicated to explaining what ACP is and what its potential benefits might be. To maintain clarity and manage the text volume, we created a glossary and a frequently asked questions sections on the website, where essential terms specific to ACP and dementia, in the Belgian context, are explained. For instance, these sections describe terms such as 'Do Not Resuscitate' (DNR), quality of life, family caregivers, organ donation, palliative care, patient

rights, power of attorney, capacity, euthanasia, or advance directives and the legal frameworks surrounding them. To support ACP reflection and communication, a part of the website provides a set of recommendations on communication about ACP. We developed two interactive communication tools. The first tool, the 'Life Wishes Cards' (Levenswensen kaarten in Dutch) is an adaptation of the 'Go-Wish' cards developed in the United States. The cards are designed to facilitate discussions about wishes and preferences regarding the end-of-life, using preformulated statements that can be sorted. We previously translated and culturally adapted the original cards for use in Flanders, Belgium[52] and digitised them for our website. The second interactive communication tool, named 'Thinking Now About Later', is a fill-in tool that guides users through a reflective process by offering prompts and questions to think and talk about the future. Its primary goal is to help users think and talk about and write down their preferences for the present as well as the future, taking the lens of 'what matters most'. It also helps users in the process of choosing a proxy decision-maker, in deciding whether they want to document any preferences in formal advance directives, and in determining the next steps including conversations with family and friends as well as health professionals. LVdB and CD led the development of this fill-in tool drawing on the expertise of the project management group. Finally, to support ACP documentation, we provide access to existing templates for advance directives in Belgium[53] and encourage users to discuss these with health professionals.

The pre-sprint was dedicated to determining the look and feel of the ACP support website. Based on the content specification phase and storyboard, the advisory group selected a mood board (i.e. colour scheme, illustration style, etc.). For instance, neutral or depressing colours were rejected in favour of more uplifting and positive colours. Furthermore, the advisory group and the project group planned for the development of the website and the content of the following sprints was determined. Sprint 1 evaluated the homepage and structure of the website, sprint 2 focused on the information components of the website, and sprint 3 concentrated on the communication tips and interactive communication tools. Sprint 4 evaluated the final prototype composed of the entire website.

Usability testing

Participant Characteristics

In total, 17 people with dementia and 26 family caregivers took part in the usability testing of the ACP support website prototypes. Of these, there were 10 dyads, while 7 people with dementia and 16 family caregivers participated on their own. Table 2 shows their demographic and dementia-related characteristics. People with dementia rated their computer skills between 5 (SD = 3.6) and 6.6 (SD = 1.5), while family caregivers rated their computer skills between 7.8 (SD=1.1) and 8.4 (SD=1.5) (scale 1 to 10).

Table 4: Characteristics of Study Participants

Characteristic	Sprint 1[*] (n=10)	Sprint 2 (n=9)	Sprint 3 (n=12)	Sprint 4 (n=12)
People with dementia, n (%)	**5 (50)**	**3 (34)**	**3 (25)**	**6 (50)**
Age, n (%)				
45-54	1 (20)	0 (0)	0 (0)	0 (0)
55-64	4 (80)	2 (66)	1 (34)	4 (66)
65-74	0 (0)	0 (0)	2 (66)	1 (17)
75+	0 (0)	1 (34)	0 (0)	1 (17)
Sex, n (%)				
Female	2 (40)	1 (34)	1 (34)	2 (34)
Male	3 (60)	2 (66)	2 (66)	4 (66)
Dementia diagnosis, n (%)				
Alzheimer's	5 (100)	2 (66)	2 (66)	5 (83)
Frontotemporal dementia	0 (0)	0 (0)	1 (34)	1 (17)
Parkinson dementia	0 (0)	1 (34)	0 (0)	0 (0)
Mean self-rated computer skills (SD)	6 (3.4)	5 (3.6)	6.6 (1.5)	5.1 (3.3)
Family caregivers, n (%)	**5 (50)**	**6 (66)**	**9 (75)**	**6 (50)**
Age, n (%)				
18-24	1(20)	0 (0)	0 (0)	0 (0)
25-34	0 (0)	2 (33)	1 (11)	1 (17)
35-44	0 (0)	0 (0)	1 (11)	1 (17)
45-54	0 (0)	0 (0)	1 (11)	1 (17)
55-64	3 (60)	3 (50)	2 (23)	2 (33)
65-74	0 (0)	1 (17)	3 (33)	1 (17)
75+	1 (20)	0 (0)	1 (11)	0 (0)
Sex, n (%)				
Female	5 (100)	4 (66)	6 (66)	6 (100)
Male	0 (0)	2 (34)	3 (34)	0 (0)
Family member diagnosis, n (%)				
Alzheimer's	4	6	5	4
Frontotemporal dementia	0	0	2	1
Lewy Body dementia	0	0	1	0
Other	1	0	1	1
Mean self-rated computer skills (SD)	8.4 (1.5)	7.8 (1.1)	7.8 (2)	7.8 (2.3)

[*] Sprint = short development timeframe of approximately four weeks

Iterative development and usability testing of the ACP support website (Sprint 1 to 3)

Three iterative sprints of usability testing were conducted to fully develop and refine the ACP support website. The time from the completion of a usability testing sprint to the implementation of website revisions and addition of new content was approximatively 1 to 2 months. Figure 3 shows the means of the SUS score for people with dementia and family caregivers in each sprint. Overall, users gave the website prototypes a total mean usability score ranging from 72.5 (SD=11.5) to 82.5 (SD=7.5). Participants' feedback on the prototypes ranged from comments on design, navigation or content, to comments on the device used to test the website. An overview of suggestions made by participants and the advisory group and the resulting modifications are described in Table 5.
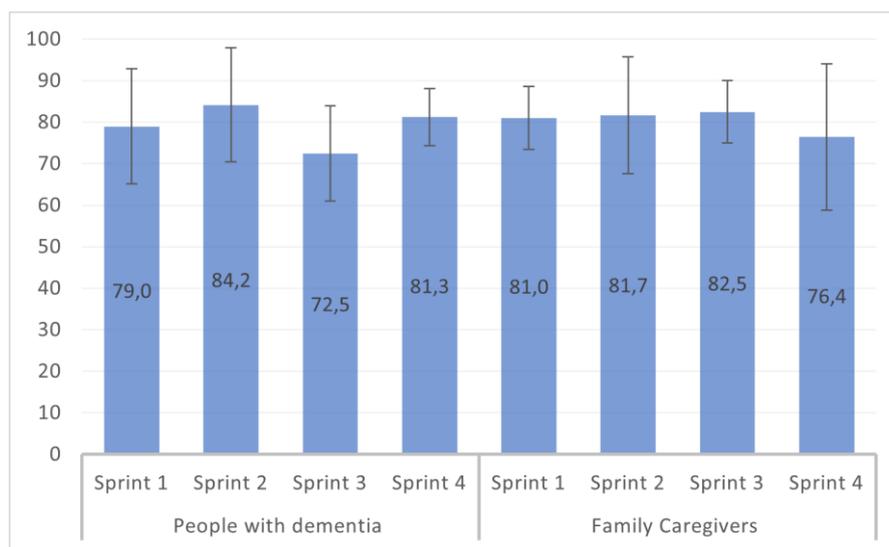
Figure 3: Mean SUS scores and SD per sprint for people with dementia and family caregivers

Table 5: Usability testing feedback and revisions made from pre-sprint to sprint 3

Sprint	Content of the sprint	Usability feedback from users and advisory group	Revisions made
Sprint 1	Homepage and structure of the website (i.e. menu bar)	Website Design: Users felt that the font on the website was too small.	Incorporated a font size functionality, so that users can choose the font size that suits them best
		Website Design: Some users and the advisory group felt that some pictures were not inclusive enough and focused too much on loss of ability and old age (e.g. picture of people in a wheelchair)	Pictures were replaced by more inclusive and active photos, that were provided by a dementia association and senior association

		Website Design: Quotes taken out of the testimonials of people with dementia were difficult to distinguish from regular text	Added a picture of the person saying the quote and framed the quote
		Content: Users felt that the abbreviation of ACP was not always clear.	Ensured minimal use of the abbreviation and added explanations when the abbreviation is used.
		Navigation: Users were confused because subheadings did not appear directly under the main headings	The menu bar was redesigned so that subheadings appeared below the corresponding main heading
		Device: Some users tried to use the computer screen as a touchscreen	Ensured that the website is also user-friendly on tablets
Sprint 2	Addition of webpages that provide information: i.e. what is ACP, Glossary, Frequently Asked Questions	Website Design: Some users and the advisory group felt that there were too many colours, which was perceived as confusing	Removed the colour orange from the colour palette, so that the look of the website is more simple and harmonised
		Website Design: Users felt that the webpages were too busy and had big blocks of text	Incorporated a line spacing of 1.15 so that the text looks less bulky. Also incorporated a text-to-speech functionality and added videos to reduce amount of text
		Navigation: Users disliked the fact that the menu did not stay open when they clicked on a subheading, which made it hard to identify where they were on the website.	Ensured that the menu stayed visible when browsing through the subheadings and indicated with a darker colour which subheading the user is currently reading
		Content: Users found that the homepage content was very descriptive and did not really encourage the use of the website.	Added calls-to-action on the homepage to encourage users to explore different parts of the website
		Content: Users suggested some additional questions and words that they found difficult to understand	Added the content requested by users to the FAQ and the glossary
Sprint 3	Addition of webpages that provide communication tips and interactive tools to support ACP	Website Design: Some users experienced some difficulty reading the website because of the contrast	Incorporated a contrast functionality
		Website Design: Users and the advisory group felt that the voice of text-to-speech functionality was too fast and disliked the fact that the accent was Dutch rather than Flemish	Changed text-to-speech software so that speed and accent can be adapted

Website Design: Users found that the Life Wishes interactive tool was difficult to use, because all cards did not fit in the columns and instructions were not clear	Redesigned the Life Wishes interactive tool so that all cards can be sorted and fit in the columns.
Content: Users found that the structure of the website was not always logical and could be confusing	Restructured the website and divided information for people with dementia and for family caregivers separately
Content: Users felt that there was too much textual content on the website.	Prepared videos with health professionals, people with dementia, and family caregivers to complement the textual content
Navigation: Users and the advisory group suggested options for the URL of the website	Incorporated the suggestions and created the URL of the website

Usability testing of the final prototype of the ACP support website (Sprint 4)

The last usability testing sprint was conducted to test the entire website with users. Overall, family caregivers rated the usability of the whole website with a mean SUS score of 76.4 (SD=17.6) and people with dementia with a mean SUS score of 81.3 (SD=6.8) (see Figure 2). The feedback revolved around the following themes regarding the website: clarity, usefulness, user experience on the website, and layout. Table 6 presents the final revisions that were made to obtain the final prototype.

In the semi-structured interviews, most participants described a positive user experience on the website. Some reported small issues such as encountering broken links while they tested the website. Overall, they found the website useful and thought that the information provided was complete and the tips and interactive tools were an ideal place to start the discussion on ACP. Many participants mentioned that they would use the website regularly in the future. Both the interactive tools were particularly appreciated by most of our participants.

"It's not always so easy. It's not that simple to put things down on paper of 'what do I want?' But then when you see these tools such as the cards or the reflection and fill-in tool, that can help you in your process." – Person with dementia #1

Although the interactive communication tools were seen as useful, several participants also mentioned that it was difficult to understand how they worked exactly and that they would benefit from clearer instructions. Indeed, some had difficulties with navigating the fill-in tool, and others had issues with understanding how to skip or move the cards within the card tool.

"And then the cards… That part, I found it a bit more challenging… with the dragging. I'm not really a computer person. I have to do it, but that's all things that I didn't grow up with, you know. And I had some problems with it, and then I sat there searching. […] So I don't find it easy."
– Person with dementia #4

Most participants praised the clarity of the website, including the goals of the website, the clarity of the information provided, as well as the tips given. They noted that the language was easy to understand and that the accessibility features incorporated on the website, such as the text-to-speech option or the font size option, were helpful. However, more than half of the participants still found the text too long, and the website too busy. They suggested that the written content could be more to the point, which would also improve the clarity of the website overall.

"Also, I share the opinion that the sentences are too long. I think you could write the same text much more concisely and much more understandable. And someone should proof-read it carefully as well." – Person with dementia #3

Due to the length of the textual content, most family caregivers and two people with dementia also noted that people with dementia would not necessarily be able to use the website on their own, and that they would most probably need assistance from family caregivers.

Finally, all participants seemed to be satisfied with the navigation of the website. One feature that was noted by several participants was the advantage of being able to go through the website in their preferred order, and not having to go through a linear process.

"Sometimes you have to go through a whole bunch of pages before you actually get to the page that you want. Here you can actually go directly to your page and I think that's an advantage. Each item is separate from the other and I actually like that." – Family caregiver #4

Participants also noted some inconsistencies in font sizes or in use of colour on different webpages, which they found lead to a lack of harmony on the website.

Table 6: Overview of revisions made following sprint 4

Theme	Revisions made
Interactive communication tools	Instruction videos in the form of tutorials were added to explain how to use the communication tools on the website.
Clarity	The textual content was rewritten with the help of an organisation that specialises in making information more accessible to broad audiences by simplifying language.
Layout	Font size and colours were harmonised throughout the whole website.
User experience	Fixed minor technical issues such as broken links

Figure 4 provides a screenshot of the final website home page, see Appendix 3 for additional selected screenshots of the website.
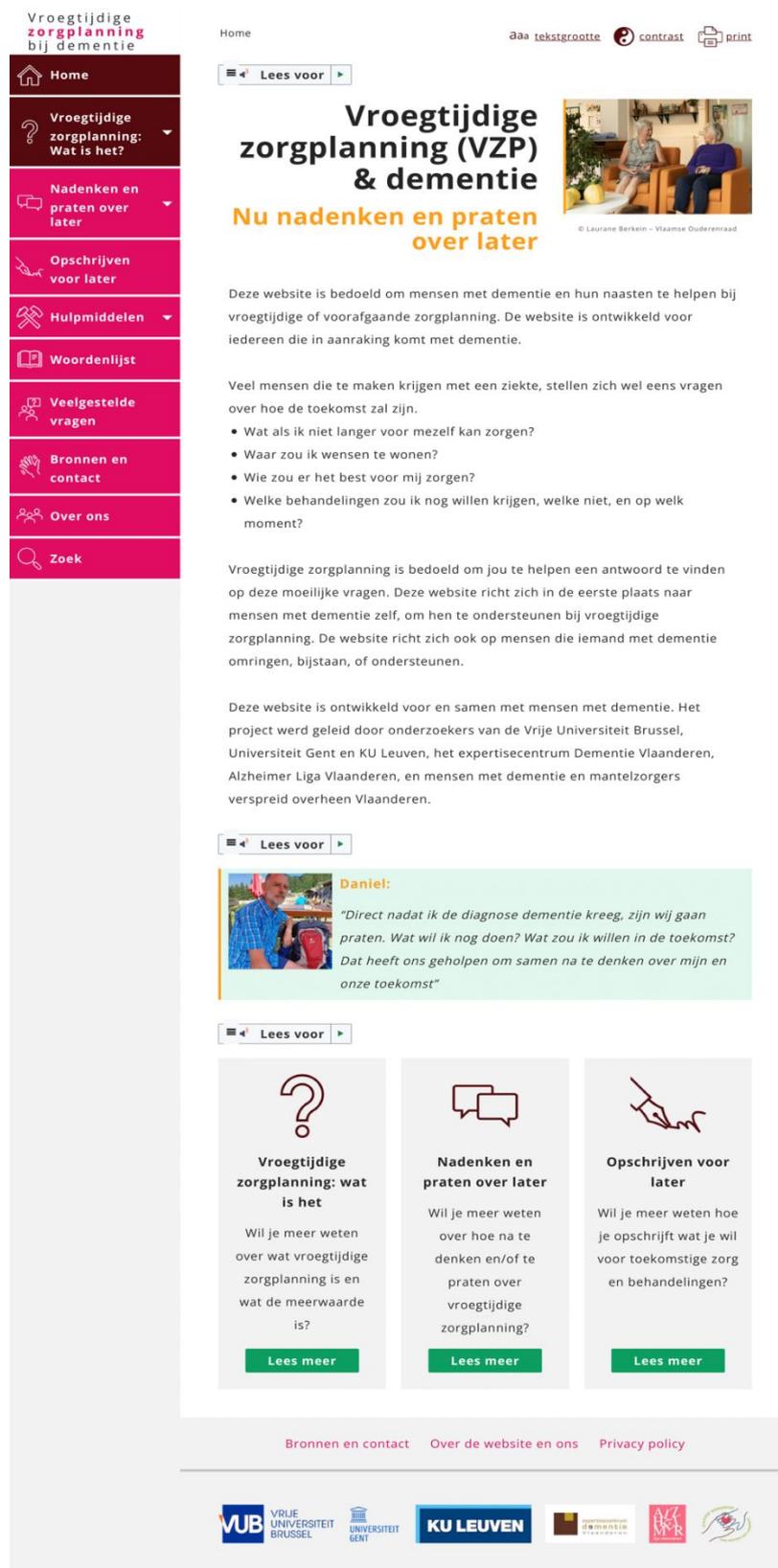

Figure 4: Screenshot of the ACP support website homepage (in Dutch)

Discussion

This study outlines the outcomes of an iterative and user-centred development process of a website to support people with dementia and their family caregivers to engage in advance care planning (ACP) in the family context. It resulted in a website developed for and with people with dementia and family caregivers designed to inform and support them in communicating and engaging in ACP. It provides access to a range of information ranging from what ACP is and what its benefits can be, to explanations of advance directives and the legal frameworks that influence them, as well as explanations for difficult terms and jargon used in ACP (e.g. decision making capacity or DNR) and responding to frequently asked questions (e.g. with whom should ACP be discussed first). The website also provides tips on how to communicate about ACP within the family context as well as with health professionals, both for people with dementia and for family caregivers. Moreover, we developed and tested two interactive communication tools that users can use to reflect about ACP or to facilitate their ACP conversations: (1) the 'Life Wishes Cards', which allow users to sort statements about their wishes for future care and (2) the 'Thinking Now About Later' tool, a fill-in tool that allows users to reflect about preferences for what matters most to them now and in the future. Features integrated on the website included a font size option, a text-to-speech option, a contrast option, several videos from health professionals and testimonials from people with dementia and family caregivers about ACP.

The ACP support website presents several innovative features that distinguish it from other ACP web-based tools. Notably, our website takes a 'what matters most' approach to ACP. By focusing on 'what matters most' to people in the present and for the future, the website encourages the identification of, not only of preferences for medical aspects of care, but also preferences and wishes on social aspects of care and future meaningful daily activities. This approach enables users to have ACP conversations that include broader range of content or topics. As advocated by the public health approach in palliative care, these broader conversations about what matters most can allow people with dementia and family caregivers to thoroughly reflect and talk about their values and wishes. These conversations can serve as a valuable starting point for more detailed and specific conversations and decision-making with health professionals about medical aspects of care such as treatment preferences[7,54].

Additionally, unlike other ACP web-based tools or interventions that primarily focused on completing advance directives or centred on professional settings[27,55], our website promotes ACP conversations within the family context by providing people with dementia and family caregivers with information and giving them the opportunity to engage in ACP either by themselves or together. The ACP support website encompasses a range of topics, including information, communication, and documentation.

It also encourages users to reach out to their health professionals and address ACP with them. It can therefore serve as a complement to ACP conducted with health professionals in a professional context.

Furthermore, the ACP support website deviates from the standard linear navigation pathways found in other web-based tools to support ACP. Previous web-based ACP tools developed for the general public typically follow predefined steps, starting with the provision of information, prompting reflections, moving on to communication, and ultimately concluding with the completion of advance directives or other forms of documentation[33]. However, research has shown that ACP readiness plays a pivotal role in the ACP process. The optimal timing of conversation about future care can be a subject of distinct divergence between people with dementia and family caregivers[4,56]. While some people with dementia can wish to have such discussions immediately after diagnosis, others often perceive ACP as an emotional and complex process and prefer to 'live in the present' and focus on their current capabilities [6]. The diverse views on the ideal time to initiate ACP conversations depending on readiness levels have been shown to be significant barriers to ACP initiation by health professionals[4,57,58]. The non-linear, flexible navigation of the ACP support website allows people with dementia and family caregivers to engage in the process accordingly to their needs and readiness level. Users can select which section of the website they would like to use, without having to go through the rest of the website. Moreover, people with dementia and family caregivers can pause and return to the website as they wish.

Participants in our study had positive ratings for the usability of the ACP support website. We found that usability was influenced by factors such as text length, formulation of content, and the incorporation of media such as videos. People with dementia and family caregivers encountered some difficulties with the use of the interactive communication tools particularly. Our participants also noted that people with dementia may face challenges using the website independently, which raised some concerns. This raises issues such as digital literacy or access to a family caregiver to assist with the ACP support website. Furthermore, users could (over)rely on family caregivers' abilities, potentially creating a burden to family caregivers[59]. To attempt to address these difficulties, we included tutorial videos to explain how to use the reflection and communication tools visually and support the use of the website.

The strength of our approach lies in its evidence- and theory-based, user-centred and iterative development process. The iterative user-centred approach included the perspectives of people with dementia, family caregivers, and different stakeholders in all stages of the development from content specification to creative design. We actively involved people with dementia and their family caregivers, following recommendations of previous research and organisations groups such as Alzheimer

Europe[13,18,60], which emphasise the importance of user input in the development of technology and interventions for people with dementia. Our development process also incorporated insights from regional stakeholders and experts, ensuring that the ACP support website also aligned with their values and interests, thereby helping to facilitate the website's reach. We adopted a unique development process based on several approaches such as the MRC framework for the development of complex interventions[29], a process map for the development of web-based decision support interventions[28], and the scrum method[32] rooted in agile development and user-centred approaches. This combination of approaches allowed us to provide a thorough description of both the content specification and creative design phases of the ACP support website development process. Furthermore, the development of the content of the website was grounded in theory. We aligned website outcomes and content with established theories and explicitly selected theoretical change methods, thereby taking steps towards ensuring a well-founded intervention[61]. These strengths enhance the relevance and potential for implementation and dissemination of the ACP support website.

However, there are limitations that need to be considered. The user group of people with dementia was smaller than the group of family caregivers. This was due to considerable challenges in recruitment in sprints 2 and 3 especially, where people with dementia represented only a third and a quarter of the samples. In addition to the usual recruitment challenges typically encountered when including people with dementia or people with cognitive impairment in research[62], multiple other factors may have contributed to the lower inclusion rate of people with dementia. Firstly, participation in this study implied using a computer or a tablet, which are tools that are potentially not well mastered by some people with dementia or their family caregivers. Limited access to an appropriate device to use the ACP support website may have prevented eligible individuals from participating in the study. Furthermore, the sensitivity of the topic of ACP may have discouraged some people from participating. Finally, the recruitment period coincided with the COVID-19 pandemic which proved very challenging.

For future research, our study can be an example in terms of development methods for web-based tools targeting people with dementia and their family caregivers. We recommend establishing early collaborations among researchers, software developers, regional stakeholders, and end users from the start of the project. Such a collaborative approach increases the chance that web-based tools that are well-suited for their intended purpose and enhances the potential for successful implementation. Regarding the ACP support website itself, a thorough evaluation study on the website's acceptability, feasibility, and potential effectiveness in engagement in ACP is necessary before wider implementation. This evaluation is currently being conducted[63].

Conclusion

This study presented the development of a website to support ACP in the family context for and with people with dementia and their family caregivers. The iterative, user-centred approach incorporated insights from people with dementia, family caregivers, and regional stakeholders. The ACP support website's distinctive 'what matters most' approach; its non-linear and flexible navigation; and its innovative user-centred, evidence- and theory-based development process based on a unique combination of approaches set it apart from previous web-based ACP tools. While usability was generally positively rated, challenges with the interactive communication tools provided on the website highlight the need to address digital literacy and accessibility. Future research will focus on the evaluation of the ACP support website, including its acceptability, feasibility, and effectiveness to facilitate engagement in ACP.

Supplementary materials

Appendix 1: Interview topic guide for sprint 4

Appendix 2: Full summary of objectives, methods and findings of each sub-study of the needs assessment phase and input for the ACP support website

Appendix 3: Selected screenshots of the ACP support website

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Conflict of interest

The authors declare that they have no competing interests

Author contributions

Study concept and design: All authors. Acquisition of data: CD. Analysis and interpretation: FM and CD. Drafting of the manuscript: FM. Critical revision of the manuscript: All authors. All authors gave final approval of the version to be published.

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Supplementary materials of Chapter 5

Appendix 1: Interview guide of sprint 4

Welcome and informed consent/ demographics questionnaire
Ask permission to record
Website content, layout, face validity and readability
- Do you feel that the website brings enough information about ACP?   - Do you feel that the website gives enough tips to help support people in ACP?   - Do you feel like you can put into action the information and tips received?   - Do you feel that the website meets the targets that are presented on the homepage, ie support people with dementia and family caregivers in ACP?   - What do you think of the lay-out of the website?   - Is it clear, at first read, what information you will find in each part of the website?   - Is the website easy to navigate?   - Was the website easily understandable?   - Did you encounter any difficulties to understand the content of the website?   - Did the videos, the text-to-speech option help in understanding the content of the website?   - Did you have any difficulties in using sections of the website?   *Prompt: Go over each section of the website*
Conclusion and usability questionnaire

Appendix 2: Full summary of objectives, methods and findings of each sub-study of the needs assessment phase and input for the ACP support website

Table 1A: Objectives and methods of each sub-study conducted within the needs assessment phase

	Objectives	Methods
Sub-study 1[33]	• Perform a systematic review of web-based ACP support tools • Describe the characteristics of the identified tools • Evaluate the readability of the content provided by these tools • Assess the quality of the content within the web-based ACP support tools • Investigate the presence and methods of evaluation applied to these tools	• Search strategy: (1) systematically searched web-based grey literature databases (OpenGrey, ClinicalTrials.gov, ProQuest, British Library, Grey Literature in the Netherlands, and Health Services Research Projects in Progress), (2) conducted searches on Google and app stores, (3) consulted experts for input • Eligibility criteria: web-based, designed for the general population, accessible to everyone, interactive, in English or Dutch • Employed the Quality Evaluation Scoring Tool for content evaluation • Used 4 data extraction tables to synthesise information on: characteristics of ACP tools, readability of content, quality of content, evaluation methods used
Sub-study 2[34]	• Gain insight into the ACP content provided on dementia associations' websites in Europe.	• Conducted content analysis of dementia associations' websites in Europe • Used both deductive and inductive approaches • Developed an analysis reference framework derived from two ACP definitions
Sub-study 3[35]	• Gather the perspectives of the EWGPWD (a group advocating for and representing the interests of people living dementia in Europe) and their supporters on how advance care planning is currently defined and develop recommendations for changes to the definition.	• Conducted an in-depth qualitative study using online focus groups and interviews • Used thematic analysis as analytical approach. • Included 12 people with dementia and 9 supporters.
Sub-study 4[36]	• Define the content of an interactive ACP support website for people with dementia and their family caregivers • Assess the barriers and facilitators for potential users to find and use such a website	• Conducted online focus groups with family caregivers (serving both as potential users and proxies for people with dementia) and healthcare professionals caring for people with dementia

		• Used thematic framework analysis with a combination of deductive and inductive approaches to coding.

Table 1B: Evidence collected during the user needs assessment and evidence synthesis

Evidence source	Summary of Results	Input for the ACP support website

Sub-study 1[33]	• We found a total of 30 tools. The majority of the tools mentioned a clear aim (n=24):
	  ○ to support reflection and/or communication (n=7),
	  ○ to support people in making decisions (n=7)
	  ○ or to document decisions (n=8), and
	  ○ two mention all of these aims.
	• The majority of the tools (n=24) targeted the general population in ACP, although some (n=6) also targeted healthcare professionals. The tools used websites (n=15), online portals (n=10), apps (n=3) and a combination of these three (n=3) as formats.
	• All but one tool were linear, step-by-step tools. However, this can suggest that ACP is linear instead of an iterative process, and restrict users.
		• Although all tools are "ACP" tools, not all tools aim to support the whole ACP process (based on the European consensus definition endorsed by the EAPC), which should be done on the ACP support website.
		• Tools have often 1 format and websites are the most commonly used.
		• Avoid the linear, step-by-step configuration on the website.

Sub-study 2[34]	• We included 26 dementia associations' websites from 20 countries and one European association, covering 12 languages. • Ten websites did not mention ACP. • The information on the remaining 16 websites varied in terms of themes addressed and amount of information given. • Four explicitly define ACP. • Several websites made multiple references to legal frameworks (10 websites, 705 excerpts), choosing legal representatives (12 websites, 274 excerpts), and care and treatment preferences (14 websites, 89 excerpts)	• ACP should be clearly defined on the website. • Not all website address the whole ACP process (based on the European consensus definition endorsed by the EAPC).

	- Themes such as communication with family (9 websites, 67 excerpts) and professionals (9 websites, 49 excerpts) or identifying personal values (9 websites, 73 excerpts) were mentioned on fewer websites or addressed in fewer excerpts.	

Sub-study 3[35]	- The focus groups involved 21 participants, of which 12 were people with dementia and 9 supporters. The interviews were conducted with 9 people with dementia and 7 supporters.
	- The first theme was elements to change in the ACP definition, subthemes ranged from the inclusion of people with decreasing decisional capacity, the reflection of the role of the family and/or trust-based relationships, the focus on end-of-life and medical decisions, and the need for more social aspects of care.
	- Elements to keep in the ACP definition, ranged from the need for ACP to be a process that is regularly reviewed, the emphasis on communication and documentation, highlighting ACP as an option rather than an obligation and the focus on choosing a proxy decision maker.
		- ACP should be framed on the website as a process that includes both communication and documentation and should not only focus on medical decisions, but also on:
		   o The meaning of decisional capacity and its role in ACP
		   o The role of family and friends in ACP
		   o Social aspects of care, as well as medical aspects of care, including end-of-life care.

Sub-study 4[36]	- We conducted 4 focus groups with family caregivers of people with dementia (n=18) and 3 with healthcare professionals (n=17). - Regarding the content of the ACP support website, participants highlighted that information on ACP (what it is and why it is done) and guidance on how to start and conduct ACP conversations throughout the dementia trajectory should be included on the website. - Information on ACP should go further than explanations on advance directives and would ideally be presented using testimonials of	- The aims of the website should be to provide information regarding ACP and support in ACP communication - It is important to include testimonies from people with dementia and family caregivers who have already engaged in ACP to support the information and communication tips given on the website. - The website should be interactive - The website should be relatively simple and provide

	people with dementia and their families.	clear instructions to improve usability.
	• To increase the usability of the website, most participants considered that it should be interactive and that a text-to-speech and a print option as important functionalities.	• The website should include functionalities such as text-to-speech and font size options.
		• The content of the website should be printable.
	• A lack of computer literacy was found to be the most significant barrier to finding and using the website.	

Appendix 3: Selected screenshots of the ACP support website

Vroegtijdige zorgplanning bij dementie

- Home
- Vroegtijdige zorgplanning: Wat is het?
  - Wat is het?
  - Wat is de meerwaarde?
- Nadenken en praten over later
- Opschrijven voor later
- Hulpmiddelen
- Woordenlijst
- Veelgestelde vragen
- Bronnen en contact
- Over ons
- Zoek

Home » Vroegtijdige zorgplanning: Wat is het?

aaa tekstgrootte   contrast   print

Lees voor ▶

Wat is vroegtijdige zorgplanning?

© Joris Herregods – Vlaamse Ouderenraad

Samen met zorgverleners, familie, vrienden en mantelzorgers:

- nadenken en praten over jouw toekomst. Wat wil jij voor later? Welke zorg en behandelingen wil je nog? En welke liever niet meer?
- opschrijven wat voor jou belangrijk is

Vaak wordt gedacht dat vroegtijdige zorgplanning een document is dat moet worden ingevuld. Opschrijven van wensen over toekomstige zorg en behandeling kan ook onderdeel van vroegtijdige zorgplanning zijn. Het is belangrijk om te praten over wat jij zou willen met zorgverleners en met je naasten. Vroegtijdige zorgplanning is met andere woorden een communicatieproces. Meestal gaat het ook niet om één gesprek maar om meerdere gesprekken.

In onderstaande video legt verpleegkundige Gerda Okerman uit wat vroegtijdige zorgplanning is.

Bronnen en contact   Over de website en ons   Privacy policy

Figure 3A: Screenshot of the webpage 'What is advance care planning' (in Dutch)

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Vroegtijdige
zorgplanning
bij dementie

- Home
- Vroegtijdige zorgplanning: Wat is het?
- Nadenken en praten over later
- Nadenken en praten over later
- Praten met zorgverleners
- Opschrijven voor later
- Hulpmiddelen
- Woordenlijst
- Veelgestelde vragen
- Bronnen en contact
- Over ons
- Zoek

Lees voor ▶

Nadenken en praten over later

© Sian Verstraeten – Vlaamse Ouderenraad

Personen met dementie vinden het vaak moeilijk om na te denken over de toekomst omdat deze erg onzeker is. Sommigen hebben behoefte om erover te praten. Anderen denken er liever zelf over na. Iedereen is anders.

In het filmpje hieronder vertellen Daniel, Lucrece en Paul:
- hoe ze samen praten
- waarover ze praten
- en wat moeilijk is

Nadenken en praten over vroegtijdige zorgplanning (Deel 1)

Partager

Regarder sur YouTube

Hoe start je vroegtijdige zorgplanning?

Hieronder vind je tips en voorbeelden over hoe je vroegtijdige zorgplanning kan starten. Hoe kan jezelf nadenken en hoe je met anderen praten.

Lees voor ▶

Ik heb dementie	Mijn naaste heeft dementie
Hoe start je met nadenken over wat belangrijk is voor jou en wat je zou willen voor je toekomstige zorg en behandelingen	Als naaste van iemand met dementie kan je met vragen zitten over vroegtijdige zorgplanning. Wat vindt hij of zij belangrijk voor de toekomst?
Lees meer	**Lees meer**

Bronnen en contact   Over de website en ons   Privacy policy

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Figure 3B: Screenshot of the webpage 'Thinking and talking about later' (in Dutch)

Figure 2C: Screenshot of the interactive fill-in tool 'Thinking now about later' (in Dutch)
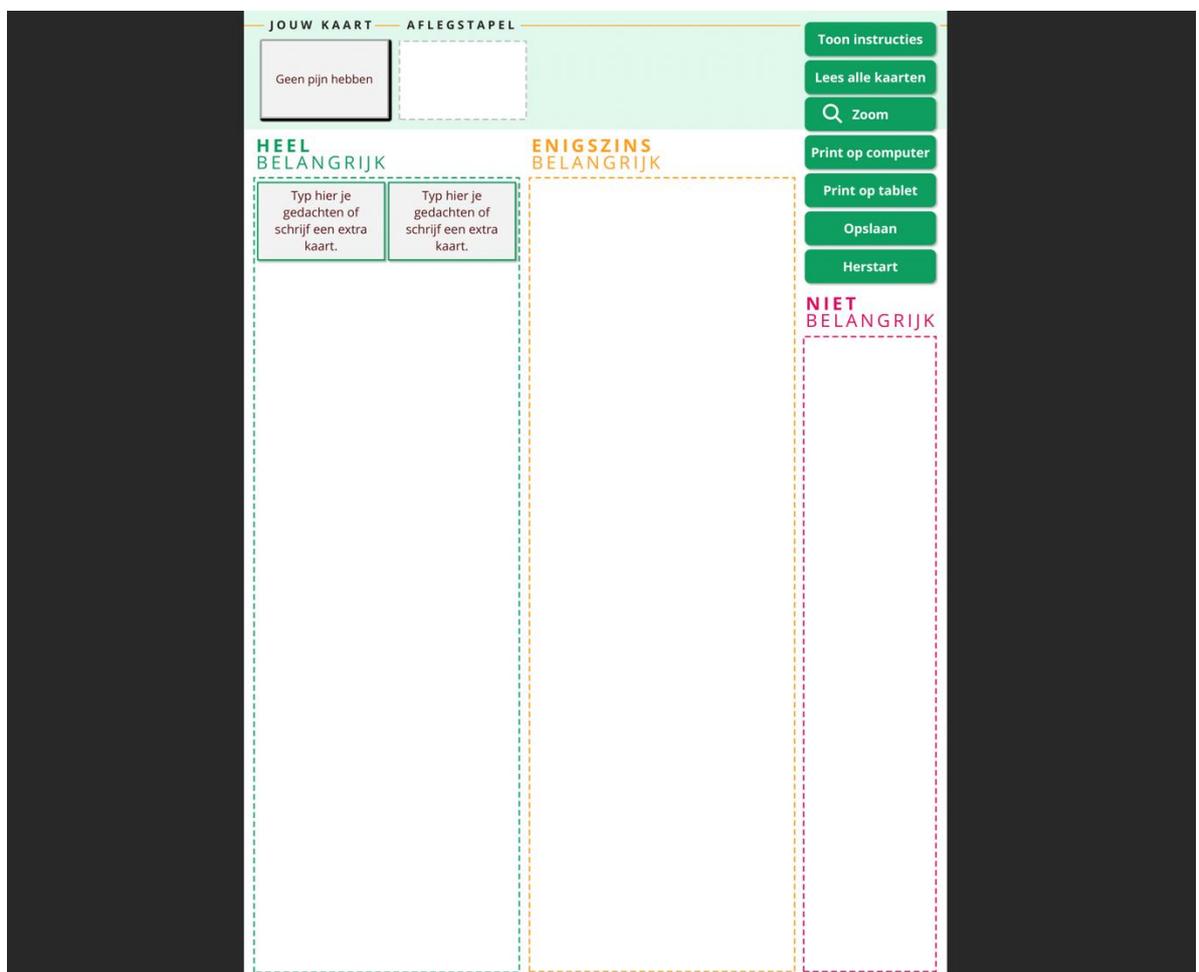

Figure 3D: Screenshot of the interactive 'Life Wishes Cards' (in Dutch)

Vroegtijdige
zorgplanning
bij dementie

aaa tekstgrootte · contrast · print

- Home
- Vroegtijdige zorgplanning: Wat is het? ▾
- Nadenken en praten over later ▾
- Opschrijven voor later
- Hulpmiddelen ▾
- Woordenlijst
- Veelgestelde vragen
- Bronnen en contact
- Over ons
- Zoek

≡◀ Lees voor ▶

Woordenlijst

Hieronder staan enkele woorden die vaak worden gebruikt wanneer het gaat over vroegtijdige zorgplanning.

Dementie ▲

≡◀ Lees voor ▶

Dementie is een verzamelnaam voor een groep aandoeningen waarbij meerdere stoornissen in het cognitieve functioneren samen optreden. Cognitieve functies zijn onder meer: het geheugen, het leervermogen, het taalgebruik en het kunnen begrijpen en uitvoeren van complexe en dagelijkse handelingen. Doorgaans is dementie chronisch en progressief van karakter. Geheugenverlies staat meestal op de voorgrond, maar dat is niet bij alle vormen zo. De stemming, persoonlijkheid en het gedrag kunnen ook veranderen.

Welke symptomen er precies optreden wordt bepaald door de aard, lokalisatie en ernst van de afwijkingen in de hersenen. De stoornissen hangen dus af van de oorzaak van de dementie. Er zijn veel verschillende oorzaken van dementie, maar de meest voorkomende zijn de ziekte van Alzheimer, fronto-temporale dementie, vasculaire dementie en dementie bij de ziekte van Parkinson. Er wordt pas van dementie gesproken als de stoornissen in het denken, de stemming en het gedrag zo ernstig zijn, dat iemand wordt beperkt in zijn algemeen dagelijks functioneren.

Bron: Expertisecentrum Dementie Vlaanderen

Voor meer informatie over dementie kan je terecht verschillende organisaties **je hier kan terugvinden.**

DNR (Do Not Resuscitate' of 'Do Not Reanimate) ▾

Euthanasie ▾

Kwaliteit van Leven ▾

Naaste(n) ▾

Mantelzorger ▾

Orgaandonatie ▾

Palliatieve zorg ▾

Patiëntenrechten ▾

Vertegenwoordiger ▾

Vertrouwenspersoon ▾

Vroegtijdige zorgplanning of voorafgaande zorgplanning ▾

Wilsbekwaamheid ▾

Wilsverklaring ▾

Zorgvolmacht ▾

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Figure 3E: Screenshot of the webpage 'Glossary' (in Dutch)

Home » Veelgestelde vragen

aaa tekstgrootte   contrast   print

Home

Vroegtijdige
zorgplanning:
Wat is het?

Nadenken en
praten over
later

Opschrijven
voor later

Hulpmiddelen

Woordenlijst

Veelgestelde
vragen

Bronnen en
contact

Over ons

Zoek

≡◀ **Lees voor** ▶

Veelgestelde
vragen

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Op deze pagina staan enkele veel gestelde vragen. Staat de vraag die je hebt er
niet bij? Ga dan naar de **contactpagina**. Op deze pagina staan contactgegevens
van verschillende organisaties waar je ook terecht kan met je vragen over
vroegtijdige zorgplanning en dementie.

Met wie moet ik best eerst praten?   ▲

≡◀ **Lees voor** ▶

Misschien vind je het moeilijk om alleen na te denken wat je belangrijk vindt en
wat je zou willen. Je kan er dan misschien over praten met iemand uit je
directe omgeving. Of je kan een afspraak plannen met een zorgverlener met
wie je een vertrouwensband hebt. Die laatste kan een arts zijn – een huisarts,
neuroloog, geriater, of andere arts – of een andere zorgverlener
(verpleegkundige, zorgkundige, maatschappelijk assistent of andere) – zoals je
zelf wenst. Het is sowieso belangrijk om met de (huis)arts, verpleegkundige,
zorgkundige of andere mensen die betrokken zijn bij de zorg voor iemand met
dementie te praten over de toekomstige zorg en behandelingen. Zorgverleners
willen namelijk graag de zorg geven aan mensen die afgestemd is op de noden
en wensen of voorkeuren van patiënten of cliënten.

**Wat als niet iedereen het eens is in de familie over vroegtijdige
zorgplanning?**   ▼

Kan ik euthanasie krijgen als ik dementie heb?   ▼

**Heeft vroegtijdige zorgplanning alleen betrekking op het einde van
het leven?**   ▼

Hoe begin ik aan vroegtijdige zorgplanning?   ▼

Hoe kies ik een vertegenwoordiger?   ▼

Is vroegtijdige zorgplanning de taak van de arts?   ▼

**Kan je van gedachten veranderen over eerdere beslissingen rondom
toekomstige zorg en behandelingen?**   ▼

Vervangt de zorgvolmacht de wilsverklaringen?   ▼

Voor wie is vroegtijdige zorgplanning?   ▼

Wanneer neemt een vertegenwoordiger mijn beslissingen?   ▼

**Wat als ik niemand heb om vroegtijdige zorgplanning mee te
bespreken?**   ▼

Wat als de arts er niet over wil praten?   ▼

**Wat is het verschil tussen een vertrouwenspersoon en een
vertegenwoordiger?**   ▼

Wat moet mijn arts weten rondom mijn vroegtijdige zorgplanning?   ▼

Bronnen en contact   Over de website en ons   Privacy policy

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Figure 3F: Screenshot of the webpage 'Frequently Asked Questions' (in Dutch)

CHAPTER 6

Evaluation of interactive web-based tools to stimulate reflection and communication about advance care planning with people with dementia and their family caregivers

Fanny Monnet, Lara Pivodic, Charlèss Dupont, Tinne Smets, Aline De Vleminck, Chantal Van Audenhove, Lieve Van den Block

Abstract

Background: People with dementia and their family caregivers often encounter challenges in engaging in advance care planning (ACP), such as a lack of information and difficulties in engaging in ACP conversations. Using a user-centred design, we developed two interactive web-based tools as part of an ACP support website to stimulate ACP reflection and communication: (1) the 'Thinking Now About Later' tool, with open-ended questions about 'what matters most', and (2) a digital version of the 'Life Wishes Cards', a card tool with pre-formulated statements that prompt reflection about wishes for future care. This study aimed to evaluate the use of and experiences with two web-based tools by people with dementia and their family caregivers.

Methods: During an eight-week period, people with dementia and family caregivers were invited to use the ACP support website in the way they preferred. The mixed-method evaluation of the ACP tools involved capturing log data to assess website use and semi-structured qualitative interviews to capture experiences. Analyses included descriptive statistics of log data and framework analysis for qualitative data.

Results: Of 52 participants, 21 were people with dementia and 31 were family caregivers. The 'Thinking Now About Later' tool and 'Life Wishes Cards' were accessed 136 and 91 times respectively, with an average session duration of 14 minutes (SD =27.45 minutes). 22 participants actively engaged with the tools, with the majority using the tools once, and seven revisiting them. Those who used the tools valued the guidance it provided for ACP conversations between people with dementia and their family caregivers. Participants reported that people with dementia experienced barriers to using the tools on their own, hence family caregivers usually facilitated the use and participation of people with dementia. Some highlighted not knowing what next steps to take after completion of the tools online.

Conclusions: Although not all people used the ACP tools, those who used them found them helpful to facilitate communication between people with dementia and their family. Family caregivers of people with dementia played a crucial role in facilitating the use of the web-based tools.

Keywords: Advance care planning, communication, reflection, web-based tools, dementia

Introduction

Advance care planning (ACP) refers to a dynamic process in which individuals can explore and identify their values, reflect upon the meanings and consequences of serious illness scenarios, define their goals and preferences for future care, identify proxy decision makers, and document preferences[1,2]. It is an ongoing communication process between patients, families, and health professionals[1,2]. ACP often focuses on considerations related to end-of-life and medical care preferences. However, our previous research has shown that people with dementia and their family caregivers find it important to discuss 'what matters most' for the future, without solely focusing on end-of-life and medical preferences[3]. This perspective resonates with the public health approach to ACP which considers ACP as a way to normalise conversations about end-of-life preferences, death and dying, and a way to align medical and physical concerns with broader concerns of both patients and family caregivers[4–6].

ACP can be relevant and valuable for people with dementia and their family caregivers[7–9]. Considering the progressive cognitive decline associated with dementia, ACP provides people with dementia the opportunity to express preferences for future care[10]. Additionally, engaging in ACP may enable family caregivers to gain insight into the values and preferences of the person with dementia, as their role in the decision-making process becomes more important[11]. Nevertheless, people with dementia and family caregivers often encounter significant barriers to engaging in ACP, including challenges such as the lack of information about what ACP is and difficulties in initiating and engaging in ACP conversations[10,12].

Using a user-centred design, we developed an ACP support website for and with people with dementia and family caregivers[13] with the aim to inform people with dementia and family caregivers about ACP and support them in reflecting and communicating about ACP. The website incorporates information about what ACP is and its relevant legal framework in Belgium, provides communication support on how to start discussing ACP within families and with health professionals, and advises them to discuss their wishes with health professionals. To support ACP reflection and communication, the website includes two interactive ACP tools: the 'Thinking Now About Later' tool, which is a fill-in reflection and communication tool with open-ended questions about 'what matters most to you', developed specifically for this website, and the 'Life Wishes Cards' tool (Levenswensen kaarten in Dutch) with pre-formulated statements that prompt reflection about what is important for future care and treatment, based on the Go-Wish cards developed in the United States[14] and the cultural adaptation and translation of the Go-Wish cards in Belgium[15]. This study aimed to explore the use of the two web-based reflection and communication tools by people with dementia and family caregivers and to evaluate their experiences with using them.

Methods

Over an 8-week period, people with dementia and their family caregivers were invited to use the ACP support website in the way they preferred. We used a mixed-method evaluation design i.e. use was evaluated by capturing the log data (continuous data collection logging user activity on the website) and semi-structured qualitative interviews to capture user experiences. This study was part of an evaluation study of the ACP support website as a whole, which is published separately[16].

Overview of the web-based reflection and communication tools for ACP

Using a user-centred, evidence-based, and theory-informed design process, we developed an ACP support website for and with people with dementia and their family caregivers in Flanders, the Dutch-speaking part of Belgium[13]. The website aims to inform and support people with dementia and their family caregivers in communicating and engaging in ACP.

The development process included people with dementia, family caregivers, healthcare professionals, and regional dementia associations. As part of this ACP website, two web-based ACP tools were developed and tested, focused on stimulating reflection and communication concerning ACP between people with dementia and their family caregivers: (1) the 'Thinking Now About Later' tool, with open-ended questions about 'what matters most', and (2) a digital version of the 'Life Wishes Cards' (Levenswensen kaarten in Dutch), a card tool with pre-formulated statements that prompt reflection about what is important for future care, based on the Go Wish cards developed in the US[14,15]. To increase user-friendliness, tutorial videos are provided to explain how to use each web-based tool. Print and save options are also offered, so that users can record their progress.

Tool 1: The 'Thinking Now About Later' web-based tool

The 'Thinking Now About Later' tool is a self-guided fill-in tool designed to facilitate a reflective process regarding ACP. Through prompts and questions, users are guided to contemplate and discuss their present and future preferences, with a focus on identifying 'what matters most'.

The need for a focus on 'what matters most' became apparent as part of a qualitative study with the European Working Group of People with Dementia (i.e. a multinational group composed of people with dementia who are nominated by their national associations, and their supporters, coordinated by Alzheimer Europe), which we had performed earlier to inform the development process of the ACP support website. This work highlighted the need for strengthening the focus on social aspects of care in ACP and on what matters most to people for their future. The European Working Group of People with Dementia found that current ACP definitions focus too much on medical care alone, and

recommended that broader aspects of what matters to people for the future, on social care, and on future meaningful daily life activities should be included[3].

LVdB and CD developed a first version of the 'Thinking Now About Later' tool, involving the expertise of the project management group (FM, CD, TS, LP and LVdB) who made all final decision about content and design of the website[13]. As part of the iterative user-centred and stakeholder-informed design, the tool was reviewed by an advisory group composed of people with dementia, family caregivers, palliative care experts, and representatives from dementia associations and was tested with several groups of research participants including people with dementia and family caregivers[13].

Divided into nine sections, the 'Thinking Now About Later' tool offers a comprehensive exploration of personal values and preferences related to present and future care. Users can navigate all sections through prompts addressing key aspects, such as current and future priorities (e.g. your health, your independence, daily activities that are important to you, what you still want to do in the future, where you reside, social connections, seeing family/ friends/ colleagues regularly, expressing your faith, or experiencing nature or culture), preferences for care and treatments (e.g. consent or refusal of treatments if they would not improve comfort), identification of trusted individuals and/or legal representatives, documentation of preferences through advance directives, and the articulation of any additional considerations important to the person. The tool is meant to be flexible in use, allowing users to skip sections if desired, and acknowledges the subjective nature of responses, highlighting that there are no right or wrong answers. Furthermore, the tool provides practical guidance on next steps, encouraging users to share their preferences with family, friends, and healthcare professionals. For those who are still unsure about what they find important and want for their future care and treatments, the tool suggests using the 'Life Wishes Cards' (Levenswensen kaarten in Dutch) as a reflective aid.

An English translation of the 'Thinking Now About Later' tool can be found in Appendix 1.

Tool 2: The 'Life Wishes Cards' web-based tool

The 'Life Wishes Cards' (Levenswensen kaarten in Dutch) are an adaptation of the Go-Wish cards developed in the United States[14]. They serve as a tool to foster conversations on end-of-life preferences and preferences for future care through preformulated statements that can be organised according to perceived importance for the user. In our previous work, we undertook the translation and cultural adaptation of the original cards for application in Flanders, Belgium[15]. For inclusion on the ACP support website, we subsequently digitised them.

The 'Life Wishes Cards' tool consists of 37 cards, each containing brief statements reflecting preferences for end-of-life scenarios (e.g. "Dying at home", "Keeping my dignity" or "Being surrounded by my family"). For the digital version, users are asked to categorise the statements into three columns: Very important, somewhat important, or not important. If uncertain, users can place cards on a discard pile. Participants are prompted to reflect on the importance of each statement, envision its role in their future, and consider how their dementia diagnosis may influence their perspectives. If specific priorities are not covered by the preformulated statements, two 'wild cards' allow users to add unique considerations that they deem important. The original paper version of the 'Life Wishes Cards' required people to rank the cards they selected as very important to prioritise their 10 top priorities. However, it was found that people with dementia experienced difficulties with such ranking, therefore the digital version did not include this ranking exercise[15].

The tool serves both reflective and communicative purposes. Users can engage in conversations, explaining their reasoning for each card's importance, and gather insights from others. Additionally, users can save and print their selections, providing a tangible resource for discussions with others, including healthcare professionals. Users can also come back to their selection and reorganise the cards if they want to.

An English translation of the digitised "Life Wishes Cards" tool can be found in Appendix 2.

Participants and recruitment

The evaluation study took place in Flanders, the Dutch-speaking part of Belgium, and with Dutch-speaking participants in Brussels, where both Dutch and French are official languages. People with dementia and family caregivers were recruited to the study as dyads; family caregivers were recruited on their own. Eligibility criteria are summarised in Table 1.

Table 1: Eligibility criteria

For people with dementia	Being diagnosed with young- or late-onset dementia
For family caregivers	Taking active care (physical, emotional, social, etc.) of the person with dementia
For both	Having an interest in and being willing to try out the ACP website
	Being able to consent to study participation
	Speaking and understanding Dutch
	Having a device that can open the website (computer, tablet, mobile phone)
	Did not participate in the cognitive testing of study materials in a previous study phase
	At least one member of the dyad should be able to navigate the website (e.g. the person with dementia and the family caregiver cannot both have disabilities preventing them from using the ACP support website)

Participants were recruited through regional dementia organisations and neurologists working in two memory clinics. Health professionals were asked to identify and approach potentially eligible participants. If participants expressed an interest in the study, they were referred to the researchers who sent them an information letter and an informed consent form. We organised onboarding sessions where participants were able to discuss their participation in the study, provide informed consent, and were introduced to the ACP support website. The evaluation study aimed to include a diverse group of participants (i.e. different ages, genders, types of dementia, and relationships between the person with dementia and the family caregiver). The published research protocol provides a comprehensive account of recruitment strategies[16].

Data collection

Sociodemographic data, encompassing age, gender, computer literacy, type of diagnosis, and date of diagnosis, was collected through a survey administered at the beginning of the 8-week study period. During the 8-weeks study period, continuous data collection was conducted by logging user activity on the website. This log data was used to record type, frequency, and timeframe of usage of all components and features of the ACP support website. In this study, we focused on the interactions with the web-based reflection and communication tools.

We conducted semi-structured interviews with dyads composed of people with dementia and family caregivers, or with family caregivers alone, to explore their experiences of using the ACP website. Interviews were conducted at the end of the 8 week-study period. The interviews were conducted in Dutch, between October 2022 and May 2023 and took place in the participants' homes. The interview questions included questions about participants' experiences with the different components of the ACP support website including the two interactive ACP tools. Follow-up questions were asked as needed to clarify participants' answers. All interviews were completed by the third author (CD) or a research assistant.

Data analysis

Descriptive statistics were used to analyse participants' sociodemographic characteristics, using SPSS. To analyse the log data of the interactions with the web-based tools, we used R. The data was summarised using descriptive analysis.

All interviews were recorded and transcribed verbatim. All transcripts were pseudonymised. We conducted thematic framework analysis[17], with the assistance of the qualitative analysis program NVivo. The process of thematic framework analysis involves several key stages. They encompass data

familiarisation, the development of a thematic framework, indexing all data against this framework, charting to condense the data, and finally, mapping an interpretation. Transcripts were read through while listening to the audio recording. FM and CD then read and re-read the transcripts to familiarise themselves with the interview data. Next, analysing a subset of the interviews, they established subcodes based on the interview guide and created new subcodes when necessary, forming a preliminary framework for analysis. The two researchers then compared their coding, and differences were discussed and resolved as to agree to a definite framework. FM and CD then systematically applied this framework to all the interview transcripts. In the final step, data were abstracted to create final themes. The researchers reviewed the final themes to reach consensus in the interpretation of the data.

Ethics

This study received approval from the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel on 07 October 2022 (B.UN 1432022000179), and all participants provided written informed consent. We obtained informed consent from potential participants using a double-consent approach (i.e. consent for patients' participation is signed both by themselves and by their family caregivers acting as witnesses). The researchers ensured participants' understanding of the study and their rights by engaging in discussions regarding the information presented in the informed consent form with both people with dementia and their family caregivers[16].

Results

In total, we included 52 participants in the study, of which 21 were people with dementia and 31 were family caregivers of people with dementia. All people with dementia participated together with their family caregivers, and 10 family caregivers participated on their own. Reasons for participating on their own were that the person with dementia: (1) was unable to provide consent to participate in the study, (2) did not wish to participate in the study, (3) recently moved to a nursing home, or (4) did not want to discuss ACP. An overview of the participants' characteristics is provided in Table 2.

Table 2: Sociodemographic characteristics of people with dementia and family caregivers

Number of people with dementia		21
Age, mean (SD)		62.1 (10.9)
Age range		50-78
Gender, n (%)		9 female (43), 12 male (57)
Type of diagnosis, n (%)	Alzheimer's disease	15 (71)
	Vascular dementia	1 (5)
	Frontotemporal dementia	3 (14)
	Lewy body dementia	1 (5)
	Unknown	1 (5)
Highest education level, n (%)	Primary school	6 (29)
	High school	5 (24)
	Applied sciences	7 (33)
	University	3 (14)
Profession, n (%)	Employed	1 (5)
	Retired	20 (95)
Relationship to caregiver, n (%)	Partner	18 (86)
	Parent (in law)	3 (14)
Self-rated computer skills, mean (SD), scale range: 0-10		4.2(3.1)
Number of family caregivers		31
Age, mean (SD)		62.8 (10.4)
Age range		34-84
Gender, n (%)		21 female (68) , 10 male (32)
Type of diagnosis, n (%)	Alzheimer's disease	20 (64)
	Vascular dementia	3 (10)
	Frontotemporal dementia	3 (10)
	Lewy body dementia	1 (3)
	Parkinson's dementia	1 (3)
	Unknown	3 (10)
Highest education level, n (%)	Primary school	3 (10)
	High school	5 (16)
	Applied sciences	14 (45)
	University	9 (29)
Profession, n (%)	Employed	16 (52)
	Retired	15 (48)
Relationship to person with dementia	Partner	25 (81)
	Son/daughter (in law)	6 (19)
Self-rated computer skills, mean (SD), scale range: 0-10		7.5 (2.1)

Frequency and type of use of the web-based reflection and communication tools

During the 8-week period, the 'Thinking Now About Later' tool and the 'Life Wishes Cards' tool were visited a total of 136 and 91 times respectively. The time spent per session on one of the tools ranged from 1 to 90 minutes, for an average of 14 minutes (SD = 27.45). The log data showed that, of the 52 participants, 22 actively used the web-based tools, i.e. sorting cards in the 'Life Wishes Cards' tool and filling in the 'Thinking Now About Later' tool. Among participants who used the web-based tools, 15 participants used them once. Seven participants revisited one of the tools at another time.

Perceived usefulness of the web-based reflection and communication tools

In the interviews, those who had used the tools mentioned that they particularly valued the web-based tools, i.e. the 'Life Wishes Cards' tool and the 'Thinking Now About Later' tool. Both people with dementia and family caregivers highlighted the inherent value of such tools in providing guidance for supporting ACP conversations between people with dementia and their family caregivers. This guidance was seen as a way to eliminate the need for users to independently generate topics for discussion. They appreciated that the web-based tools provided concrete examples and scenarios to discuss and welcomed the interactive aspects of the tools such as the opportunity to fill in boxes or sort statements according to importance.

> *"That's precisely the added value of that website, you know. That you have tools - that you don't have to come up with things yourself about what we're going to talk about this time. You have a tool. You have a structure. That is important because otherwise you are a bit unfocused - or not really unfocused, but... Now it's really... There's a guiding line to it. That's good."*
> *– Person with dementia #21*

Furthermore, family caregivers noted that the tools were valuable for their family member living with dementia, as it allowed them to express thoughts that they deemed significant but struggled to communicate. The tools allowed participants to identify topics that they found important to discuss and gave them the opportunity to start these conversations. One family caregiver mentioned that while using the cards, her partner had emphasised the importance of discussing death and dying and admitted that he had rarely engaged in such discussions. The card tool on the website provided the prompt needed to open the conversation about this topic.

> *"He also mentioned that he has always considered discussing death important. He feels that he doesn't do it enough. And there was actually a card in there [in the Life Wishes cards] about 'Talking about what death means to me,' that was something on that card."*
> *– Family caregiver #8*

Finally, both people with dementia and family caregivers mentioned that they found it important to be able to revisit the web-based tools and not only use it once. They noted that it would not be sufficient to only use it once, as ACP topics required a significant amount of reflection and communication. Many saved the results of their first-time use with the intention of revisiting their preferences and perhaps adapting them based on new information provided on the website or by health professionals. Some participants also noted that they would like to keep using the tools after the study period.

> We filled it [the Life Wishes cards] out at the beginning and then filled it out again after the 8 weeks. By actually reading everything and understanding how to approach these topics, there were some aspects that I used to think were unimportant, that I now find important. – Family caregiver #26

Perceived barriers to using the interactive reflection and communication tools

Although most participants found both the web-based tools useful and user-friendly, some family caregivers noted that they could be more concrete. They found the tools a good way to initiate conversations but were unsure about what the next step should be once they had discussed the different prompts on the 'Life Wishes Cards' tool or the 'Thinking Now About Later' tool. Furthermore, five participants, both people with dementia and family caregivers, also pointed out that there were many prompts and it felt like they would never be done, which could be frustrating. They compared it with the fact of filling in an advance directive, which they argued can be more satisfying as it could lead to having the feeling of a completed document and the feeling of having their affairs in order. They mentioned that with the use of the web-based tools, they remained in a state of reflection, which could give them the feeling of an uncomplete process and 'not being finished'.

> "Well, I have the sense of 'That's not finished yet.' But that probably won't be possible, right? But at some point, you want such a finished document, where you say, 'We've discussed that enough now; it's done!' And then you save it somewhere or print it out once, for example, to discuss it with the children. But I don't have the feeling now of 'We've gone through it completely.' Maybe I haven't gone into it deeply enough... I don't know how to explain it, but I don't think you can do it in one go. I want to look at it a few more times, so to speak, to see, 'Is that what you want? Are you sure?" – Family caregiver #2

Although no technical difficulties were reported, people with dementia preferred to use the website together with family caregivers due to a lack of confidence and out of fear of doing something wrong. Several family caregivers also reported that their family member with dementia would not be able to

use the website on their own. This was either because the stage of dementia was too advanced, or because of a lack of digital skills. In the case that family caregivers felt the person with dementia struggled to use the web-based tools, family caregivers took the lead in the use of the website and guided their loved ones through the web-based tools. Some family caregivers explained the measures they took to use the interactive tools together with their family members with dementia and support them in using these tools. For both tools, but especially the 'Life Wishes Cards' tool, they read each prompt out loud and clearly asked them whether they found it important, somewhat important, or not important. While these dispositions seemed to facilitate and enhance the participation of people with dementia in some instances, in other cases family caregivers noted that it did not result in in-depth conversations, or that they needed to ask several small follow-up questions to help clarify the preferences of their family members with dementia.

"I start with - 'What's your reaction when you see that card?' And then organising, how important do you find it? If it's very important, then I try to confirm with a few more questions what he meant." – Family caregiver #16

Finally, a few family caregivers and people with dementia used the interactive tools together and then mentioned that they would wait until their appointment with their doctor before revisiting them. They mentioned that they may gain new insights into possible treatments and that would help them to revisit their preferences using the web-based tools. Thus, discussions with health professionals seemed to be seen as an important facilitator or support in the use of the web-based tools.

"After using the interactive tools, we now have a list of what he finds important - occasionally, I do say, 'We'll take another look at that.' We've created a sort of ranking from 1 to 10 of the things he finds the most important. We need to go to the doctors in February, where we can discuss possible treatments that he would and wouldn't undergo. Afterwards we'll try again to see, 'Is it really the order you deemed important?" – Family caregiver #19

Discussion

In this study, we described and evaluated two web-based reflection and communication tools on ACP for people with dementia and their family caregivers, namely the 'Thinking Now About Later' tool and the 'Life Wishes Cards' tool. Both are grounded in a 'what matters most to you now and in the future' approach and aim to provide a flexible way to support ACP within the family context. Our results showed that more than half of the participants that used the ACP support website did not use the web-based reflection and communication tools. However, for those that did use the tools, they were perceived as useful and provided a framework or guidance for people with dementia and family

caregivers to engage in ACP conversations. The 'Thinking Now About Later' tool and the 'Life Wishes Cards' tool encouraged people with dementia and family caregivers to think about and talk about their preferences for current and future care and medical treatments from the perspective of 'what matters most' to them. This 'what matters most' approach was well received by participants in our study, and they found it a useful way to engage in ACP conversations. Barriers to use included a lack of concrete steps to take once the web-based tools were completed. Furthermore, participants experienced challenges with the use of the 'Life Wishes Cards' particularly, as people with dementia sometimes had difficulties using them on their own and family caregivers had to assume a facilitating role by explaining the pre-formulated statements to encourage reflection and communication.

Out of the 52 participants, 22 participants actively used the web-based reflection and communication tools. The ACP support website on which the web-based reflection and communication tools were embedded had two main goals: providing information about ACP and supporting initiation and engagement in ACP conversations between people with dementia and family caregivers. The web-based tools were mainly developed to address the second aim. In both the development study and the evaluation study of the ACP support website as a whole, we found that people with dementia and family caregivers navigated the website in a flexible manner (i.e. some only read the information provided on the website, only used the advance directives provided on the website, or preferred to use the web-based tools more intensively)[13,16]. This flexible navigation is meant to accommodate diverse ACP readiness levels observed in people with dementia and family caregivers[10,18–20] and thus may explain why half of the participants actively used the tools and the other half did not.

People with dementia experienced barriers to using the web-based tools, with family caregivers stating that this was due to either a lack of digital skills or due to the cognitive decline associated with dementia. Family caregivers often took the lead in the use of the tools, adopting different strategies to include the person with dementia through simplified explanations of the content of the web-based tools or prompts and follow-up questions to stimulate participation from the person with dementia. This is consistent with previous studies that emphasise the significant contribution of family caregivers as primary providers of support and guidance for people with dementia[21,22]. In the context of the use of technology particularly, family caregivers frequently play a vital role in in ensuring accessibility and overcoming challenges to technology use[21,22]. However, in instances where people with dementia may heavily rely on the digital skills of family caregivers, it could potentially place an added burden on the family caregivers[23]. This also implies a lower accessibility to the tools for people with dementia who do not have family caregivers or other people who can help them with this. There is a need to explore

strategies to address potential support needs of people with dementia, while also ensuring that family caregivers are adequately supported in their facilitating roles.

However, the challenges experienced by people with dementia, especially with the 'Life Wishes Cards', may not be solely due to the web-based nature of the tool. Paper-based card sorting tools have been shown to be effective in eliciting preferences for people with dementia[14,15,24,25], yet they can present similar challenges to those encountered in our study. Previous research into eliciting ACP preferences with card tools has found that a more thorough facilitation process may be required depending on factors such as cognitive decline, impaired sight or loss of motor skills[26]. This may include turning statements into questions for the person with dementia or revisiting the use of the cards at a later time.

A lack of concrete steps to take after the completion of the web-based tools was pointed out. Although the web-based tools explicitly encouraged users to communicate preferences with family members, friends, and health professionals, some of our participants mentioned lacking guidance on the next steps to take after having used the web-based tools and lacked the feeling of having finished or completed the ACP process. This finding might be related to the remaining idea among some participants that there always needs to be a concrete product such as an advance directive in an ACP process. It might also be related to the need of some people to have tangible and concrete outcomes or outputs when engaging in a planning process. Earlier research has found that people with dementia and family caregivers often associate ACP with medical planning, often through advance directives[29]. However, it should be noted that some participants in our study did describe the concrete steps they would talk after having used the tools i.e. bring the results from their use of the tools to their next medical appointments to discuss them with their healthcare providers. This again shows the difference between people in how they approach an ACP process and what they find supports this process. It also highlights the potential role of health professionals in supporting the use of the web-based reflection and communication tools and providing more concreteness after the use of the web-based tools.

The web-based reflection and communication tools included in our study are the first to address the specific ACP needs of people with dementia and family caregivers. The evidence-based nature of the tools, rooted in international ACP literature and cultural adaptation processes, positions them as valuable resources for diverse populations. Whilst the local legal and regulatory context influenced some of the content of the two web-based reflection and communication tools, the 'what matters most' approach and the flexible navigation adopted in the web-based tools can be widely applicable. A recent systematic review has shown that most web-based ACP tools available to the public do not provide information about their development process, are not evidence-based, and are not evaluated

in a study. Our study provided a transparent and detailed description and evaluation of the two web-based ACP tools.

A few limitations need to be considered in this study. Firstly, the interviews involved family caregivers on their own or joint interviews with both the person with dementia and their family caregiver. There may be a risk of the family caregivers' perspectives overshadowing those of the people with dementia, possible leading to an incomplete understanding of the latter's experiences. Additionally, while efforts were made to include a diverse sample, participants predominantly represented a highly educated demographic.

Future research should further evaluate how people with dementia and family caregivers use the web-based communication and reflection tools and their potential role in discussing ACP with health professionals in the professional context. Additionally, researchers should focus on how to best support the use of the web-based reflection and communication tools, and whether an element of human interaction, such as a training, could effectively support people with dementia and family caregivers.

Conclusion

This study presented and evaluated two web-based reflection and communication tools to support ACP for people with dementia and family caregivers, the 'Thinking Now About Later' tool and the 'Life Wishes Cards' tool, which were part of an ACP support website. While not all participants visiting the ACP support website used the web-based reflection and communication tools, those who did use the tools had positive perceptions regarding the usefulness of the tools. We identified certain barriers in the use of the web-based tools, including a lack of concrete steps to take after completion of the tools and challenges in practical usage for some people. The study also highlighted the pivotal role of family caregivers as facilitators in using the web-based tools and the need for tools that allow flexible use tailored to people's needs.

Supplementary materials

Appendix 1: English translation of the 'Thinking Now About Later' tool

Appendix 2: English translation of the 'Life Wishes Cards' tool

Appendix 3: Interview topic guide

Declarations

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Conflict of interest

The authors declare that they have no competing interests

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Author contributions

Study concept and design: All authors. Acquisition of data: CD. Analysis and interpretation: FM and CD. Drafting of the manuscript: FM. Critical revision of the manuscript: All authors. All authors gave final approval of the version to be published.

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Supplementary Materials of Chapter 6

Appendix 1: English translation of the 'Thinking Now About Later' tool

Tool

'Thinking Now about Later'

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This tool helps you reflect on what is important to you regarding future care and treatments. It assists you in preparing yourself and others for difficult choices later.

- You will encounter various questions about what is important to you now and in the future.

- You don't have to answer all the questions.
  Do you want to skip a question? Then tap 'next'.

- Your answers are personal. There are no right or wrong answers.

- You can always modify or add to each answer.

- You don't have to answer all the questions at once.
  You can save what you've noted and continue later.

- You can download your answer as a PDF. Or you can print them out.

- You can complete the questions on your own or with someone close to you.
  Maybe this will help you start a conversation about advance care planning.

- Do you find some of the questions too challenging?
  Discuss them with a doctor or healthcare provider you trust.

- This tool is entirely anonymous. No one can see your answers.

Learn more about your privacy [external link]

My choices

Print

Save

Restart

Overview

Below, you'll find the full contents of this tool. Don't want to view a particular section? Then click on the next arrow to skip that part.

1. Use and fill in the 'Thinking Now about Later' tool.

2. What is important to me now and in the future?

3. What do I want for my future care and treatments in the future or at the end of life?

4. Who is my trusted person and legal representative?

5. Do you want to document your preferences and choices in an advance directive?

6. Are there other things that are important to you?

7. Next steps: What now?

8. Still unsure about what you find important and want for your future care and treatments?

9. End

Click on the arrow to go to the next page

Using and filling in the 'Thinking Now about Later' tool

Below, you'll find some important questions to help you determine what is important to you and what you would like for your future care and treatments. Each question also includes some explanations and examples to get you started. These questions are meant as inspiration; you don't have to answer them all. There are no right or wrong answers to the questions in this tool. Your answers are likely never complete either. It's about what you find important and what you would or wouldn't prefer. You can and may always modify or supplement your answers. You also don't have to answer all the questions. By clicking on the next arrow, you can skip a question.

Click on the arrow to go to the previous page

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What is important to me now and in the future?

This is not an easy question. By answering this question, you can get an idea of what is important to you and what you value. This can be about the present but also about the future. You can think about different things: your health, your independence, what activities are important to you, what you still want to do in the future, and where you want to reside. You may also think about your social connections, seeing family, friends, and colleagues regularly, expressing your faith, and experiencing nature or culture. These are just a few examples of what could be important to someone.

WHAT IS IMPORTANT TO ME IN MY LIFE?

Additional questions for inspiration

Type here what is important to you in your life.

WHAT IS IMPORTANT TO ME IN MY FUTURE?

Additional questions for inspiration

Type here what is important to you in your future.

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WHAT IS IMPORTANT TO ME IN MY LIFE?

Additional questions for inspirations could be:

- Who is important to me?

- Which daily activities are important to me?

- What brings me happiness?

- Where do I derive my energy from?

- What makes my life meaningful?

- What do I value in my life?

WHAT IS IMPORTANT TO ME IN MY FUTURE?

Additional questions for inspirations could be:

- What do I hope the future will look like?
- What do I definitely still want to do in the future?
- What do I hope not to lose?
- When would life be less meaningful to me?
- When I think about the future, what do I worry about?
- When I think about dementia, what is the best and worst that could happen to me?

My choices

Print

Save

Restart

What do I want for my future care and treatments in the future or at the end of life?

In the future, decisions will need to be made about the care or the treatments that you will need. This could be about a variety of things. It could be about where you live, the people providing you care, as well as decisions you would make at the end of life.

Additional questions for inspiration

I WOULD STILL LIKE TO…

Type here what you would still like.

I WOULD RATHER NOT…

Type here what you would rather not want.

WHAT DO I WANT FOR MY FUTURE CARE AND TREATMENTS?

The following questions can help you think about this:

- Do I want to live as long as possible even if my quality of life is lower?
- Would I prefer to be comfortable and pain-free, even if this means I live a shorter life?
- Where would I like to receive care at the end of life? Where not?
- Would I want to go to a hospital? When would I, when would I not?
- Would I want to go to a hospital to die? How important is for me to die at home or in my nursing home?
- Are there specific treatments I no longer want, such as artificial nutrition, surgery, artificial ventilation, or resuscitation?
- Would I want palliative care?
- Would I want life-prolonging treatments?
- Would I still want treatments if they do not improve my comfort?

Your past experiences can also influence what you want for your future care and treatments. Questions you can ask yourself include:

- What experiences have I had in the past, and what have I learned from them for myself?
- How does that influence what I want for my future care and treatments?

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Who is my trusted person and my legal representative? (1/2)

A trusted person is someone you choose yourself and who can assist you in exercising your patient rights (think, for example, of assisting you during your appointments with a doctor). A legal representative is someone who makes decisions on your behalf, defends your interests, and exercises your rights, but only when you are no longer able to do so yourself. These can be the same person, but they can also be different people. When selecting a trusted person and/or a legal representative, it is best to choose someone you trust completely, such as a family member or a close friend, who agrees to be your trusted person and/or legal representative.

Some people know well who their trusted person and/or legal representative can be; others are not so sure, and that's okay. If you do not designate anyone as your legal representative, it is legally determined who would make decisions on your behalf if you are unable to do so yourself.

On the next page, you can write down who your trusted person or legal representative is, if you have chosen one. It is important that the person you want as your trusted person and legal representative is aware of this. Therefore, it is important to discuss this with them.

Who is my trusted person and my legal representative? (2/2)

MY TRUSTED PERSON IS

First name: Type here the first name

Last name: Type here the last name

Your relationship with this person: Type here your relationship

If you want to, you can write down the reason why you picked this person:

Type here your reason.

MY LEGAL REPRESENTATIVE IS

First name: Type here the first name

Last name: Type here the last name

Your relationship with this person: Type here your relationship

If you want to, you can write down the reason why you picked this person:

Type here your reason.

Do you want to document your preferences and choices in an advance directive?

What you want and do not want for your future care and treatments can be documented in an advance directive. Advance directives are documents that can be completed when you have legal capacity (legal capacity refers to someone's ability to understand the consequences of a particular action, situation, or decision). They are intended to guide end-of-life decisions IF you are entirely lacking capacity. In Belgium, there are five advance directives. More information on how to fill them out can be found here [external link].

Filling out advance directives can be difficult. The language is also sometimes very legal in nature. There is often a lot of confusion among the public about what they are exactly and when they apply. Therefore, it is advisable to discuss these advance directives in consultation with a doctor or healthcare professional.

Are there other things that are important to you?

Perhaps in this tool, you haven't been able to write down everything that is important to you or what you would like for the future. Are there specific things that are important to you as you approach the end of life? This could involve specific wishes regarding your funeral or certain rituals (religious or otherwise) that are important to you:

THIS IS ALSO IMPORTANT TO ME:

Type here what is important to you.

Next steps: what now?

If you don't share what you've written in this tool with others, they won't know what you would like. Therefore, it's important to talk to others about it. This can happen in multiple conversations. You can discuss this with your caregiver, family, friends, or other people close to you. It's also crucial to talk to the (family) doctor, nurse, healthcare professional, or other people involved in your care. Healthcare providers want to provide you with care that aligns with your wishes and preferences.

Still unsure about what you find important and want for your future care and treatments?

Perhaps you found it difficult to formulate answers to the open-ended questions in this tool, or you're still uncertain about what might be important. You can also use the Life Wishes cards. By using the Life Wishes cards, you can get an initial idea of what might be important and what you would or would not want. You can use the cards on your own to reflect quietly or together to discuss.

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My choices

Print

Save

Restart

The End.

Click above on **Print** to print your choices from this tool.
You can also click on **Save** and exit this tool to come back
and review your choices later.

To exit this tool, you can close this tab.
Afterwards, you can continue exploring the website.

Appendix 2: English translation of the 'Life Wishes Cards' tool

Life Wishes cards

To help you think and talk about what is important to you and what you would like for your future care and treatments, you can use the Life Wishes cards. Life Wishes contain 37 cards. On these are brief statements that can help you think and talk about what is important. Below is a short video with instructions:

Go to the cards

Being surrounded by good friends

Keeping my sense of humor

Show instructions

Read all cards

🔍 **Zoom**

Print on computer

Print on tablet

Save

Restart

VERY IMPORTANT

Type here your thoughts or write and extra card.	Type here your thoughts or write and extra card.
Not being in pain	Not being afraid
Having physical contact	That my family is prepared for my death
Being able to say goodbye to my loved ones	

SOMEWHAT IMPORTANT

Not being short of breath	Being neat and tidy
Dying at home	Being able to take care of unfinished business with family or friends
Being treated the way I wish to be treated	Keeping my dignity

NOT IMPORTANT

Being able to share my memories and accomplishments with others

Type here your thoughts or write and extra card.

Using the Life Wishes:

In total, there are 37 cards with short statements (for example, "having no pain", "keeping my sense of humor"). Some of these statements may be important to you, while others may be less so. **To assist your thoughts on "what is important to me or not"**, there are three piles where you can place the cards.

Read each card and consider: To me, does this card belong on:
- **Pile 1:** the cards that you find very important
- **Pile 2:** the cards that you find somewhat important
- **Pile 3:** the cards that you do not find important

If you're unsure, place the card on the **discard pile**.

Questions you can ask yourself while using the cards:
- Do I think this is important?
- Would I want this in the future?
- Does my diagnosis influence how I think about this later?

Do some of the things that are important to you not appear on the cards? If so, you can use the 'wild card'. Wild cards allow you to write down something that is important to you but is not on the other cards. Type in the 'Wild card' field what you still find important. For example: walking in nature or having someone take care of my pets. You can find the wild cards in the "very important" pile.

You can use the cards to reflect on what is important to you. The cards can also be used to talk together. Explain to the person you are using the cards with the reasons why you find a card important or not. They can also tell you their thoughts on the card. The piles you create are not fixed. The choices you make today may change later. Feel free to drag the card back or place it in one of the other piles. You can also print what you have laid out. For example, you can take this document be to the doctor or another healthcare provider to discuss with them.

Start with the Life Wishes

Below, you can read all the possible cards. Click on the arrow to see the next cards

1	Not being in pain
2	Not being short of breath
3	Being neat and tidy
4	Not being afraid
5	Having physical contact
6	That my family is prepared for my death
7	Dying at home
8	Being able to say goodbye to my loved ones
9	Being able to share my memories and accomplishments with others
10	Being able to take care of unfinished business with family or friends
11	Being treated the way I wish to be treated
12	Keeping my dignity
13	Keeping my sense of humor
14	Being surrounded by good friends
15	Having someone who listens to me
16	Not being a burden to my family
17	Being able to do something for someone else
18	Being able to talk about what scares me
19	Being surrounded by my family

Below, you can read all the possible cards. Click on the arrow to see the previous cards

20	Feeling that my life is complete
21	That the doctor sees me as a whole person
22	Not dying alone
23	Be clear-headed
24	Being able to pray
25	Having a spiritual counselor as support
26	Being able to talk about death
27	Be at peace with God
28	Getting my financial affairs in order
29	Knowing how my body and mind will change
30	Avoid discussions by ensuring my family knows what I want
31	Having someone to speak up for what I think is important
32	Being able to trust my doctor
33	Having a healthcare professional I feel comfortable with
34	Arrange my funeral in advance
35	Not being dependent on machines to keep me alive
36	Being able to choose when and how I die
37	Being able to record my choices

Appendix 3: Interview topic guide

Introduction
Interview questions on the website as a whole on the following topics: • Awareness and knowledge of ACP   • Reflections and experiences about ACP   • Experiences with advance directives   • Usability of the ACP support website   • Acceptability of the ACP support website   • Feasibility of the ACP support website
User experiences with the website and the interactive tools   • How did you experience using the website? (Discuss different elements of the website, including the Life Wishes and the 'Thinking Now About Later' tool)   • How did you feel about the interactive tools? Were they useful? Did you experience any difficulties?   • How did you feel when using the website, and the two interactive tools?   • Did you feel you could apply the tips discussed in the interactive tools?   • Would you keep using the tools in the future?
Conclusion

– PART IV –

RECOMMENDATIONS FOR FUTURE WEB-BASED TOOLS TARGETING COMMUNICATION AND DECISION-MAKING FOR PEOPLE WITH DEMENTIA

CHAPTER 7

Usability of web-based tools designed for communication and decision-making in dementia: systematic review and design brief

Fanny Monnet, Michael P Craven, Charlèss Dupont, Lieve Van den Block, Lara Pivodic

Abstract

Objective: To identify usability requirements, usability testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care.

Methods: We conducted a systematic review with narrative synthesis. Five databases were systematically searched in February 2023. The quality of the included studies was assessed using the Mixed Methods Appraisal Tool.

Results: A total of 1,032 articles were identified and 7 fulfilled inclusion criteria. Web-based tools addressed technology usage, health promotion, home modification information, shared decision-making facilitation, and information needs and social isolation. Methods to test usability included surveys, interviews, focus groups, cognitive walkthroughs and think-aloud procedures. Findings suggested reducing cognitive load, enhancing readability, providing clear language, and emphasising the need for additional support for people with dementia.

Conclusion: Usability requirements ranged from visual appearance and navigation to delivery of content and support needed. This review contributes to efforts to improve design and development of web-based tools targeting communication and decision-making in dementia care. Further research should address tailored support to enhance usability for people with dementia.

Practice implications: Design recommendations include optimising information delivery and presentation, enhancing visual elements, streamlining navigation, providing concrete examples, using clear language, and offering training and tailored support.

Protocol registration: PROSPERO ID - CRD42022338438

Introduction

Dementia is a progressive neurodegenerative illness that leads to significant cognitive and functional decline. Dementia is generally characterised by impairments in memory, language, and sensory awareness as well as changes in personality[1]. During the dementia trajectory, people with dementia and their families may be required to make important decisions concerning various aspects of daily living such everyday activities or financial decisions, as well as decisions such as treatment options or choices for end-of-life care[2]. Decision-making can be hampered by the decline in cognition associated with dementia, such as the decline in communication abilities which is a key component of decision-making[3]. Indeed, the ability to communicate can be greatly affected throughout the dementia trajectory, creating obstacles like word-finding difficulties, reduced contextual understanding, or an inability to concentrate during conversations[4]. These communication challenges can cause frustration and stress for people with dementia and their caregivers and can have a negative impact on their social relationships, personal well-being, and self-image[5,6].

The availability and use of web-based tools designed for people with dementia and their family caregivers have seen a notable surge over the years and have targeted, among others, communication and decision making[7–9]. These tools encompass a wide range of software, spanning from websites to communication programs, and are all accessible through computer, tablet, or mobile interfaces[10]. However, the loss of cognitive functions associated with dementia can also impact individuals' experiences and use of web-based systems[11,12]. For instance, people with dementia can struggle with tasks such as remembering where they are during a task or process within a system, or experience increased problems with perception of colour, shape and movement[11]. Because of the dementia related changes experienced by people living with dementia, many have recognised the importance of designing dementia-inclusive interfaces with a focus on usability[11,13,14]. Usability is defined as the degree to which a product, service or system can be used with effectiveness, efficiency and satisfaction by certain users in a specific context to achieve an objective[15]. According to the World Wide Web Consortium (W3C), the international community for the development of web standards, there are certain usability barriers that are common to web users with disabilities, which can be grouped on the basis of four principles: perceivability, operability, understandability, and robustness[16]. These principles are the required foundation to develop any accessible web content.

Previous systematic reviews have mostly focused on evaluating usability with family caregivers [17] or have investigated usability of cognitive intervention technologies[18] or of mobile apps for dementia care[19,20]. However, little is known about usability requirements of web-based tools for people with dementia and their family caregivers targeting decision-making or communication. Given the increase

of web-based tools in dementia care, there is an urgent need for high quality and user-friendly web-based tools that support communication and decision-making and that are appropriate for the varying cognitive level of people with dementia. To improve the design of such web-based tools, a better understanding of usability requirements for people with dementia is required. The aim of this systematic review is to synthetise usability requirements for the use of web-based tools and design suggestions reported in studies geared towards supporting communication and aiding decision making for people with dementia. Specifically, this systematic review aims to: (1) identify the usability requirements of web-based tools specifically designed for people living with dementia and aimed at supporting communication or decision making, (2) explore the various usability testing methods employed to evaluate web-based tools designed for people with dementia, and (3) examine and compile the suggested improvements derived from studies focusing on web design, evaluation, and usage of web-based tools aiming to supporting communication or decision making for people with dementia. It is expected that this review will help inform the development of new web-based tools to be adapted to the needs of people with dementia and their caregivers.

Methods

We carried out a systematic review of the literature following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidance[21]. Narrative synthesis was selected for this review as it can be used to translate the evidence into a clear and structured design brief on how to design web-based tools for people with dementia[22].

Eligibility criteria

Studies were included if they met the following criteria:

- The study population included people living with any type of dementia/mild cognitive impairment (MCI) or a blend of people living with dementia/MCI and caregivers; and
- The study included web-tools mainly or partly aimed at supporting communication or decision making concerning living with dementia; and.
- The study described measurements or characteristics of usability testing.

Studies were excluded if they met the following criteria:

- The study included web-tools that are intended for therapeutic purposes only; and
- The identified paper was a systematic/literature review, a meta-analysis, an editorial, a newspapers article, a magazine, a book chapter, or a conference paper; and
- The paper was written in a language other than English.

Data sources and search strategy

We developed search strategies (see appendix 1) with guidance from an information specialists at the University of Nottingham. Literature searches were conducted in MEDLINE, Embase, PsychINFO, Web of Science, and Scopus on 10 February 2023 with no limit on publication date. We adapted search strategies with relevant Boolean operators and search characters for each database. A combination of search terms for 'dementia, 'web-based systems' and 'usability' was used to capture all relevant literature. We used a combinations of MeSH terms and keywords to search the databases. EndNote 20 was used to store and manage the references exported from the databases alongside identifying and removing duplicate citations. The references were then uploaded into Rayyan QCRI, a systematic review application tool.

Study selection and data collection

Two reviewers (FM and CD) independently reviewed titles and abstracts against the inclusion and exclusion criteria. They obtained full-text articles for the included studies and assessed their content against the inclusion and exclusion criteria. Disagreements were resolved through discussion between the two reviewers. FM reviewed the final list of selected studies.

Data extraction

The primary reviewer (FM) extracted the data using standardised data extraction forms. Data were extracted on (1) study information and characteristics, (2) participant demographics, (3) description of the tools (i.e. aims, topic and features), (4) methods used to evaluate usability, (5) usability results (positive, negative, and successful elements/suggestions for improvements). CD provided a second independent review of the completed data extraction forms. Information was then qualitatively synthesised to identify common themes.

Quality assessment

The primary reviewer (FM) completed the initial quality assessment. CD provided a second independent review of the quality assessment. Given the diversity of the included studies, the Mixed Methods Appraisal Tool (MMAT) was used to evaluate the quality of the studies [23]. The MMAT was selected for its capacity to evaluate different study designs. Reponses were assessed using a categorical scale, where each response was categorised as "no", "can't tell", or "yes" based on specific methodological quality criteria[23]. The scores were calculated as high, moderate, or low quality based on the MMAT matrix. Disagreements were resolved through discussion between the two reviewers.

Results

Overview

The web-based database identified a total of 1726 references. After duplicates were removed, 1032 references remained, and their titles and abstracts were screened according to the inclusion and exclusion criteria. Of these, 966 were excluded as they did not focus on people with dementia or on relevant tools, leaving 66 papers for full-text screening. After a full-text screening process, 7 references were included in the review. Figure 1 presents the PRISMA flow diagram[21].
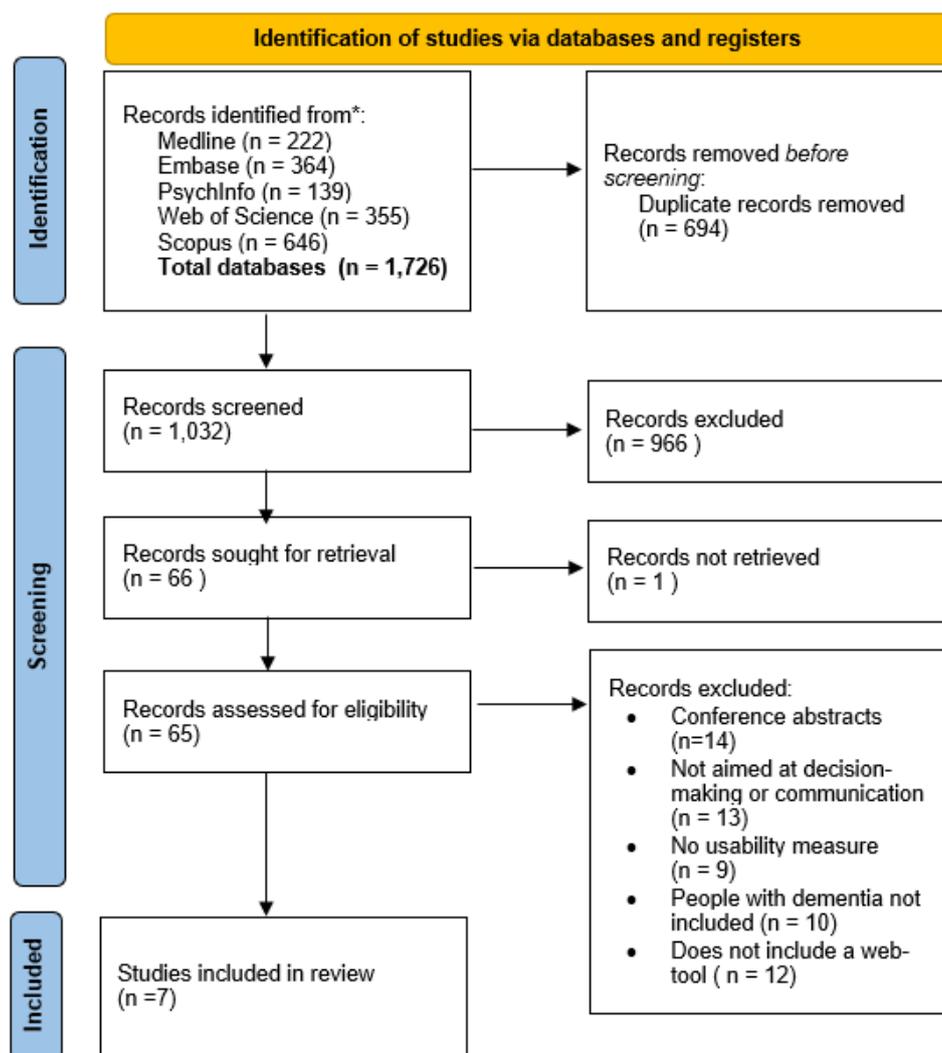

Figure 1: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram of the search and review process

Study characteristics and summary of web-based tools

An overview of the study characteristics is presented in Table 1. Included studies were conducted in 6 countries: United States, Spain, United Kingdom, Netherlands, France, and Italy. Most of the included articles were published within the past three years (n=5)[24–28]. Two included articles evaluated ehcoBUTLER (global ecosystem for the independent and healthy living of elder people with mild cognitive impairments), using different methods[26,27]; and three included articles evaluated Caregiverspro-MMD (platform for self-managed interventions and mutual assistance community services), using different methods[24,29,30].

The target populations for the web-based tools included people with dementia or MCI (n=172), family caregivers (n=127), health professionals (n=21), and case managers (n=7). The web-based tools focused on a variety of topics, including decisions for technology use in care[28]; promoting health, well-being, and independence[26,27]; providing information about home modifications[31]; facilitating shared decision-making[32], addressing information needs and social isolation[24,29,30].

The web-tools reviewed in the studies aimed to support people with dementia and their family caregivers through a range of features. Usability enhancements, including clear and simple navigation systems, were found in 2 out of 7 studies[26,27]. Options for customisation or personalisation of topics were included in 2 out of 7 studies[29,30]. Multimedia elements such as images, videos, links, and audio were used in 5 out of 7 studies[26–30]. These web-tools aimed to provide engaging and user-friendly experiences tailored to the specific needs and challenges faced by people with dementia and their family caregivers.

Quality assessment

The quality of included studies was moderate to high: 5 out of the 7 studies appraised using the MMAT met above 80% of quality criteria[24,26,28–30], whereas 2 out of 7 met between 50% and 79%[27,32]. An overview of the quality assessment tool and scores can be found in appendix 2.

Table 1: Summary of web-tools targeting information or communication for people with dementia and their caregivers

Study (year)	Design	Aims of the study	Web-tool name and aim	Content of the web-tool	Specific features described	Setting (country)	Sample
Berridge et al (2022)[28]	Pilot study	Describe the intervention's motivation and development process, and the feasibility of using this self-administered web application intervention in a pilot sample	Let's Talk Tech Self-administered web application that aims to facilitate conversation, decisions, and planning for technology use in elder care.	4 featured technology modules (location tracking, in-home sensors, web cameras, and artificial companion robots). Each module aims to: give information about the technology and communicate the risks and benefits of the technology, prompt discussion between the dyad and encourage documentation of the preferences of the person with dementia.	(1) Provision of a summary document that summarises choices, (2) automatic audio option, (3) sentences reviewed for clarity.	United States	29 dyads of people living with dementia and family caregivers
Castilla et al (2020)[27]	Usability study	Test the usability of the ehcoBUTLER for people with MCI	ehcoBUTLER Information and Communication Technology that aims to promote the health, well-being, and independence of older people, especially those with MCI at the social level	Offers different modules about: healthy lifestyle, leisure and free time, emotional, social, and cognitive care.	(1) navigation system, which follows a linear structure (step-by-step), (2) human-looking avatar that explains where they are on the platform and what they can do next through audio and text, (3) buttons have different colours	Spain	28 people with MCI

					depending on type of action they allow, green to continue, red to interrupt, and orange for secondary actions		
Contreras-Somoza et al (2022)[26]	Qualitative focus group study	Explore the perceptions and feedback level of the ehcoBUTLER potential primary users and stakeholders to improve the development of this platform according to their needs, preferences, and suggestions.	ehcoBUTLER Information and Communication Technology that aims to promote the health, well-being, and independence of older people, especially those with MCI at the social level	Offers different modules about: healthy lifestyle, leisure and free time, emotional, social, and cognitive care.	(1) ergonomic design, (2) especially designed for use on tablets, (3) linear navigation system, (4) human-looking avatar, which provides explanations, (5) different colours for each button depending on actions	Spain	49 participants (13 people with MCI, 13 people with dementia, 12 family caregivers, 11 health professionals)
Howe et al (2020)[29]	RCT	Assess the extent to which family caregivers and people with dementia engage with the CAREGIVERSPRO-MMD platform and explore users' feedback on how useful and usable the platform is.	CAREGIVERSPRO-MMD platform Online platform that aims to provide informational and social support to community-dwelling people with dementia (with mild to moderate dementia)	Social media style "News Feed" that provides informational articles covering a wide range of topics such as memory loss, health and social care, caring, local support groups. Social networking element which allows users to send messages	(1) Home screen which contains links to the news feed function and the friends function, (2) users can connect to each other as "friends", (3) users make posts and can comment on or like any posts that are shared with them, (4) users can select which	United Kingdom	37 dyads of people with dementia and family caregivers

				and their informal caregivers.	and share information with other users.	topics they are interested in receiving information about		
Span et al (2014)[32]	Development and usability study	Identify design issues that should be considered for designing a user-friendly interactive web tool to facilitate shared decision making in care networks of people with dementia.	DecideGuide Interactive web tool that aims to facilitate people with dementia, family caregivers and case managers to communicate with each other in making shared decisions.	Web tool based on the principles of open communication and information, which is composed of: (1) three perspectives: i.e the care manager, the family caregiver, the person with dementia, (2) each participant uses the tool on their own, (3) three pillars: chat function, deciding together, and individual opinion.	(1) Available for tablets, laptops, and computes	Netherlands	6 people with dementia, 4 family caregivers, 7 case managers
Wolverson et al (2022)[24]	RCT	Explore the experiences of dyads consisting of people with dementia and family caregivers using the Caregiverspro-MMD website.	CAREGIVERSPRO-MMD platform Website that aims to address information needs and isolation through provision of information about dementia and caring, and a social network to facilitate peer support.	The website incorporates: (1) A newsfeed similar to those on social media, which delivers information and can be used to post content, like and comment on posts by users, (2) calendar, (3) resources section with information about local and national agencies, (4) the ability to save	(1) training and support programme with an initial home-based training session, written user guides, and regular group trainings.	United Kingdom	22 people with dementia and 21 family caregivers

				'favourite' information for future use, (5) brain training games			
Zafeiridi et al (2018)[30]	Usability study	Evaluate the usability and usefulness of Caregiverspro-MMD platform for people with dementia or MCI, family caregivers, and health and social professionals.	CAREGIVERSPRO-MMD platform Web-based platform that aims to improve the quality of life of people with dementia or MCI and reduce caregivers stress.	Early prototype of the platform which features: (1) a home page that enable users to share and reply to messages, (2) a personal profile, social network and invitations pages, (3) calendar, (4) a forum which allows sharing of information, tips and support from users, (5) questionnaires to monitor health and well-being, (6) information about local resources	(1) gamification engine designed to increase user engagement, (2) machine learning engine to present the features of the platform to users	Italy, United Kingdom, Spain, France	24 people with dementia or MCI, 24 family caregivers, and 10 professionals

Table 2: Usability evaluation methods and user feedback

Study	Method	Positive feedback	Negative feedback	Successful elements or suggestions for improvement
Burridge et al (2022)[28]	Survey; Interviews	Overall assessment • Perceived as useful. Visual appearance • Length and amount of information Delivery of content • Descriptions clearly worded. • Balanced (neutral), presentation of information.	Delivery of content • Difficulty relating the scenarios to their own lives; need for more concrete and visual examples.	• Give concrete scenarios to illustrate the information provided. • Consider length and amount of the information provided
Castilla et al (2020)[27]	Task analysis; Interviews	Overall assessment • Users rated the system as easy to use and useful. Navigation • High task completion rates, suggesting an intuitive design.	Overall assessment • Users pressed the screen for too long, activating the second button (e.g., copy) instead of the primary button (e.g., continue) Delivery of content • The avatar's synthetic voice was too fast. Navigation • Attentional focus towards the centre of the screen to the detriment of the elements placed at the bottom or sides.	• Combine linear navigation with audio and help text and a design in which the main interactions (e.g., to continue the task) are placed in the centre of the screen. • Adjust the speed of the synthetic speed and add short time separation between phrases.

			• Users clicked outside of the buttons.	
Contreras-Somoza et al (2022)[26]	Focus groups	Overall assessment • Portable and large touch screen Visual appearance • Simple appearance • Ergonomic design • Appropriate colours and font Delivery of content • Personalised content and experiences • explanations and instructions	Overall assessment • Difficulty using keyboard or mouse. Delivery of content • Artificial appearance and voice Support needed • Difficulty to use independently for people with dementia.	• Personalise the system for the users. • Include larger icons and keep amount of text small. • Offer pre-training for users
Howe et al (2020)[29]	Survey	Overall assessment • Perceived as useful. • Easy to use	Overall assessment • Generally, more useful to family caregivers than to people with dementia Support needed • Help needed for people with dementia to use.	• Provide training sessions to demonstrate how to use the platform
Span et al (2014)[32]	Focus Groups; Cognitive walkthrough; Think-aloud	Visual appearance • Combination of buttons and icons • Green colour • Predominantly simple webpages	Navigation • Difficulty with login • Unclear navigation structure • Too many webpages Visual appearance	• Use pleasant and harmonious colours. • Use clear and harmonious buttons throughout the interface.

			Font and buttons size too small, and too close together.	
		Delivery of content • Personalised tool • Provides examples	• Lack of contrast • Technical issues with the chat and timeline functions • Excessive information and examples • Excessive use of colours in the examples • Colour red associated with danger or feeling unwell. Delivery of content • Use of smileys perceived as childish and unclear. • Unclear formulation of questions or text • Tool is too directive	
Wolverson et al (2022)[24]	Interviews; Focus groups	Delivery of content • Continued access to information • All information grouped on one platform. • Both formal and informal information provided Support needed • Regular support and training sessions	Delivery of content • Difficulties to use a tablet. • Lack of time to use the tool	• Develop a website where users can easily access, use and save information, without lengthy searches. • Ensure balanced tone and content of information

		• Written user-guides and handouts		
Zafeiridi et al (2018)[30]	Survey (quantitative and qualitative)	Visual appearance • Bigger colour contrasts and font sizes • Images and icons rather than text menus	Overall assessment • Concerns for privacy of information put in the platform. Visual appearance • Emoticons were confusing. Navigation • Difficulty to find previously posted content Delivery of content • Content too direct, e.g. avoid the use of "dementia" for "memory problems"	• Prefer less busy pages, more images, larger font sizes and colour contrasts, and fewer colours on each page • Provide clear explanations about privacy clauses

Key findings

Across the 7 articles, several general themes were apparent: overall usability assessment, visual appearance, navigation, delivery of content, and supported used of web-based tools. An overview of the study methods and outcomes from user feedback is presented in Table 2.

Usability requirements of web-based tools designed for people with dementia

Overall usability assessment

More than half of the studies provided a general assessment of the usability of their platform (n=4 out of 7)[27–30]. Overall, users found the platforms useful and user-friendly[28,29], although participants in one study mentioned that it would be more useful for caregivers than for people with dementia[29] and prior knowledge in technology was needed[29]. Three studies reported on the usability of the devices used, with tablets being perceived as easy to use in one study[26] and difficult to use in two other studies[24,27]. Using a keyboard and a mouse was reported to be too difficult for people with dementia in one study[26]. Finally, participants expressed concerns for the privacy of their data in one study[30]. More detailed feedback revolved around the following themes: visual appearance, navigation, delivery of content, and support needed.

Visual appearance

One of the main characteristics that emerged from the majority of studies (n=4 out of 7) is the necessity for a sophisticated and harmonious design. Participants in three studies provided feedback on the need to use appealing, simple and clear colours[26,30,32]. Platforms that used simple colour schemes were appreciated by people with dementia or MCI. Furthermore, two studies also observed a preference for larger font sizes, larger button sizes, and larger image or icon sizes[26,30]. Finally, platforms with excessive text were not considered visually appealing and decreased usability for people with dementia[28,32]. Participants highlighted the need for shorter amounts of texts in two studies[28,32]. Similarly, participants in two studies preferred the use of icon and images over text[30,32]. Although, one study noted that the use of icons should always be used in context, as participants in their study found the use of emoticons confusing[30].

Navigation

Three studies addressed navigation-related issues[27,30,32]. Difficulty in finding specific buttons was reported by people with dementia in one study[27]. Other issues included lack of signposting and challenges in understanding the navigation structure, mentioned in one study[32], and an attentional focus towards the centre of the screen at the detriment of elements placed at the bottom of the screen

which was mentioned in another study[27]. However, overall intuitive navigation and high task completion rates were observed in one study[27]. Participants in one study also mentioned disliking having to navigate through too many webpages or screens[32]. Finally, difficulties with login[32] and difficulties with finding content from previous sessions[30] were mentioned in one study each.

Delivery of content

The delivery of content received significant attention in six studies[24,26–28,30,32]. Two studies addressing decision-making about technology use and shared decision-making reported on the need to provide clear and concise textual content and also identified difficulties with understanding of examples or relating to examples provided, suggesting the need for concrete and visual examples[28,32]. Furthermore, user feedback in four studies emphasised the need to have a balanced, neutral or non-directive presentation of information[24,28,30,32]. Challenges related to an assistive voice, which provides information about where they are on a page and what users could do next. This assistive voice being too fast was noted in two studies[26,27]. The possibility to personalise content and the ability to use the web-tool in a flexible and independent manner were noted to increase usability in one[24] and two[26,32] studies respectively. Finally, positive user feedback was reported in one study regarding the availability of dementia-related information on a single platform[24].

Supported use of web-based tools

Support needs were highlighted in three out of the seven included studies[24,26,29]. Difficulty using the web-tool independently for people with dementia and extra support needed was mentioned by participants in two studies[26,29]. Recommendations for support were formulated by the researchers in three studies and included providing regular training sessions[24,26,29] offering assistance for technical difficulties[25], individually tailored support to use the web-tool[26], and providing different levels of content and difficulty based on users' cognition levels[26].

Usability testing methods

Studies conducted with people with dementia or MCI, family caregivers, health professionals, and case managers used several different methods to collect usability feedback. In total, 3 studies used surveys to identify whether users were likely to use and accept the website features[28–30]. Of these one combined both quantitative and qualitative surveys[30], while the others used solely quantitative surveys [28,29]. Five studies with people with dementia also used interviews and focus groups to record users' experience of using the web-tools[24,26–28,32]. Furthermore, one study employed a cognitive walkthrough procedure and a think-aloud procedure by recording users' thoughts as they used the website[32]. One study conducted usability tests by observing tasks completion rates[27]. Two studies only used one of

the methods above to assess usability[26,30], three combined two of these methods[24,27,28], and one used a combination of three methods[32].

Successful design elements or suggestions for design improvements

Based on their findings, all studies gave an overview of the successful elements of their designs or suggested improvements to increase usability. Three studies recommended ensuring sufficient colour contrast, using larger font and button sizes, and using understandable language to contribute to a better user experience[26,30,32]. One study suggested to carefully consider the length and amount of information presented, and to provide clearly formulated textual content and concrete examples to contribute to a user-friendly experience[28]. Furthermore, researchers of two studies recommended to provide a simple and intuitive interface that aligns with users' interests and cognitive levels, for example by opting for linear navigation (n=2)[24,27]. Recommendations for support were addressed in three studies and included providing regular training sessions[24,26,29] offering assistance for technical difficulties[25], individually tailored support to use the web-tool[26], and providing different levels of content and difficulty based on users' cognition levels[26]. Table 3 summarises these recommendations into a design brief for web-based tools for people with dementia.

Discussion

Main findings

This article presents the findings of a systematic review aimed at identifying and synthesising usability requirements for web-based tools targeting communication and decision-making for people with dementia and their family caregivers. We identified seven studies, which covered a broad spectrum of topics, including care technology usage, health promotion and independence, home modification information, shared decision-making facilitation, and addressing information needs and social isolation. The studies employed a range of methods including surveys, interviews, focus groups, cognitive walkthroughs and think-aloud procedures to gather usability feedback. Most studies included in the review reported positive feedback on the usability of the platforms, with users generally finding them useful and user-friendly. However, concerns were raised about the need for prior technological knowledge and the need for additional support. Findings from this systematic review ranged from user feedback on visual appearance and navigation, to delivery of content and support needed to use web-based tools.

Visual appeal emerged as a pivotal factor, emphasising the importance of a sophisticated and harmonious design, simple colour schemes, larger fonts, and images over excessive text. Navigation challenges were also reported, including difficulty finding specific buttons and understanding navigation structures, highlighting the need for intuitive designs. Moreover, suggestions were made for effective content delivery, demonstrating the importance of clear and concise information. Overall, these findings align with the research of Ancient and Good[11,12] and the guidelines of the World Wide Web Consortium (W3C) (i.e. the main international standards organisation for the World Wide Web) on cognitive accessibility[33–37], which stated the need for clear and concise language, predictable and consistent design, and user-friendly features that support comprehension and task completion. Our findings thus further reinforce these key considerations, and contribute valuable insights to the existing body of knowledge on designing user-friendly web-based tools for people with dementia, especially for tools targeting communication and decision-making in dementia care. Furthermore, this systematic review's focus on web-based tools complements findings from previous reviews investigating usability for mobile apps in dementia care[19,20]. Engelsma and colleagues et al. (2021) formulated design suggestions for mHealth based on usability barriers related to cognition (e.g. show limited information), perception (e.g. implement speech recognition), physical ability (e.g. use large screen- and font sizes), and frame of mind (e.g. provide video communication when applicable)[20]. While design suggestions in terms of visual appearance seem to align, our findings provide specific insights into the usability of web-based tools in terms of navigation and content delivery, which differ from considerations for mobile apps.

Additionally, our systematic review reveals that even web-based tools deemed user-friendly by people with dementia and their family caregivers still require additional support for people with dementia. This underscores the importance of providing various forms of assistance to enhance usability. Previous research has demonstrated that people with mild dementia can learn or re-learn to use technology such as touchscreen technology for instance through training interventions[38]. Assistance and guidance – either by a family caregiver or a designated person – has led to positive outcomes in terms of adoption of technology by people with dementia and family caregivers[39], however our findings point to the need for continuous support following adoption to facilitate usability of web-based tools. Key forms of support identified in this review are: tutorials and instructions embedded within the platform, offering step-by-step guidance, and face-to-face training provided by trained personnel.

Another notable finding is that most of the studies included in this review were conducted within the last three years. This temporal emphasis reflects the recent recognition of the potential of web-based tools in supporting people with dementia[40]. This could be due to an improved technological literacy

among people with dementia over the years, although some cohort differences may still be present[41]. It may also reflect several other factors such as the development of better and more affordable technology over time, as well as a more favourable disposition towards technology use among the current generation of people with dementia compared to a decade ago[42].

Practice recommendations

Taking account of the findings from this review, we have constructed a design brief to help tailor new and existing web-based tools targeting communication or decision making for people with dementia (Table 3).

Table 3: Design brief for the development of web-based tools for communication or decision-making designed for people with dementia

Recommendations for the design of web-based tools targeting communication and/or decision-making in dementia care	
Visual appearance	**For web designers:** • **Enhance visual appearance**: increase colour contrast, use larger fonts and buttons, and incorporate recognisable icons for improved visibility and interaction. • **Create harmonious interface**: Use pleasant colours, minimise busyness, include more images, and maintain consistency in button design for a user-friendly experience. **For researchers or clinicians:** • **Optimise information**: Condense and organise information into smaller pieces with clear headings for easier comprehension.
Navigation	**For web designers:** • **Enhance navigation**: Implement a combination of linear navigation, audio cues, and help text to guide users through the web-based tool. Place essential interactions, such as task continuation, prominently in the centre of the screen for ease of use. • **Streamline information access**: Develop a web-tool that allows users to easily access, use, and save information without the need for lengthy searches. Employ efficient search functions, clear organisation, and intuitive categorisation to facilitate seamless information retrieval and enhance user efficiency.
Delivery of content	**For web designers:** • **Personalise the system**: Customise the web-based tool to cater to individual users' needs and preferences. Incorporate options for user preferences, such as font size, colour schemes, or language settings, to enhance usability and accommodate diverse user profiles.

	For researchers or clinicians:
	• **Provide concrete scenarios**: Illustrate the information provided through tangible and relatable examples or scenarios. This helps people with dementia better understand and apply the content, improving engagement and retention.
	• **Use understandable language**: Use clear and easily comprehensible language throughout the web-based tool. Avoid jargon or complex terminology, opting instead for simple and concise explanations. This promotes clarity and accessibility for people with dementia, facilitating their understanding and interaction with the tool.
Support	**For researchers or clinicians:**
	• **Offer training and pre-training**: Provide training sessions to demonstrate how to use the web-based platform effectively. Additionally, consider offering pre-training materials or resources that familiarise users with the tool's functionalities, enhancing their confidence and competence in using it.
	• **Provide tailored support**: Offer individually tailored support to users, addressing their specific needs and challenges in using the technology. This may involve one-on-one guidance, personalised tutorials, or assistance from trained personnel to ensure a smooth user experience.

Strengths and limitations

This is the first systematic review focusing specifically on the usability of web-based tools designed to address communication and decision-making needs for both people with dementia and their family caregivers. Our findings have revealed important evidence-based usability requirements for web-based tools targeting communication and decision-making for people with dementia. Furthermore, our study offers practical recommendations that can directly inform the development of web-based tools for people with dementia and their family caregivers. Despite its contributions, this systematic review has certain limitations. We limited our search to articles published exclusively in English, potentially excluding valuable research conducted in other languages. Furthermore, we did not factor in the quality assessment of the included studies, as the majority of the included studies demonstrated good to fair methodological quality. Studies with varying degrees of methodological quality were all considered equally in the review to maintain a comprehensive representation of perspectives. However, it could potentially affect the overall robustness of the synthesised findings and our recommendations.

Implications and future directions

The results of this systematic review add to increasing our understanding of digital health in the context of dementia and have revealed important usability requirements for web-based tools targeting communication and decision-making for people with dementia. Importantly, it highlights the need to provide additional support to facilitate the use of web-based tools for people with dementia and their caregivers, even when usability of web-based tools is positively evaluated. To optimise support for people with dementia, future research should explore innovative approaches in delivering tailored tutorials and instructions aligned with cognitive abilities and preferences. This is especially essential given the growing reliance on online tools and services in healthcare. Another area of future research is the visualisation of information and content for people with dementia. Presenting information in a clear, concise, and visually appealing manner is crucial for people with cognitive impairments. Exploring how to effectively design and present information on web-based tools to enhance comprehension and engagement for people with dementia is an important avenue for future investigation. Furthermore, people with dementia and their family caregivers represent a diverse and heterogeneous group, varying in their needs, preferences, and technological literacy. Caution should be exercised when applying the recommendations derived from this review to people with dementia and their caregivers without considering their specific characteristics and circumstances. The recommendations emerging from this review would also benefit from being reviewed by people living with dementia, through patient and public involvement for example. Finally, the rapid advance in artificial intelligence (AI) technology and machine learning is likely to influence web accessibility in the future[43], therefore future research may look into the benefits and challenges of integrating AI in web-based tools for people with dementia.

Conclusion

This systematic review identified key recommendations highlighting the need to reduce cognitive load, improve readability, and provide clear and concise language in web-based tools that aim to support communication and decision-making for people with dementia and their family caregivers. Additional support for the use of web-based tools in the form of tutorials, instructions, or face-to-face training is necessary and warranted to enhance usability for people living with dementia. This systematic review contributes to the growing understanding of usability requirements for web-based tools targeting people with dementia, paving the way for improved design and development of web-based supporting communication and decision-making.

Supplementary materials

Appendix 1: Search strategy performed in the databases Medline, Embase, PsychInfo, Web of Science Core Collection, and Scopus

Appendix 2: Quality assessment tables

Declarations

Authors' Contributions

All authors have substantially contributed to the research and approved the version to be published. All authors contributed to the review conception and design. The search, screening, selection, and synthesis were performed by FM and CD. The original draft was prepared by FM. MPC, CD, LVdB and LP were involved in the review and editing of the manuscript. MPC, LVdB and LP were involved in supervision.

Conflicts of interest

The authors declared no potential conflicts of interest regarding the research, authorship and publication of this research.

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Supplementary materials of Chapter 7

Appendix 1: Search strategy performed in the databases Medline, Embase, PsychInfo, Web of Science Core Collection, and Scopus

Platform and database: Ovid MEDLINE
Date searched: 22/02/2023

#	Search term(s)	Result(s)
1	exp Dementia/	200,331
2	(dement* or alzheimer*).tw,kw,kf.	271,566
3	1 or 2	312,437
4	exp internet/ or exp software/	258,834
5	(website* or interface* or software* or app or apps or application* or online or internet).tw,kw,kf.	2,202,416
6	("web-tool*" or "web tool*" or "web-based tool*" or "web based tool*" or "web-based learning tool*" or "web based learning tool*" or "web-based intervention*" or "web based intervention*" or "web-based system*" or "web based system*" or "browser-based tool*" or "browser based tool*").tw,kw,kf.	6,789
7	4 or 5 or 6	2,326,708
8	3 and 7	29,266
9	(usability or "user experience" or UX or "human computer interaction*" or HCI or "human factor*" or "user feedback" or "user satisfaction").tw,kw,kf.	36,573
10	8 and 9	227
11	limit 10 to english language	222

Platform and database: Embase
Date searched: 22/02/2023

#	Search term(s)	Result(s)
1	exp Dementia/	478,136
2	(dement* or alzheimer*).tw,kw,kf.	378,434
3	1 or 2	517,613
4	exp internet/ or exp software/	609,137
5	(website* or interface* or software* or app or apps or application* or online or internet).tw,kw,kf.	2,692,933
6	("web-tool*" or "web tool*" or "web-based tool*" or "web based tool*" or "web-based learning tool*" or "web based learning tool*" or "web-based intervention*" or "web based intervention*" or "web-based system*" or "web based system*" or "browser-based tool*" or "browser based tool*").tw,kw,kf.	8,495
7	4 or 5 or 6	2,945,146
8	3 and 7	51,729
9	Human Computer Interaction/	8,191
10	(usability or "user experience" or UX or "human computer interaction*" or HCI or "human factor*" or "user feedback" or "user satisfaction").tw,kw,kf.	46,176
11	9 or 10	52,122
12	8 and 11	371
13	limit 12 to english language	364

Platform and database: Ovid APA PsycInfo

Date searched: 22/02/2023

#	Search term(s)	Result(s)
1	exp Dementia/	91,622
2	(dement* or alzheimer*).hw,tw.	99,826
3	1 or 2	119,968
4	exp Internet/ or exp Computer Software/	326,706
5	(website* or interface* or software* or app or apps or application* or online or internet).hw,tw.	131,003
6	("web-tool*" or "web tool*" or "web-based tool*" or "web based tool*" or "web-based learning tool*" or "web based learning tool*" or "web-based intervention*" or "web based intervention*" or "web-based system*" or "web based system*" or "browser-based tool*" or "browser based tool*").hw,tw.	490
7	4 or 5 or 6	391,297
8	3 and 7	14,913
9	exp Human Computer Interaction/	36,300
10	(usability or "user experience" or UX or "human computer interaction*" or HCI or "human factor*" or "user feedback" or "user satisfaction").hw,tw.	33,756
11	9 or 10	55,119
12	8 and 11	143
13	limit 12 to english language	139

Platform and database: Web of Science Core Collection

Date searched: 22/02/2023

#	Search term(s)	Result(s)
#1	dement*OR alzheimer* (TOPIC)	390,364
#2	website* OR interface* OR software* OR app OR apps OR application* OR online OR internet (Topic)	7,337,768
#3	"web-tool*" OR "web tool*" OR "web-based tool*" OR "web based tool*" OR "web-based learning tool*" OR "web based learning tool*" OR "web-based intervention*" OR "web based intervention*" OR "web-based system*" OR "web based system*" OR "browser-based tool*" OR "browser based tool*" (Topic)	12,020
#4	#2 OR #3	7,343,260
#5	#1 AND #4	37,297
#6	usability OR "user experience" OR UX OR "human computer interaction*" OR HCI OR "human factor*" OR "user feedback" OR "user satisfaction" (TOPIC)	152,205
#7	#5 AND #6	362
#8	#5 AND #6 Refined By: Languages: English	355

Platform and database: Scopus

Date searched: 22/02/2023

#	Search term(s)	Result(s)
#1	TITLE-ABS-KEY (dement* OR alzheimer*)	411,531
#2	TITLE-ABS-KEY (website* OR interface* OR software* OR app OR apps OR application* OR online OR internet)	11,241,541
#3	TITLE-ABS-KEY ("web-tool*" OR "web tool*" OR "web-based tool*" OR "web based tool*" OR "web-based learning tool*" OR "web based learning tool*" OR "web-based intervention*" OR "web based intervention*" OR "web-based system*" OR "web based system*" OR "browser-based tool*" OR "browser based tool*")	16,912
#4	#2 OR #3	11,246,098
#5	#1 AND #4	41,493
#6	TITLE-ABS-KEY (usability OR "user experience" OR UX OR "human computer interaction*" OR HCI OR "human factor*" OR "user feedback" OR "user satisfaction")	320,526
#7	#5 AND #6	657
#8	#5 AND #6 Refined By: Languages: English	646

Appendix 2: Quality assessment

	General screening		Mixed methods				
	Are there clear research questions?	Do the collected data allow to address the research questions?	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? (see further)
Berridge et al (2022)	Y	Y	Y	Y	Y	C	Y
Castilla et al (2020)	Y	Y	N	N	N	N	N
Contreras-Somoza et al (2022)	Y	Y					
Howe et al (2020)	Y	Y					
Span et al (2014)	Y	Y					
Wolverson et al (2022)	Y	Y					
Zafeiridi et al (2018)	Y	Y					

Y = YES, N = NO, C = Cannot tell

Appendix 2 : Quality assessment (continued)

	Qualitative					4. Quantitative descriptive				
	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?
Berridge et al (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Castilla et al (2020)	Y	Y	N	N	N	Y	Y	Y	C	Y
Contreras-Somoza et al (2022)	Y	Y	Y	Y	Y					
Howe et al (2020)						Y	Y	Y	N	Y
Span et al (2014)	Y	Y	C	N	N					
Wolverson et al (2022)	Y	Y	Y	Y	Y					
Zafeiridi et al (2018)	Y	Y	Y	Y	Y					

Y = YES, N = NO, C = Cannot tell

– PART V –

GENERAL DISCUSSION

CHAPTER 8

Interpretation and implications of dissertation findings

Introduction

The aim of this dissertation was threefold, namely, (1) to explore current definitions of advance care planning (ACP) and provide recommendations from the perspectives of people with dementia and their families, (2) to develop an ACP support website for people with dementia and their families and evaluate user experiences, and (3) to draft recommendations for future web-based tools targeting communication and decision-making for people with dementia. To address these aims, we undertook several studies, each with different methods and participant groups. In Chapter 2, we examined the ACP content provided on dementia associations' websites in Europe. In Chapter 3, we investigated the perspectives of the European Working Group of People with Dementia (EWGPWD) and their supporters on how ACP is defined and developed recommendations for changes to the definition of ACP. In Chapters 4 and 5, we outlined the protocol and the results of our approach to develop and test the usability of an ACP support website for people with dementia and their family caregivers. In Chapter 6, we explored the use of the two web-based reflection and communication tools by people with dementia and family caregivers and evaluated their experiences using them. Finally, in Chapter 7, we identified usability requirements, usability testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care.

In this part, we will (1) summarise the main findings of this dissertation, (2) discuss methodological considerations, strengths and limitations, (3) interpret the main findings in relation to other existing evidence, and (4) suggest implications and recommendations for future research, practice, and policy.

Summary of main findings

1. Exploring current definitions of advance care planning and providing recommendations from the perspectives of people with dementia and their families

In the content analysis of dementia associations' websites (<u>Chapter 2</u>), we found 16 (out of 26) websites of dementia associations' websites in Europe that provided some content on ACP. Of these, only three websites addressed all ACP themes mentioned in the reference framework we used, which is based on two recognised definitions of ACP. The overarching categories of the reference framework were: (1) defining ACP; (2) the legal and medical aspects of ACP; and (3) the quality of life, social and practical aspects of ACP. The final ACP themes included within these overarching categories were, for the first category, definition of ACP; for the second category, legal frameworks, legal representatives, care and medical treatment preferences, including end-of-life care, documentation of decisions; and for the third category, personal values and life goals, communication and discussions with family, communication and discussions with health professionals, documentation sharing, timing, meanings and consequences of potential serious illness scenarios, and uncertainties of serious illness scenarios. ACP was clearly defined on four websites. The ACP content on the websites was characterised by a strong emphasis on legal and medical aspects of care. Most dementia associations' websites that addressed ACP focused on the completion of advance directives, which dealt with medical care, legal affairs, and financial affairs. Other key themes, such as communication with family, communication with health professionals, sharing of decisions and the identification of personal values and life goals, were given less attention. Furthermore, additional themes emerged from the data and seemed specifically targeted to the needs of people with dementia (gradual loss of decisional capacity, need to regularly review conversations, difficulties of having ACP conversations, and consequences of not doing ACP).

We also examined accessibility and readability for people with dementia and family caregivers of ACP information on dementia associations' websites. Based on the DEEP guidelines on creating websites for people with dementia and on writing dementia-friendly information, we found that most websites had clear formatting, home link, and headings as well as showed a clear sitemap. However, features such as print option, text-to-speech option or font and contrast adjustments were less often offered. Furthermore, although most offered content in a simple language, the use of pictures and videos to support content was less widespread.

In our qualitative study with the European Working Group of People with Dementia (EWGPWD) (Chapter 3), we collected the perspectives of the EWGPWD and their supporters on the definition of ACP supported by the European Association for Palliative Care (EAPC) and made recommendations based on their input. We included 21 participants in online focus groups, of which 12 were people with dementia and 9 were supporters. We conducted additional individual follow-up interviews with 9 people with dementia and 7 supporters. The EWGPWD members expressed support for several aspects of the current ACP definition which they considered essential, such as the fact that ACP should be a process and that it should be regularly reviewed. The EWGPWD members also agreed that ACP should encourage communication and documentation of decisions about future care, and should not be limited to the completion of advance directives. However, they also highlighted the need for the definition of ACP to include people with declining decisional capacity, to better reflect the role of families or trust-based relationships, and to better address social aspects of care. The members of the EWGPWD disliked that the current ACP definition explicitly states ACP is for 'individuals with decisional capacity', thereby excluding people with dementia who have less or lack capacity from the definition. Yet, they did not wish for a separate definition of ACP for people with dementia, but rather advocated for adapting the existing definition to be more inclusive of people with dementia and applicable to people with or without conditions influencing cognitive capacities.

Our findings also highlighted the need for a more relational approach to ACP. Members of the EWGPWD and their supporters emphasised the role of family and trust-based relationships in ACP, as they were generally considered to have great personal knowledge of the person with dementia, and they are often an important point of contact in communication and decision-making in the later stages of dementia. Our participants found this crucial role of families and trust-based relationships under-addressed in the definition of ACP.

Additionally, the EWGPWD and their supporters highlighted the need for the definition of ACP to better reflect the importance of social aspects of care in ACP. They found that the definition focused too much on medical care, while it should include broader conversations on 'what matters most' in the future, such as social care, or future meaningful activities. Based on these results, we provided tangible recommendations for future adaptations to the definition of ACP that reflect these perspectives.

2. Developing an ACP support website for people with dementia and their families and evaluating user experiences

In the development and usability study of the ACP support website (Chapters 4 and 5), we outlined the development process of a website to support people with dementia and their family caregivers to engage in ACP in the family context[1]. The study followed the process map for developing web-based decision support interventions and the development phase of the Medical Research Council (MRC) framework for complex interventions. Our approach was centred around two phases: a content specification phase and a creative design phase. We developed a website that has as its objective to inform people with dementia and their family caregivers about ACP and to support them in communicating about ACP. We adopted a 'what matters most' approach to ACP (i.e. enabling people with dementia and family caregivers to identify what matters most for them in the present and in the future), focusing on promoting ACP conversations by providing people with dementia and family caregivers with information and giving them the opportunity to engage in ACP within the family context and encouraging communication with health professionals. The ACP support website provides access to a range of information ranging from what ACP is and what its benefits can be, to explanations of advance directives and legal frameworks, as well as explanations of difficult terms and jargon used in ACP, and answering frequently asked questions. The website also provides tips on communicating about ACP within the family context and with health professionals, both for people with dementia and for family caregivers. We also developed two interactive communication tools that users can use to reflect about ACP or to facilitate their ACP conversations: (1) the 'Life Wishes Cards', which allow users to sort statements about their wishes for future care, and (2) a fill-in reflection and communication tool that allows users to think about, discuss and write down their preferences for what matters most to them now and in the future, including but not limited to preferences for proxy decision makers and for future treatment. We designed the navigation of the ACP support website to be non-linear and flexible, allowing users to engage in the process according to their needs and readiness levels. Features integrated on the website included a font size change option, a text-to-speech option, a contrast option, several videos from health professionals and testimonials from people with dementia and caregivers about engaging in ACP.

We conducted four iterations of usability testing through think-aloud and semi-structured interviews and a usability survey with a total of 17 people with dementia and 26 family caregivers. We found that the usability of the ACP support website was influenced by factors such as visual appearance, text length, formulation of content, and the incorporation of media such as videos. To improve usability, we shortened and simplified the website's textual content, minimised the use of abbreviations and added explanations when abbreviations had to be used. A non-intuitive navigation was found to

negatively influence usability in the first prototypes of the ACP support website. Finally, we found that people with dementia and their family caregivers encountered some difficulties using the interactive communication tools provided on the ACP support website. Participants also noted that people with dementia may face challenges in using the website independently. To attempt to address these difficulties, we included tutorial videos on the website to explain how to use the interactive communication tools and support the use of the website.

Within a mixed-method evaluation study (Chapter 6), we sought to explore the use and the experiences of people with dementia and their family caregivers when using two web-based reflection and communication tools, namely the "Thinking Now About Later" tool and the 'Life Wishes cards'. These tools were part of the ACP support website.

We used log data that was captured on the ACP support website during the study period and data from interviews with people with dementia and family caregivers that took part in an 8-week mixed-method evaluation study in Flanders[2]. Dyads composed of people with dementia and family caregivers, or family caregivers on their own, were interviewed after having used the website at their own pace during the study period. Fifty-two participants took part in the study, of which 21 were people with dementia and 31 were family caregivers. 22 participants actively engaged with the tools, with the majority using them once, and seven revisiting them. For those that did use the tools, the 'Thinking Now About Later' tool and the 'Life Wishes Cards' encouraged people with dementia and family caregivers to think about and talk about their preferences and wishes for current and future care and medical treatments from the perspective of what matters most to them. Both people with dementia and family caregivers particularly appreciated using the interactive communication tools provided on the website, as they allowed them to have a more structured framework to guide ACP conversations. Barriers to use included a lack of concrete steps to take once the web-based tools were completed and people with dementia had difficulties using the web-based reflection and communication tools. Several family caregivers raised the issue that their family member with dementia would not be able to use the web-based reflection and communication tools independently. Family caregivers tended to take on a facilitating role, not only in terms of technical support but also in providing emotional and cognitive support.

3. Drafting recommendations for future web-based tools targeting communication and decision-making for people with dementia

In <u>Chapter 7</u>, we report the results of a systematic review of usability requirements for web-based tools targeting communication and decision-making for people with dementia and their family caregivers. We systematically searched five databases and seven studies met the inclusion criteria. The studies included in the systematic review employed various methods including surveys, interviews, focus groups, cognitive walkthroughs and think-aloud procedures to gather usability feedback from people with dementia and family caregivers. First, visual appearance emerged as an important usability requirement for people with dementia and family caregivers. The different studies emphasised the importance of a sophisticated and harmonious design, simple colour schemes, larger fonts, and images over excessive text. Navigation challenges were also reported as barriers to the usability of web-based tools, highlighting the need for intuitive designs. Participants in three of the seven studies reported navigation challenges such as difficulties in identifying specific buttons or understanding navigation structures. Finally, content delivery received significant attention in six out of seven studies. Challenges related to content delivery lead to suggestions such as providing clear and concise textual content, providing concrete and visual examples, and adopting a balanced, neutral, or non-directive presentation of information. The possibility to personalise content and the ability to use the web-based tools in a flexible and independent manner were noted to increase usability.

Our systematic review revealed that even web-based tools deemed user-friendly by people with dementia and family caregivers still required additional support for people with dementia. Three of the seven studies included in the systematic review provided recommendations on supporting people with dementia and family caregivers in using web-based tools for communication or decision-making. Key forms of support identified in this systematic review include tutorials and instructions embedded within the web-based tools, offering step-by-step guidance, and face-to-face training provided by trained personnel.

Methodological considerations, strengths and limitations

In the following sections, key methodological considerations, strengths and limitations are discussed.

1. Overarching strengths and limitations of the dissertation

An overall strength of this dissertation is the variety of research methods employed. This dissertation leverages multi-method and multi-source data to meet the research aims and objectives. Chapter 2 was based on a content analysis of dementia associations' websites in Europe, with deductive and inductive approaches to analysing content using a reference framework derived from two ACP definitions. Chapter 3 was based on an in-depth qualitative study, analysing focus groups and follow-up interviews with thematic analysis. In Chapter 4 and 5, we described the design of a development and usability study of a website to support ACP for people with dementia and family caregivers, where we combined the use of the MRC framework for complex interventions and the process map for developing web-based decision support interventions developed by Elwyn and colleagues[3,4]. We integrated several methods in this study, such as evidence synthesis, intervention mapping principles to create preliminary content for the ACP support website, storyboarding, and iterative usability testing through think-aloud interviews, semi-structured interviews, and surveys. Chapter 6 was based on a mixed-methods evaluation study of the ACP support website with a convergent parallel mixed-methods pretest-post-test design that examined users' experiences with the ACP support website, and where we focused on the use of and experiences using two web-based reflection and communication tools. To do so, we used framework analysis to analyse interviews, and descriptive statistics to analyse log data collected on the ACP support website. Finally, Chapter 7 was based on a systematic review of articles describing the usability of communication and decision-making web-based tools for people with dementia and family caregivers. This variety of research methods enabled us to obtain more nuanced, comprehensive insights on developing and using the ACP support website. Furthermore, a notable strength of our research lies in the comprehensive integration of all dissertation findings to develop or improve the ACP support website[4]. This approach not only ensured a robust understanding of ACP support in the context of dementia but also contributed to the practical application of our research findings.

There are also some overarching limitations that should be considered. In terms of recruitment strategy in this dissertation, we identified potential participants through organisations such as the Flemish Alzheimer League and memory clinics. Through these recruitment channels, we mostly reached people who were already affiliated with dementia organisations, or actively involved in care at memory clinics. Therefore, our samples may not be representative of the larger population of people

with dementia and their families. Furthermore, we used convenience sampling, which resulted in samples that were predominantly under 65 years of age, lived with their partners, were diagnosed with Alzheimer's disease, and were highly educated, and speaking Dutch. It is important to be cautious when generalising our findings to the larger population of people with dementia. Furthermore, we did not collect any information about ethnicity or cultural background. To enhance diversity and representativeness in our study population, random sampling of participants with diverse characteristics may facilitate a more in-depth understanding of how to support ACP for people with dementia and their family caregivers. Our inclusion criteria also required participants to be willing to use and test a website or to have a device on which the website could be opened. This may have excluded people with dementia and family caregivers who might have been interested in and benefited from using the ACP support website but did not have the appropriate device to use the website or the computer skills to take part in our research. Finally, the characteristics of our sample also mean that we cannot simply assume that our findings are valid for all people with dementia, especially those in the more advanced stages of dementia. The advanced stages of dementia are typically characterised by severe cognitive decline, loss of memory and language skills, behavioural symptoms such as agitation and aggression, as well as declining physical health. It can be supposed that the use of the ACP support website may not support ACP in the later stages of dementia. Moreover, since none of our participants were in the advanced stages of dementia, caution in terms of transferability of our findings is necessary. Thus, the ACP support website may not be applicable or usable for all people with dementia.

2. Content analysis of dementia associations' websites

We employed a qualitative content analysis of the ACP content on dementia associations' websites in Europe, following the method described by Bengtsson[22]. A directed content analysis was conducted[23], which allowed the development of a comprehensive reference framework that can be used in practice by those wishing to develop ACP information for people with dementia and family caregivers. Furthermore, our approach, which has a strong international focus, provided a good representation of dementia associations across Europe, with associations included from northern, eastern, central, southern, and western Europe.

However, despite the important number of dementia associations included in our study, we cannot exclude having missed important content on the websites that were included in the analysis. Even though the websites were thoroughly screened, we asked dementia associations to collaborate on this project by providing any missing ACP content, or warning us if regional dementia associations provided

additional ACP content. Only eight associations responded to our request and double-checked the ACP content extracted from their website for this study. Moreover, considering the global reach of the Internet, it is essential to acknowledge the possibility that people in Europe may come across information about ACP on websites originating from other regions and not covered in this study. Finally, the translations of ACP content were one-way translations, lacking verification of equivalences between the English version and the original text.

3. Focus groups and follow-up interviews with the European Working Group of People with dementia and their supporters

Using focus groups and follow-up interviews, we identified and examined the perspectives of both people with dementia and family caregivers, enabling us to present rich and in-depth data regarding the definition of ACP. We provide examples of meaningful inclusion of people with dementia in qualitative research. In our qualitative study with the EWGPWD (Chapter 3), we demonstrated that people with dementia can meaningfully participate in online focus groups or in interviews by (1) providing adapted materials such as visual support and preparation materials, and (2) adapting data collection procedures by limiting the time and number of participants in focus groups or including a supporter to provide assistance to the person with dementia for instance. Additionally, we conducted focus groups and follow-up interviews in English with participants whose first language was not necessarily English. This was enabled by the presence of supporters who were fluent in both English and the first language of the participant with dementia, and who acted as interpreters. It might be deemed a limitation that focus groups and follow-up interviews were not conducted in the first language of all participants. However, this could also be considered a strength given that this approach enabled participants who were not fluent in English and who would have otherwise been excluded from contributing to our research. However, there is a limitation in the lack of heterogeneity of our sample. The members of the EWGPWD are members of one or several advisory groups and tend to be rather politically and socially active, which does not reflect the population of people with dementia.

4. User-centred development and usability testing of the advance care planning support website

In Chapters 4 and 5, we outlined our development approach based on the development phase of the MRC framework for complex interventions and the process map for developing web-based decision support interventions developed by Elwyn and colleagues[3,4]. These two approaches align, as they both emphasise the importance of a theoretical and evidence basis. However, the process map provided more specific guidance on the practical aspects of developing web-based decision-support

interventions within the broader framework provided by the development phase of the MRC framework for complex interventions. Together, they offered a comprehensive guide for developing the ACP support website for people with dementia and their family caregivers. Additionally, we combined the use of these frameworks with an agile development approach rooted in user-centred design. This led to a content specification phase that was based on several needs assessment studies and several theories identified through a methodology inspired by intervention mapping[5]. The iterative development process conducted in the creative design phase facilitated the provision of feedback from end-users. This unique combination of approaches can support researchers in developing web-based tools that consider user needs throughout the development process.

We also describe an inclusive approach to the development of the ACP support website by emphasising the combination of patient and public involvement (PPI) input and user-centred development methods. We actively involved people with dementia and family caregivers as research participants and as members of our advisory group, following recommendations of previous research and organisations such as Alzheimer Europe[6–9]. Although PPI is widely recommended, not many studies explain how PPI is integrated into the development process of web-based technologies. A particular strength of this dissertation relates to the step-by-step description of our development process and how we approached the involvement of multiple key stakeholders in all phases of the development of the ACP support website.

Our advisory group was composed of people with dementia, family caregivers, representatives from regional dementia associations, and palliative care experts (nurse and consultant for ACP). Establishing a multi-stakeholder is another strength of our approach, as it allowed us to involve all relevant stakeholders in the development process, and enabled interactions between them to obtain comprehensive insights from various perspectives. Additionally, it facilitated the involvement of people with dementia as integral members of the development team. The involvement of people with dementia at a sufficiently early stage was crucial[10]. Especially when involving people with dementia and/or family caregivers in the development of technology, early meaningful involvement is critical in increasing acceptance rates for innovations[11,12]. It has been shown that when involvement is restricted to later stages, the opportunity for PPI members to influence change is greatly limited[11]. The advisory group in our study was involved as soon as the content and structure of the website had to be specified.

Moreover, we conducted think-aloud and semi-structured interviews with people living with dementia and family caregivers on their perspectives of and their use of the ACP support website. This allowed us to identify the most pressing issues for participants when using the ACP support website and highlighted the potential of people with dementia to act as active, insightful, and meaningful contributors to the development and evaluation of web-based tools.

We meaningfully integrated feedback from our advisory group and feedback stemming from our think-aloud and semi-structured interviews during usability testing. Insights from our advisory group meetings either confirmed or complemented findings from usability testing with participants and allowed us to run decisions by PPI members before their integration on the ACP support website. The input of the advisory group contributed to the quality and relevance of the prototypes being tested with research participants. Using a combination of both PPI and qualitative research allowed us to include a greater diversity of feedback than through one of these approaches alone and may lead to more user-friendly and acceptable web-based tools.

There are some limitations in our development approach. The first limitation lies in the creative design phase and the use of an agile development method. Using an agile development approach required a quick turnaround for prototypes in terms of development and evaluation[13]. This approach based on rapid design, testing and adaptations proved to be challenging, as research activities with people with dementia and family caregivers required significant time for recruitment and organisation. The limited time between iterations may, in part, explain the difficulties in recruitment encountered during the development and usability study, leading to participants with dementia being less represented in our sample than family caregivers. Second, it is essential to acknowledge a limitation within the dynamics of our advisory group. Despite our efforts to establish an inclusive environment, we cannot exclude that power dynamics may still have been present, potentially impacting the level of influence and contribution of people with dementia and family caregivers. Another potential limitation of our approach could be the representativeness of the advisory group. While efforts were made to include a diverse range of stakeholders, it may still fall short of capturing the full spectrum of perspectives and experiences within the broader population of people with dementia, family caregivers, and other relevant stakeholders. The composition of the advisory group may not fully reflect the diversity in terms of cultural backgrounds, socioeconomic status, or variations in the severity and nature of dementia diagnosis.

5. Mixed-method evaluation of web-based reflection and communication tools

In Chapter 6, we used a mixed-method evaluation design to evaluate two web-based reflection and communication tool. This study was part of a larger evaluation study of the ACP support website, which is published separately[2]. Over an eight-week mixed-methods evaluation study people with dementia and family caregivers were invited to use the ACP support website the way they preferred. We analysed log data and qualitative data from interviews with people with dementia and family caregivers, using descriptive statistics and framework analysis. Given that the larger evaluation study concentrated on examining the usage, usability, acceptability, feasibility, and effects of the ACP support website as a whole[2], the web-based reflection and communication tools were not analysed separately. This study allowed us to provide a thorough overview of two innovative web-based reflection and communication tools and evaluate user experiences with the interactive components of the ACP support website. The web-based reflection and communication tools analysed in our study represent a groundbreaking initiative in meeting the unique ACP needs of people with dementia and their family caregivers. These tools are evidence-based (i.e. based on insights from global ACP literature and cultural adaptation processes), making them potential beneficial resources for various demographics. Although the content of the two web-based reflection and communication tools was influenced by the local legal and regulatory context, their 'what matters most' approach and adaptable navigation have broad applicability.

However, some limitations should be noted in our evaluation study. Firstly, the interviews involved family caregivers on their own or joint interviews with both the person with dementia and their family caregivers. There may be a risk of the family caregiver's perspectives overshadowing those of the people with dementia, possibly leading to an incomplete understanding of the latter's experiences. Additionally, while efforts were made to introduce some diversity in the sample, it remains noteworthy that the participants predominantly represented a highly educated demographic.

6. Systematic review

In Chapter 7, we conducted a systematic review of usability requirements for web-based tools targeting communication and decision-making for people with dementia and their family caregivers. To our knowledge, this was the first systematic review dedicated to specifically evaluating the usability of web-based tools tailored for addressing communication and decision-making needs among people with dementia and their family caregivers. Moreover, our study provides practical recommendations that can directly guide the development of such tools for people with dementia and family caregivers.

Despite these contributions, certain limitations must be acknowledged. Our search was confined to articles published in English, potentially omitting valuable research in other languages. Additionally, the quality assessment of the included studies was not taken into account when formulating the design recommendations stemming from this systematic review, as a majority of studies demonstrated a good to fair methodological quality. Thus, studies with varying methodological qualities were treated equally, potentially impacting the overall robustness of the synthesised findings and the ensuing recommendations. Finally, it should be acknowledged that the results from our own usability study (Chapter 5) were absent from the systematic review of usability requirements for web-based tools designed for communication and decision-making in dementia (Chapter 7). This arose from an overlap in the timeframes to conduct the usability study and the systematic review. However, we were able to leverage the findings from the systematic review to compare the ACP support website's design against the design recommendations, and ensure that the ACP support website was in line with them. Our study's outcomes aligned with the systematic review findings (i.e. optimising information delivery and navigation, enhancing visual elements, using clear language and examples, and offering support).

General discussion of the main findings

In the following section, we provide a further in-depth discussion of the main findings of this dissertation in relation to each other and the recent literature.

1. Supporting people with dementia and family caregivers in the advance care planning process

The importance of using a dementia-inclusive definition of advance care planning

ACP is advocated as an essential component of palliative care for people with dementia[14,15]. Yet, there is a lack of consensus on which ACP definition should be used for people with dementia[14,16]. In Chapter 3, we aimed to give a voice to people with dementia and family caregivers in the scientific development in ACP, by obtaining the perspectives of a multinational group of people with dementia (i.e. the EWGPWD) on how ACP is defined, filling an important gap in the work that led to the definition of ACP. This allowed us to identify 3 overarching and 16 specific recommendations for a modified ACP definition that is inclusive of people with dementia. We used these recommendations to ensure that the content developed for the ACP support website (Chapter 5) was in line with the perspectives of people with dementia on what the ACP process should be. ACP for people with dementia requires specific attention to family involvement as the disease advances, adapting to varying levels of decision-making capacities, or addressing communication challenges[17]. Thus, the development and use of a dementia-inclusive definition of ACP is essential to ensure that interventions and policies are acceptable and reflect the needs of people with dementia and their families in terms of ACP.

Very recently, at the end of 2023, a new consensus definition of ACP specifically for dementia was published. This work was supported by the European Association for Palliative Care (EAPC). It was developed through an international Delphi panel consensus and defines ACP as a "*process of communication about future care and treatment preferences, values and goals with the person with dementia, family, and the health care team, preferably with ongoing conversations and documentation. This process is continued when the person with dementia becomes unable to make their own decisions*"[18]. Furthermore, recommendations on how to perform ACP with people with dementia in practice are provided. This Delphi study was conducted concurrently to our qualitative study with the EWGPWD on the definition of ACP (Chapter 3). Even though patient representatives were not directly included in the expert panel, some of the findings from our study with the EWGPWD align with those of the Delphi study. Three issues were identified by the expert panel as deserving particular attention in ACP in dementia, which were (1) capacity, (2) family, and (3) engagement and

communication[18]. This links to two key issues identified by the EWGPWD for an ACP definition that is inclusive of people with dementia i.e.: (1) issues of decision-making capacity, (2) family involvement.

An important aspect of our research that diverges from the work on the consensus definition of ACP in dementia is that the members of the EWGPWD and their supporters did not wish for a separate definition of ACP for dementia. They rather advocated for the existing definition of ACP to be adapted in a dementia-inclusive way so that it can be applicable to people with or without conditions that influence cognitive capacities. This highlights two different approaches, which are either dementia-inclusive or dementia-specific. The 'dementia-inclusive' approach to defining ACP posits that a definition suitable for people with dementia should ideally be suitable for anyone, whereas the 'dementia-specific' approach argues that a generic definition requires some adaptations to better represent additional important issues for a specific condition[18]. Generally, these two approaches have been the centre of ongoing debate within dementia care. For instance, people living with dementia seem to prefer engaging in inclusive activities rather than activities specifically labelled for people with dementia[19]. It has been argued that creating dementia-specific initiatives can sometimes lead to the further separation of people with dementia from the wider community[20]. Considering this, dementia-specific approaches remain often seen as only the first step towards dementia-inclusivity[20].

The value of a 'what matters most' approach to advance care planning

A key finding of this dissertation is that we found a difference between the way ACP is defined and the way it is framed in information targeting people with dementia and their family caregivers (Chapter 2) as well as in the way people with dementia and family caregivers experience ACP in practice (Chapter 3). Although judged as not dementia-inclusive by the EWGPWD in our qualitative study of their perspectives on how ACP is defined, the international definition of ACP developed by Rietjens and colleagues (2017) offers a relatively comprehensive conceptualisation of ACP in terms of processes. It highlights how the focus of ACP has been moving away from solely gathering treatment instructions for situations where an individual's decisional capacity is compromised. Indeed, for several decades already, the focus of the concept of ACP has been shifting towards a broader communication process about goals and preferences for future medical treatments and care for a diverse range of ages and health conditions[21,22]. Yet, according to the EWGPWD, this definition was not broad enough. Indeed, they found a strong focus on medical care in this definition (Chapter 3). The findings of our content analysis of dementia associations' websites also highlighted such a focus on medical aspects of care and on written documents such as advance directives (Chapter 2). Researchers looking at ACP from a public health perspective have proposed moving away from overemphasising medical care and end-

of-life preferences[23,24]. They argue that ACP conversations should focus on exploring broader concerns of patients and family caregivers and identifying values stemming from a person's lived experience. Similarly, previous research with people with dementia has also demonstrated that people with dementia and their family caregivers tend to think about ACP within a framework of what is important to them currently and for the future[25]. Our findings point in the same direction. Indeed, our participants highlighted that this evolution of ACP towards broader concerns was not reflected enough in the definition of ACP nor in ACP practice, and called for a definition focusing more on social aspects of care, in addition to medical aspects of care.

Based on the results of this dissertation, we suggest adopting a 'what matters most' approach to ACP for people with dementia. This 'what matters most' approach implies including broader content or topics in ACP conversations (e.g. what matters most to you in the present and in the future). Members of the EWGPWD and their supporters emphasised the importance of social aspects of care within ACP (Chapter 3). ACP conversations should include broad conversations, including preferences for medical care but also extending to what matters most to people in the future, such as social care or future meaningful daily activities. Our findings are in line with those of previous qualitative studies with people with different types of dementia diagnoses. For instance, it was previously recommended to conceptualise ACP as a holistic process, based on qualitative findings with people with young-onset dementia showing that ACP can entail a broader range of topics, including physical, social, and mental health[25]. Similarly, in a study exploring ACP experiences and needs of people with Parkinson's disease, Kurpershoek and colleagues found that people with Parkinson's disease wished for ACP to be addressed more holistically. The preferred content of ACP conversations included topics such as support for activities of daily living, access to devices, or home healthcare[26]. Our results corroborate the need for holistic ACP and highlight the fact that people with dementia should be able to discuss their wishes for social aspects of care as part of ACP with both family and health professionals. Thus, it is advisable to adopt a 'what matters most' approach throughout the ACP process, encouraging families and health professionals to be open to discussing social domains of ACP and care in addition to medical decisions. We applied this 'what matters most' approach during the development of the ACP support website (Chapter 5). More specifically, this approach particularly informed the development and provision of two interactive reflection and communication tools (Chapter 6), which aimed to enable people with dementia and family caregivers to explore social aspects of care and broader values (in addition to the more traditional medical aspects of care) that are important to consider when making decisions for future care and treatment.

The importance of involving families in the advance care planning process

In addition to broadening the content of ACP conversations, results from this dissertation highlighted the importance of involving families in ACP in the context of dementia. The EWGPWD and their supporters (Chapter 3) highlighted that the role of families and trust-based relationships in the ACP is crucial. However, they found the role of families to be under-addressed in the definition of ACP. While recognising that families have different dynamics and people with dementia should be free to choose who to involve in the ACP process, the EWGPWD pointed out that families or other people one trusts have essential personal knowledge of the person with dementia, and are an important point of contact in communication and decision-making.

We thus suggest taking a relational approach to ACP next to a person-centred approach. Family-focused interventions have been argued to be appropriate for people with dementia as they can increase communication between the person with dementia and people close to them, as families seem to play an important role in supporting people with dementia to make future decisions[27–29]. A person-centred (or individualised) approach is usually recommended in palliative care as well as dementia care[14,16,30]. However, our findings suggest that a solely person-centred approach may not be sufficient and highlight the need for a more relational approach to ACP. Several studies have also suggested adopting a relational approach to ACP either in the context of dementia or in other contexts. For instance, in the context of chronic illnesses, Killackey and colleagues posit that using a relational view of autonomy in ACP allows a better understanding of the process, as it recognises the importance of relationships, the fluctuating nature of autonomy in chronic illnesses, and the impact of vulnerability on ACP and communication processes[31]. Similarly, in the context of young-onset dementia, Van Rickstal and colleagues found that ACP should be approached holistically, flexibly and relationally in order to better reflect the importance of familial relationships in decision-making[25]. Our findings show that the involvement of families or other close relationships should be flexible in terms of timing and extent of involvement and, most importantly, should be in line with the wishes of the person with dementia. We suggest adopting a combined person-centred and family-focused approach to ACP, balancing relational and personal views on ACP, and addressing the needs of both the people with dementia and those of the people close to them while respecting the autonomy of people with dementia. In practice, such a combined approach to ACP may include conversations with people with dementia on their preferences in terms of family involvement, including the way and the extent to which they would like family members to be included in the ACP process. This can range from discussing preferences, to completing advance directives together or shared decision-making. Parallelly, this approach may enable families to have conversations in which they can discuss their experiences of dementia and their role in the ACP process.

The need to provide comprehensive and accessible information on advance care planning

The findings from our content analysis of dementia associations' websites in Europe (Chapter 2) point to a lack of comprehensive information about ACP. Not only did more than a third of the website included in our study not provide any information relating to ACP, but those that did provide ACP information largely concentrated on legal and medical aspects of ACP. Key ACP themes such as communication with both families and health professionals, as well as the identification of personal values and life goals were under-addressed on dementia associations' websites.

Lack of information was found to be an important barrier to ACP for people with dementia and family caregivers[32], and they have expressed concerns about the limited availability of information regarding, among other topics, the trajectory of dementia, ACP, and available care options[32–34]. Given that the Internet is being increasingly used to search information about health conditions and treatment options[35], and that it has become the most used source of information for people with dementia and their family caregivers[36,37], it is important that information about ACP provided online is complete and comprehensive. The reference framework that we developed based on two recent ACP definitions can serve as a guide for comprehensive provision of ACP information. Information about ACP should at least address all the categories identified in this reference framework. These categories are: defining ACP, legal ACP frameworks, legal representatives, care and medical treatment preferences (including end-of-life care), documentation of decisions, personal values and life goals, communication and discussions with family, communication and discussions with health professionals, sharing documents, timing, meaning and consequences of potential serious illness scenarios, and uncertainties of serious illness scenarios. However, given that the framework was developed based on two general definitions of ACP, which we found to not be very inclusive of aspects that concern people with dementia specifically, the reference framework could benefit from being supplemented and tailored with dementia-related information, such as the issue of decision-making capacity for instance. We applied this reference framework when developing the ACP support website in Chapter 5.

Our content analysis of dementia associations' websites (Chapter 2) also allowed us to identify important accessibility and readability features that can support people with dementia and family caregivers in accessing ACP information. The use of features such as options to print, text-to-speech programs, and contrast or font size adjustments are important accessibility features. Similarly, using simple language, pictures or videos can help improve the provision of information. However, we found that such features were often not provided on the websites of dementia associations. These findings were corroborated by the design recommendations derived from our systematic review of usability requirements of people with dementia and family caregivers for web-based tools targeting

communication and decision-making (Chapter 7). In the content specification phase of the development process (Chapter 5), we found that people with dementia and family caregivers also preferred to receive information in a personalised manner, for instance through peer testimonials. Based on these findings, we selected several theoretical change methods to develop the ACP support website, such as persuasive communication to target attitudes or modelling to target self-efficacy for instance. These theoretical change methods were based on theories of behaviour change and theories of learning among others. Such theoretical change methods have been used in the development of health promotion interventions and are a helpful basis to develop and design interventions[38–40].

The value of advance care planning in the family context as a complementary approach to advance care planning with health professionals

In this dissertation, we presented the development and testing of a website to support ACP in the family context, that is conversations that people with dementia have with their family or friends at home or outside of the professional setting (Chapter 4 and 5). We selected this approach because it aligns with the expressed needs of people with dementia and family caregivers to discuss ACP within the family unit, outside of the professional context[41,42]. Our approach is also in line with the public health approach to ACP and palliative care, which highlights the need to normalise and reconfigure how health and care decisions are made by reframing ACP as a health-promoting activity through public education and engagement[23,24,43]. However, there are a few important considerations that should be taken into account with regard to ACP within the family context and its relationship with ACP with health professionals.

Firstly, the two approaches, i.e. ACP in the family context and ACP with health professionals, should not be considered opposites, where one excludes the other. Rather, they should be considered complementary approaches. Health professionals are vital stakeholders in the ACP process for people with dementia, as demonstrated by their central role in the recent consensus definition of ACP in the context of dementia[18], as well as in previous ACP definitions for the general population[21,44]. Given that ACP often concerns healthcare decisions, health professionals have an important place in ACP conversations, especially in terms of exploring hypothetical future scenarios and uncertainties, establishing realistic and achievable expectations based on the preferences of people with dementia and their family caregivers, and pinpointing any potential future issues. Furthermore, conversations with health professionals are essential in the medical decision-making process concerning particular topics such as refusing certain treatments. Nevertheless, the potential of conversations on aspects such as values, wishes or preferences for care that happen within the family context should not be

underestimated[41,45]. ACP conversations in the family context can provide valuable insights into people's values and preferences, forming a foundation to guide ACP conversations and decision-making with health professionals as well[45]. To ensure that conversations in the family context and conversations with health professionals are aligned, health professionals need to be aware of people's values and preferences so that medical treatments and care goals can be aligned with these[23].

The website to support ACP for people with dementia and family caregivers could be used in combination with engaging in ACP with health professionals within a professional setting. Indeed, the findings from our evaluation of the interactive web-based reflection and communication tools (Chapter 6) hint to the potential complementary role of health professionals when using the ACP support website. Some of our participants explicitly mentioned that they would bring the results from their use of the tools to their next appointment with their health professionals. Although further research is warranted, our findings suggest that the ACP support website and the web-based tools may have applications for health professionals, who could use it as a tool to prepare people with dementia and family caregivers for the process of ACP before raising issues such as decisions for future care and treatment.

2. Supporting people with dementia and family caregivers in using and accessing the advance care planning support website

The potential of a flexible and non-linear navigation process to support advance care planning

Results from the content specification phase of the development of the ACP support website indicate that most existing web-based tools adopted a step-by-step linear approach to supporting ACP (Chapter 5). This means that they followed a fixed and predetermined sequence of steps, usually going in the following order: information provision, reflection stimulation, communication support, written documentation (e.g. through advance directives). However, the appropriateness of such predefined steps can vary depending on people's readiness, personal barriers, and preferences towards ACP[46].

Therefore, we opted for a flexible and non-linear navigation during the next steps of the development of the ACP support tool, which was particularly appreciated by people with dementia and family caregivers during the development of the website (Chapters 5). This approach allows people with dementia and family caregivers to engage in ACP conversations even though they might not feel prepared to address all aspects of ACP. In a mixed-method evaluation of the ACP support website (results not included in this dissertation), studying how people with dementia and their family caregivers used the website, we further found that there can be diverse preferences regarding the order in which people engage with various components of the ACP support website[2]. For instance,

some may start with an interest in advance directives, driven by an immediate interest in clarifying future medical decisions and preferences. On the other hand, others may prioritise exploring their wishes for their current care needs and preferences, before delving into conversations about the future. This need for flexible navigation is also reflected in our evaluation of the interactive web-based tools provided on the ACP support website (Chapter 6), where we found that half of the users of the ACP support website actively used the web-based reflection and communication tools while the other half did not. These varied entry points into the ACP process highlight the importance of a flexible approach to supporting ACP for people with dementia and their family caregivers. Research has shown that reluctance and apprehension to engage in conversations about certain difficult topics, such as end-of-life preferences or an uncertain future of cognitive decline, are substantial barriers to engaging in ACP for people with dementia and their family caregivers[47–50]. Our approach aimed to give people with dementia and their family caregivers the possibility to choose which topics align with their current readiness, and the possibility to delay conversations on topics they do not wish to discuss at a certain point in time. This approach is translated on the website by allowing users to choose specific sections of the website without navigating through the entire content and allowing users to pause their interaction with the website and return to it at their convenience.

The importance of usability testing with people with dementia and family caregivers

In terms of research methods to involve people with dementia in the development of technology, usability testing has emerged as a pivotal method to pinpoint barriers and areas requiring enhancement in technology. Widely recognised in user-centred design, usability testing is a proven technique to enhance the user-friendliness of interfaces by identifying and addressing flaws[51]. Importantly, this approach allows for the active participation of people with dementia throughout the technology development process, ensuring that the end products cater specifically to their needs. However, previous studies have often focused on the proxy opinions of family caregivers or health professionals on the usability of technology for people with dementia and the opinions of people with dementia themselves are scarcely reported[52]. In this dissertation, we used several methods (i.e. think aloud interviews, semi-structured interviews, usability survey) to gather the perspectives of both people with dementia and family caregivers on the usability of several prototypes of the ACP support website (Chapter 5).

Usability testing enabled us to identify and address important challenges and difficulties with the use of the ACP support website. We identified issues related to text length, formulation of content, or difficulties with the use of the web-based reflection and communication tools, through several

iterations of usability testing. This process allowed us to address these issues with solutions such as simplification of textual content, the incorporation of media such as videos, or the development of tutorial videos for the use of the web-based reflection and communication tools. All in all, this allowed us to produce an ACP support website that was seen as user-friendly and relevant by end-users, and that was ready to be evaluated in a larger scale. In addition to our study findings, the design recommendations formulated in <u>Chapter 7</u>, can be used by researchers to help tailor new and existing web-based tools targeting communication or decision-making for people with dementia and family caregivers. However, the use of our design recommendations cannot and should not replace the involvement of people with dementia and family caregivers in usability testing. Such testing guarantees that the perspectives of people with dementia and family caregivers are acknowledged and taken into account, as well as allows for cultural nuances and differences to be considered.

The significance of identifying the users of the advance care planning support website

In this dissertation, we aimed to include a diverse group of people with dementia and family caregivers in the development and testing of the ACP support website, in terms of age, gender, and type of dementia (<u>Chapters 5 and 6</u>). Our inclusion criteria in both studies comprised the following: (1) being aware and informed of the dementia diagnosis, (2) having an interest in and being willing to test the ACP support website, (3) having the ability to navigate the ACP support website (4) being able to consent to study participation, and (5) speaking and understanding Dutch. The formulation of our inclusion criteria deliberately targeted those who would be typical users of the ACP support website and would use such a web-based tool outside of the context of participating in research, that is people who had an interest in using a web-based ACP tool and who felt they had the ability to do so. Our participants with dementia were mainly under 65 years of age, lived at home, and were in the mild to moderate stages of dementia.

It is worth noting that none of our participants were people with more advanced stages of dementia. However, we did include family caregivers of people in the advance stages of dementia. In a mixed-method evaluation of our ACP support website (results not included in this dissertation), family caregivers indicated that although they found the website useful and informative, they would have preferred having access to it earlier in the disease trajectory of their family member with dementia, as ACP conversations as described on the ACP support website were no longer possible due to the advanced stages of cognitive decline. However, the ACP support website remained a useful resource later in the dementia trajectory, mainly for family caregivers to understand what ACP is, foster communication with the person with dementia, or when communication is more challenging to reflect on values and preferences that had potentially been discussed in previous daily conversations[2]. It is

therefore important to recognise the limits of the ACP support website, especially in terms of the population it can reach. This suggests that the principal users of the ACP support website, i.e. those who will need or benefit from using it, would be people with mild to moderate dementia together with their family caregivers, or family caregivers on their own.

The importance of recognising the presence of different user experiences and support needs

By recruiting participants as dyads or people with dementia and family caregivers alone in the development study (Chapter 5), we aimed to keep the door open for different types of use of the ACP support website. When exploring the user experiences of people with dementia and family caregivers with the web-based reflection and communication tools specifically (Chapter 6), we found that some people prefer using the tools alone and others prefer using them together. Mostly family caregivers used the website on their own, whereas people with dementia seemed to prefer using the website jointly with their family caregivers. Some people with dementia mentioned that the presence of a family caregiver while using the website was reassuring as the family caregiver could intervene, in case they needed technical assistance or help in understanding and interpreting the content of the website.

The issue of people with dementia not being able to or willing to use the website on their own had already been raised during the development of the ACP support website (Chapter 5). In a recent systematic review of the factors influencing the adoption of digital health for people with dementia, Conway and colleagues suggest that family caregivers can play a crucial role in helping people with dementia overcome barriers to the uptake and adoption of new technologies[53]. However, previous studies have also explored perceptions of this supportive role of family caregivers in technology use for people with dementia, with some perceiving it to enhance the quality of their caregiving relationships, and others perceiving it as an additional burden[53–55]. In order to minimise this potential additional burden, efforts to address technological challenges, tailor technologies to the needs of people with dementia, and develop approaches to provide personalised support when introducing new technology are essential. This could be reflected through the addition within the ACP support website of detailed tutorial videos on how to use each section and feature of the website. Such videos may also include suggestions for family caregivers on how to support their family member with dementia in using the website and the reflection and communication tools.

The need to consider the digital literacy of people with dementia and family caregivers

The growing interest in digital health has been facilitated by a considerable increase in Internet access globally over the last decades[56,57]. While the use of the Internet has become widespread since the late 1990s and more recently using mobile devices such as smartphones or tablets, there remains a significant digital divide among age and cohort groups in the distribution of Internet usage[56,58,59]. While living with dementia is often associated with being older, not all people with dementia fall into the older age category. Younger people with dementia may face different challenges when engaging with digital health. There is little information on Internet usage patterns for people with dementia, but more is known about how older people (which include many people with dementia) use the Internet. For instance, in 2020, 98% of Europeans aged 16–24 had used the Internet within the last 3 months, whereas only 61% of people aged 65–74 had done so[60]. Moreover, despite older adults becoming the fastest-growing consumers of digital technology, they still lag behind compared to younger generations[56,61,62]. This so-called digital divide extends beyond basic Internet access, encompassing attitudes, skills and usage type[63]. Recent research indicates that Belgian older adults are among the most frequent internet users in Europe in their age group[59], yet challenges persist, highlighting the need for continued efforts to bridge the digital gap among different age groups and avoid digital exclusion.

Not all older adults or people with dementia automatically experience digital exclusion, as like any other group, they are highly diverse. Regarding digital skills, there can be differences related to age, gender, social status, education, or levels of self-efficacy[64]. Therefore, the stereotypical belief that all people with dementia are not able to use technology needs to be rejected[65,66]. In this dissertation, the self-rated computer skills of people with dementia and family caregivers varied greatly, with some having a lot of experience with using computers and others close to none or very little. However, all participants had volunteered to test a website, indicating that they were interested in using web-based tools. Our results stressed that despite the user-centred development of the website to support ACP, people with dementia and family caregivers needed support using the website, particularly the web-based reflection and communication tools (Chapters 5 and 6). This was also one of the main results of our systematic review of usability requirements of web-based tools to support communication and decision-making for people with dementia and family caregivers (Chapter 7). Our findings point to the need to further consider digital exclusion and digital literacy when developing web-based tools for people with dementia and family caregivers in order to offer appropriate support.

The concept of digital literacy was first used in the 1990s to refer to "the ability to understand and use information in multiple formats from a wide variety of sources when it is presented via computers"[67]. Today, the academic literature is divided and there is no consensus on the definition of digital literacy. Terms such as digital literacy, digital skills, digital competencies, internet skills, ICT skills, or 21st-century skills have all been used interchangeably depending on the interests and scope of different studies[68,69]. However, a recent literature review by van Laar and colleagues suggests that digital skills primarily refer to the specific technical capabilities related to using digital devices and services. In contrast, digital literacy is characterised by a more comprehensive range of competencies including cognitive and social/emotional skills[70]. There is a lack of studies investigating how to support digital literacy and the use of technology for people with dementia[71]. In our systematic review of usability requirements of web-based tools to support communication and decision-making for people with dementia and family caregivers (Chapter 7), we found several main forms of support, such as tutorials and instructions embedded within the web-based tools, offering step-by-step guidance, and face-to-face training provided by trained personnel. More research is needed to investigate how each of these forms of support can support digital literacy, and ultimately lead to support that is adapted to each individual's capabilities, preferences and needs.

The value of considering future reach and access to the advance care planning support website for people with dementia and family caregivers

Websites and other web-based tools are useful ways to provide information about ACP and give access to interactive tools such as the 'Life Wishes Cards' and the 'Thinking Now About Later' tool. In Chapter 2, we identified that dementia associations' websites can be an ideal place to provide ACP information to a wide public. This is because dementia associations are usually a trusted source of information for people with dementia and family caregivers, especially when considering the large availability of information on the Internet that is of uncertain quality[36].

To enhance reach and potential access to the ACP support website, it is necessary to incorporate it and embed it within a context or system. Specifically, this means that in order to facilitate this integration of the ACP support website, collaborations with regional stakeholders from the start of the project were essential. Given the potential of dementia associations in reaching people with dementia and family caregivers with ACP information and resources, Flemish dementia associations were contacted to be part of this project. In Chapter 4 and 5, we explain how regional stakeholders, among which the Flemish Alzheimer League and the Centre of Expertise on Dementia Flanders (i.e. the two main dementia associations in Flanders), were involved in the development of the ACP support website.

Their involvement throughout the project ensured that the ACP support website was in line with their priorities and preferences, as well as allowed for discussions about a potential handover of the ACP support website to these organisations after completion of the research. Handing over the website will ensure that it is easily accessible for people with dementia, family caregivers, and health professionals in the real world.

Handing over the website will facilitate reach to a broad audience. However, it is worth noting that ACP is a process that is highly dependent on legal and regulatory contexts. Therefore, the information provided on the website will need to be kept up-to-date depending on changes in the relevant laws and regulations. Findings from a systematic review of web-based ACP tools has shown that the majority of ACP tools were not kept up-to-date, as they had not been updated in at least five years[46]. Therefore, after hand over of the ACP support website, the research team will remain involved to ensure that information is up-to-date and modify it if needed.

Recommendations for practice, policy, and research

In the following section, we will formulate several recommendations for future research, as well as for practice and policy, based on the findings of this dissertation.

1.   **Recommendations for practice**

Advance care planning could be introduced more as conversations about 'what matters most' for the future.

The dissertation's key findings highlight a disparity between the conceptualisation of ACP and the information people with dementia and family caregivers are provided and the way they experience ACP in practice. Building on these insights and recommendations from the EWGPWD on how to define ACP, we propose a shift towards a 'what matters most' approach to ACP. This approach is in line with a public health approach to ACP[23] and advocates for broader content in ACP conversations and a family-inclusive perspective. Notably, our participants underscored that the importance of social aspects of care should be emphasised. Thus, ACP conversations should extend beyond medical preferences to encompass aspects such as future social care and meaningful daily activities. In practice, ACP conversations could be introduced through conversation openers such as 'what matters most for you, now and in the future?' with both people with dementia and family caregivers and exploring how these considerations may influence future decisions. This approach would also fit within goal-oriented care strategies, which posit that care should be determined on the basis of a person's care and support needs and translated into life goals as well as care and support goals. Thus, conversations should be more proactive and personalised, including medical needs but also wider aspects of health and well-being[72].

Incorporating interactive ACP tools into practice could facilitate these 'what matters most' conversations, guiding people with dementia and family caregivers through a comprehensive exploration of values and preferences beyond medical decisions. The ACP support website developed and tested in this dissertation addresses ACP through this 'what matters most' lens, and could facilitate the initiation of ACP in practice. Research has shown that people with dementia and family caregivers would prefer that such web-based ACP tools be introduced by health professionals[42]. Therefore, we recommend that the ACP support website be used alongside professional ACP consultations. The website can serve as a way for people with dementia and family caregivers to gradually familiarise themselves with the ACP process and at their own pace, through accessing the information, resources, and interactive reflection and communication tools available.

Encourage accessible design of web-based tools according to the following criteria: visual appearance, navigation and delivery of content, and support use.

To optimise the usability and effectiveness of ACP web-based tools in dementia, it is crucial to encourage accessible design adhering to specific criteria[73]. Based on the results of this dissertation, we recommend taking into account the following considerations.

In terms of visual appearance, designers should optimise information by condensing and organising it into manageable sections with clear headings. Additionally, elevate the visual appeal by optimising colour contrast, employing larger fonts, and integrating recognisable icons for enhanced visibility and interaction. Establishing a harmonious interface through the use of pleasant colours, minimalistic design, more images, and consistency in design elements contributes to a user-friendly experience.

In terms of navigation, designers should improve navigation and streamline information access through efficient search functions and clear organisation. Additionally, systems should be tailored for individual needs, offering features such as font size or contrast adjustments. We recommend using clear and simple language throughout a web-based tool to deliver the relevant content.

Finally, solutions such as training sessions or instructional materials should be developed for user support to boost the confidence and competence of people with dementia and family caregivers. It is important to tailor support to individual needs, offering one-on-one support or personalised tutorials. By adopting these strategies, designers can ensure that web-based ACP tools can be more user-friendly, inclusive and effective in supporting people with dementia and family caregivers.

2. Recommendations for policy

Raise awareness of advance care planning as a communication process about 'what matters most' for the future.

Firstly, in order to enhance the integration of ACP into practice, we propose that policymakers (such as national or regional ministries, professional organisations, and advocacy groups) focus on raising awareness of ACP as a dynamic communication process centred around 'what matters most' to people in the present and for the future. Policies that follow this approach may promote person-centred care, and encourage the integration within the healthcare system of broader ACP conversations, and not only medical decision-making and the completion of advance directives.

Aligning with the public health approach to ACP[23], policymakers can implement a comprehensive strategy, aimed at both health professionals and the general public, which can comprise a digital platform such as the ACP support website developed in this dissertation. Such a strategy could involve launching public awareness campaigns through diverse media channels to educate people with dementia and people close to them, emphasising ACP as a communication process about 'what matters most', redefining ACP as more than a documentation process, and showing its role as a comprehensive and ongoing dialogue about values, preferences, and goals. Collaborating with advocacy groups would be crucial to reach diverse communities and to tailor messages to address cultural nuances. Professional training programs could also be established to equip health professionals with the skills to guide patients in dynamic ACP conversations about what matters most to them. Additionally, incorporating ACP education in community workshops or events could help foster open discussions about ACP. In particular, digital platforms, such as the ACP support website, can be leveraged by policymakers to disseminate information and resources on ACP as a process of communication about 'what matters most'.

Ensure that professional organisations provide comprehensive advance care planning information and resources and ensure that health professionals are trained on how to provide comprehensive advance care planning information as part of a flexible communication process.

Lack of information can be a significant barrier to ACP for people with dementia and their family caregivers[74]. In light of the findings of this dissertation, policy should prioritise the development and dissemination of comprehensive ACP information that extends beyond the legal and medical aspects of ACP and includes crucial but under-addressed themes such as communication with families and health professionals, the identification of personal values and life goals.

This could be done through professional organisations, as well as health professionals. To implement the recommendation of prioritising comprehensive ACP information, these groups can take several steps. First, all professional organisations should provide more information (about all aspects of ACP) than they currently do. In our content analysis of dementia associations' websites, we found that Belgian websites did not provide much ACP information. Only the Flemish Alzheimer League had ACP content, but it only provided information about legal and medical aspects of care, while quality of life, personal social and practical aspects of ACP were not addressed. Then, professional organisations could develop and endorse resources, such as the ACP support website, that emphasise the holistic nature of ACP (going beyond legal and medical aspects). In medical training, curricula should be updated to incorporate a holistic and comprehensive approach to ACP, ensuring that future (and

current) health professionals are equipped with the necessary skills. This includes effective communication training and how to approach ACP from a broader context than solely medical and treatment preferences. Medical institutions can facilitate workshops and continuing education programs that comprehensively focus on all aspects of ACP.

Both professional organisations and medical training institutions should actively participate in the dissemination of comprehensive ACP information. They can leverage their networks to circulate educational materials, host seminars, and utilise digital platforms to reach a wider audience. Collaborative efforts between those entities can establish best practices, ensuring that ACP information encompasses the essential elements of communication, personal values, and life goals. Such policies could play a pivotal role in helping provide comprehensive ACP information to a wide public. The reference framework developed in our content analysis of dementia associations' websites (Chapter 2) can be used as a tool to develop ACP information and ensure that all key ACP themes are addressed.

3. Recommendations for future research

Further evaluate the effects of the ACP support website and study how people with dementia and family caregivers can be optimally supported when using the website.

In this dissertation, we provide a thorough account of the development and initial testing of the ACP support website and its web-based reflection and communication tools. Before disseminating the ACP support website, further evaluation of the ACP support website is needed. After developing and testing the ACP support website, an eight-week mixed-method evaluation study was set up, which employed a convergent parallel mixed methods pretest-post-test design. This study sought to evaluate the usability, acceptability, feasibility, experiences, and effects on ACP readiness, ACP knowledge, attitudes, perceived barriers to engaging in ACP, self-efficacy, and skills to engage in ACP. This study will provide further insights into the effects of the ACP support website in supporting ACP for people with dementia and their family caregivers. The evaluation study is not part of this dissertation, however, its results will be crucial in determining further research needed on the ACP support website. Some future research directions may include, for instance, a longitudinal study examining the effects of the ACP support website over a longer timeframe. Such a study could be relevant in understanding how people with dementia and family caregivers engage in ACP in the long-term, and identifying the role of the ACP support website in the process.

Furthermore, based on the studies in this dissertation, we found that despite the thorough involvement of people with dementia and family caregivers in the development and usability testing of the ACP support website, people with dementia still relied on their family caregivers when using the website. Family caregivers also expressed doubts about whether people with dementia would be able to use the ACP support website independently. In light of these results and of the growing reliance on online tools and services in the healthcare sector[35,36], it is essential that future research focuses on innovative strategies for delivering support for the use of web-based tools for people with dementia and family caregivers. First, this includes investigating the best way to deliver tailored support that aligns with the abilities and needs of people with dementia and family caregivers. Second, future studies should delve into issues around the visualisation of information and content for people living with dementia and their family caregivers and explore effective design principles for presenting information on web-based tools to improve clarity, comprehension, and engagement. Finally, given that people with dementia and family caregivers are a diverse and heterogeneous group of individuals with different needs, preferences and levels of digital literacy, research should explore how to cater to their diverse needs in terms of support and assistance in using web-based tools. The role of health professionals in how to support the use of the ACP support website should also be investigated.

Further investigate advance care planning in the family context and its relationship with advance care planning with health professionals.

In this dissertation, based on the public health approach to ACP and palliative care, we argue that ACP in the family context (i.e. outside of professional consultations) and ACP with health professionals are two complementary approaches. Until now, a large amount of research has been conducted on supporting ACP with health professionals[75,76], while there is little evidence on how to support ACP in the family context. We aimed to address this gap by developing a website to support ACP in the family context. This ACP support website aimed to provide information and support ACP conversations between people with dementia and family caregivers.

Future studies should investigate the relationship between ACP in the family context and ACP with health professionals. Exploring how ACP conversations at home and knowledge of preferences and values stemming from lifelong conversations can influence conversations with health professionals and medical decision-making, and vice versa, will contribute valuable insights into the nuanced nature of ACP. Such research can inform the development of more effective strategies, interventions, and communication frameworks that could bridge the gap between ACP in the family context and in the medical context, ultimately fostering a more cohesive and person-centred approach to ACP.

Use a dementia-inclusive definition of advance care planning in the development of interventions.

Until now ACP interventions for people with dementia were based on many different definitions of ACP. In addition to the lack of consensus on which definition to use, all these definitions require people engaging in ACP to have decision-making capacity, and none included people with dementia in their development. Based on the perspectives of the EWGPWD on the definition of ACP (Chapter 2), we recommend using a dementia-inclusive definition in the development of future ACP interventions for people with dementia and family caregivers. Such a dementia-inclusive definition would most importantly: (1) remove the specification that ACP only applies to people with decision-making capacity, (2) highlight the essential role of families in ACP, and (3) focus more on social aspects of care.

By using a dementia-inclusive definition of ACP, researchers can increase the chances that interventions and policies better reflect the lived experiences of people with dementia and their family caregivers. Furthermore, interventions using a dementia-inclusive definition of ACP can be more likely to meet the needs of people with dementia and family caregivers and could get higher rates of acceptability and adoption in the target population. Ultimately, it could enhance the effectiveness and relevance of interventions, contributing to more person-centred research.

Facilitate and encourage the participation of people with dementia and family caregivers in research and development of technology.

The involvement of people with dementia and family caregivers is an essential part of developing interventions (digital or non-digital) that can effectively support ACP and are acceptable and feasible. Indeed, the involvement of people with dementia and family caregivers has been advocated to ensure, on the one hand, that health-related research leads to relevant findings for people with dementia and on the other hand, to ensure the development of suitable and user-friendly technologies for people with dementia[6–9,77,78]. This is especially critical for people with dementia, given their distinct needs to engage with digital health interventions. In this dissertation, we provide several examples of the successful and meaningful involvement of people with dementia and their family caregivers in research and technology development. We involved people with dementia and family caregivers in two ways. Throughout the development and testing stages of the website to support ACP (Chapters 4, 5, and 6), we involved people with dementia and family caregivers as research participants by inviting them to think-aloud or semi-structured interviews and asking them to fill out usability surveys. In parallel, we involved people with dementia and family caregivers as PPI contributors in our advisory group. To ensure the relevance of research outcomes and technological advancements in dementia care and

palliative care, it is imperative to actively facilitate and encourage the participation of people with dementia and their families in research. Inclusivity in research and technology development enhances the representation of diverse perspectives and fosters the creation of solutions that resonate with the actual needs, challenges, and preferences of people with dementia and their families.

We recommend the implementation of strategies that actively engage people with dementia and their family caregivers in the planning, execution, and evaluation phases of research projects and technology development initiatives. Researchers should prioritise accessible and transparent communication channels to disseminate information about opportunities for involvement, ensuring that people with dementia and family caregivers are aware of and feel empowered to contribute to these initiatives. Promoting active participation of people with dementia and family caregivers may be a way for policymakers to pave the way for more holistic, person-centred, and ethically grounded advancements in research and technology.

Carefully plan patient and public involvement from the start of a project and avoid tokenistic involvement of people with dementia and family caregivers.

Researchers wishing to include patient and public involvement (PPI) in their studies should be aware of some considerations when it comes to the involvement of people with dementia and family caregivers. The integration of PPI in research can be time consuming. We conducted six PPI meetings during the development period of the ACP support website, with one or two months in between each meeting. PPI meetings with the advisory group required careful preparation. Each PPI meeting included a presentation of the results of usability testing and the decisions to be made, and then facilitating discussions and allowing each member of the advisory group to provide input.

While ethical approval is typically unnecessary for PPI since members are not considered as research participants providing data, it remains essential to ensure the wellbeing and safety of people with dementia and family caregivers involved in PPI[10,79]. Although ethics approval may not be required, due consideration should be given to the potential impact on the well-being of PPI members[80]. In this dissertation, all members of our advisory group received an information letter before the start of their involvement, specifying the purpose of the advisory group and their roles in the project. Due to the Covid-19 restrictions in place during the development period of the ACP support website, we conducted PPI meetings online through a video-conferencing platform. We took several measures such as sending materials a week in advance and limiting the meetings to an hour to facilitate online participation.

Researchers should beware of tokenism, which can manifest as merely providing a symbolic "seat at the table" without genuinely considering the valuable contributions of people with dementia[81]. The time-consuming nature of PPI (and, in some cases, the pressure of fulfilling funding or ethical approval requirements) may lead some researchers to approach PPI as a checkbox exercise[10,82]. However, tokenistic involvement of people with dementia in PPI can result in a lack of impact, diminished trust, ethical concerns, missed opportunities for improvement, underrepresentation of diverse perspectives, a waste of resources, and a negative impact on the research's reputation[83]. We suggest that researchers develop a clear plan for PPI involvement, including the level of involvement they wish to include in their projects (e.g. consultation or co-creation) and clearly communicate the purpose of meetings and roles to potential PPI members.

Involve a variety of stakeholders such as people with dementia, family caregivers, and local and regional stakeholders in research and consider diversity.

In this dissertation, we used user-centred design and PPI to develop an ACP support website through an inclusive and collaborative approach, with the active participation of people with dementia, their family caregivers, health professionals, and regional dementia associations. Establishing collaborations with all key stakeholders led to a transparent development process and is the foundation for the sustainability of the website. We strongly encourage researchers to adopt such a collaborative and inclusive approach in research and development of technologies. However, careful consideration must be given to the inclusion of diverse participants. Diversity of research participants in dementia research remains a challenge, as demonstrated by recent research highlighting that there is a predominant representation of white and young participants[84-86]. This was also the case in this dissertation. By actively seeking a diverse range of perspectives, future research can bridge existing knowledge gaps, including on the effects of the ACP support website, yielding findings that are more representative, applicable, and ultimately contribute to the advancement of research and care practices. We recommend that future studies prioritise the inclusion of people with dementia and family caregivers with more diverse experiences and backgrounds such as various ethnic or cultural backgrounds.

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English summary

'What matters most?'

Supporting advance care planning for people with dementia and their families

General Introduction

Advance care planning (ACP) is defined by the European Association for Palliative care as "*a process that enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate*".

The practice of ACP has evolved significantly over the decades. Initially, it mostly focused on legal documents for patients to decline specific medical treatments. However, research has shown that ACP should be a dynamic communication process between patients, families, and health professionals, emphasising ongoing discussions and shared decision-making. Despite this, ACP practice still often centres on written documentation and advance directives. The public health approach to ACP stresses the need to explore broader concerns, aligning medical considerations with people's priorities and values. While ACP conversations often occur in a professional setting, there is a call to expand conversations within the family context (that is outside of professional consultations), fostering a more open and natural dialogue. Both ACP within the family context and ACP with health professionals are seen as complementary approaches, with professionals playing a crucial role in aligning care goals with patient and family preferences.

Dementia is a progressive neurological disorder marked by cognitive decline affecting memory, thinking, behaviour, and daily tasks. It is an umbrella term covering various conditions, with Alzheimer's disease as the most common form. Global dementia prevalence is rising, with an estimated 55 million affected in 2021, and it is expected to double by 2030 and triple by 2050. ACP, though infrequent, is vital for people with dementia, aiding in decision-making preparation and supporting family caregivers as their role becomes prominent. Despite recommendations for early initiation, research indicates ACP engagement remains low, emphasising the need for increased awareness and participation in discussions among people with dementia.

Barriers to ACP in dementia include challenges related to discussing death and the uncertain future, as people with dementia often prefer living in the present and may lack information about the disease trajectory. Cultural factors, family dynamics, and limited knowledge about treatments and decision-making roles can further complicate ACP engagement. Specific needs for ACP in dementia include a clear understanding of the disease trajectory, the increasing involvement of family or friends as cognitive abilities decline, and the recognition of the need for a surrogate decision-maker. Early initiation of ACP is crucial, considering the gradual progression of dementia, and a tailored approach that emphasises personalised care, readiness levels, and communication strategies is essential. Informal conversations within the family context can play a vital role in ACP, providing valuable insights into people's wishes and preferences. However, both people with dementia and family caregivers may encounter challenges when engaging in ACP conversations, necessitating support to communicate about ACP effectively.

Previous ACP interventions, like professional trainings or documentation booklets, have been primarily aimed at facilitating making decisions for future care and treatment in coordination with healthcare professionals, and have predominantly focused on other patient groups or healthcare professionals, with limited attention to people with dementia. Existing reviews found a scarcity of studies specifically addressing ACP for people with dementia, and those available often involved family caregivers rather than direct involvement of the person with dementia. Challenges in this field include the lack of consensus on a tailored definition of ACP for people living with dementia. Another challenge is the insufficient theoretical underpinning in ACP interventions for people with dementia, as most are either implicit or not validated for this population. Current literature emphasises ACP within professional contexts, leaving a notable gap in guidance for ACP within the family context.

Digital health (the development and use of digital technologies to improve health) offers advantages such as autonomy, tailored support, and accessibility without geographical constraints. Digital health interventions, accessible through various devices such as computers or tablets, have increased in dementia care, addressing diverse needs and promoting independence. Despite potential challenges for older people, including those with dementia, research indicates increasing internet usage and willingness to embrace digital advancements. Building on positive evaluations in other medical contexts, web-based tools hold promise in supporting ACP for people with dementia and their family caregivers. However, existing web-based ACP tools have not specifically targeted or been tested with people with dementia, representing a notable gap in the literature.

Because of the dementia-related changes (e.g. loss of cognitive functions) experienced by people living with dementia, many have recognised the importance of designing dementia-inclusive interfaces. In the evolving field of digital health, user-centred design and patient and public involvement (PPI) are crucial, especially for people with dementia, who have unique needs in navigating digital health interventions. User-centred design prioritises end-users' needs, ensuring the development of intuitive and enjoyable tools. PPI stresses the active involvement of people with dementia in shaping digital health solutions, contributing to the creation of solutions aligned with their unique needs and preferences. This inclusive approach holds promise for increased adoption and benefits, as it reflects the valued input of people with dementia, enhancing usability, satisfaction, and widespread acceptance of digital health tools in this population.

Research aims

The overarching aim of this dissertation is to advance our understanding of how to support people with dementia and family caregivers in advance care planning within the family context. This dissertation is structured around three core aims, each encompassing several objectives.

The first aim revolves around exploring current definitions of ACP and providing recommendations from the perspectives of people with dementia and their families. This included gaining insight into the ACP content on dementia associations' websites in Europe (objective 1). Additionally, it entailed gathering the perspectives of the European Working Group of People with Dementia (EWGPWD) and their supporters on how ACP is defined and developing recommendations for changes to the definition of ACP (objective 2).

The second aim focuses on developing an ACP support website for people with dementia and their families and evaluating user experiences. This involved describing the protocol for a study aiming to develop and simultaneously test the usability of a user-centred ACP support website designed for, and with, people with dementia and their families (objective 3). Then, it entailed developing and testing an evidence- and theory-based website to support people with dementia and their family caregivers when engaging in ACP within the family context (objective 4). Finally, it included evaluating the use and the experiences of people with dementia and their family caregivers with two interactive web-based tools for reflecting and communicating about ACP (objective 5).

The third aim is to draft recommendations for future web-based tools targeting communication and decision-making for people with dementia. This involved identifying usability requirements, usability testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care (objective 6).

Methods

To meet the first research aim of this dissertation, we used several methodologies. First, we conducted a content analysis of ACP information on European dementia associations' websites. Eligible websites, were assessed in multiple languages and screened for ACP content aimed at a broad audience. All relevant content, including webpages and PDF documents, was extracted from the websites. Qualitative content analysis was employed to identify themes, using a reference framework based on international ACP definitions. The accessibility and readability of the websites were also assessed, based on specific criteria outlined in the DEEP guides on creating dementia-friendly websites and information. Second, a qualitative study was conducted involving focus groups and interviews to explore perspectives on the definition of ACP among a multinational group of people with dementia and their family caregivers, specifically members of the European Working Group of People with Dementia (EWGPWD) and their supporters. Data collection included online focus groups and individual interviews. Discussions covered the presentation the consensus definition of ACP supported by the European Association for Palliative care. Data analysis followed a thematic analysis approach. The analysis identified themes and sub-themes, leading to the development of recommendations for changes to the definition of ACP.

To address the second research aim, we used a user-centred approach to develop an ACP support website for people with dementia and their family caregivers. Following Elwyn et al.'s process map for developing web-based decision support interventions and the and Medical Research Council (MRC) framework for complex interventions, the development integrated user-centred design principles and continuous stakeholder engagement. It comprised two stages: content specification and creative design. Needs assessments and evidence synthesis informed content specification, while iterative prototyping and usability testing were conducted during the creative design phase. Several website prototype versions were evaluated through think-aloud sessions and semi-structured interviews, with iterative adaptations based on user input and advisory group feedback. Framework analysis was applied to notes from think-aloud sessions during sprints 1 to 3, and to interview transcripts in sprint 4. Then, we used data from an eight-week convergent parallel mixed methods evaluation study, to provide an overview and evaluate two web-based reflection and communication, which were part of

the ACP support website. Data collection involved web log data capturing interactions on the website and semi-structured interviews with dyads or individual family caregivers. Descriptive statistics analysed sociodemographic characteristics, and RStudio was used for log data analysis. Transcribed interviews underwent a framework analysis, initially using pre-established codes and introducing new codes for emerging themes.

Finally, to address the third research aim, we conducted a systematic review to identify usability requirements, testing methods, and design suggestions from studies focusing on web-based tools for communication and decision-making support in dementia care. Searches were performed in MEDLINE, Embase, PsychINFO, Web of Science, and Scopus. Data extraction covered study information, participant demographics, tool descriptions, methods for usability evaluation, and results. A narrative synthesis was then conducted to report patterns across the included studies.

Main findings

In Chapter 2, we analysed 26 dementia association websites in Europe, of which 16 provided content on ACP. Only three addressed all ACP themes in our reference framework, which covered defining ACP, legal and medical aspects, and the quality of life, social and practical aspects of ACP. ACP was explicitly defined on four websites, and the predominant focus across websites that provided ACP content was on legal and medical aspects, particularly advance directives. Less attention was given to themes concerning the quality of life, social and practical aspects of ACP. Additionally, specific to dementia needs emerged, such as gradual loss of decisional capacity and challenges in ACP conversations. While most websites demonstrated clear formatting and structure, essential features like print options and text-to-speech functionalities were less common, and the use of supportive visuals like pictures and videos was not consistently implemented.

In Chapter 3, we gathered insights on the definition of ACP from the EWGPWD and their supporters through online focus groups and individual interviews. While the EWGPWD members expressed support for key aspects of the current ACP definition, such as its emphasis on being a continuous process and promoting communication and documentation of decisions, they urged for a more inclusive approach, addressing individuals with declining decisional capacity, acknowledging the role of families, and emphasising social aspects of care. The EWGPWD and their supporters advocated for a broader definition applicable to both people with and without conditions influencing cognitive capacities, and recommended adapting the current definition to better reflect these perspectives.

In Chapter 4 and 5, we focused on the development of an ACP support website for people with dementia and their families. In Chapter 4, we described the study protocol of the development and usability study of the ACP support website. In Chapter 5, we presented the results of the development and usability study. The study followed the process map and MRC framework, focusing on content specification and creative design to develop an ACP support website for people with dementia and their family caregivers. Employing a 'what matters most' approach, the website promotes ACP conversations by providing comprehensive information, including ACP definition, benefits, advance directives, legal frameworks, and communication tips. Two web-based tools, the 'Life Wishes Card' (Levenswensen kaarten in Dutch) (i.e. a card tool with preformulated statements) and 'Thinking Now About Later' tool (i.e. a fill-in reflection tool) facilitate engagement in ACP conversations between people with dementia and family caregivers. The website's non-linear and flexible navigation, along with features like font size change, text-to-speech, and contrast options, accommodated diverse user needs. Usability testing with 17 people with dementia and 26 family caregivers revealed factors influencing usability, leading to improvements such as shortened and simplified textual content, reduced abbreviations, and adapted navigation. Tutorial videos were integrated to address challenges experienced by people with dementia to use the two web-based reflection and communication tools.

In Chapter 6, we described in detail the two web-based reflection and communication tools, namely the 'Thinking Now About Later' tool and the 'Life Wishes Cards' (Levenswensen kaarten in Dutch). We then investigated the usage and experiences of people with dementia and their family caregivers with the two web-based reflection and communication tools. We included 52 participants (21 with dementia and 31 family caregivers) in the study. 22 participants actively used the tools. For those that did use the tools, we found that they facilitated discussions about preferences and wishes for current and future care. Both people with dementia and family caregivers appreciated the structured guidance provided by the web-based reflection and communication tools. Participants experienced some barriers to the use of the tools, including a lack of concrete steps post-tool completion. People with dementia also had some difficulties with using the web-based tools on their own. Family caregivers often played a facilitating role, offering technical, emotional, and cognitive support, and raised concerns about the independent use of web-based tools by people with dementia.

Finally, in Chapter 7, we presented the findings of a systematic review on usability requirements for web-based tools targeting communication and decision-making for people with dementia and their family caregivers. Our search across five databases identified seven studies meeting inclusion criteria, employing methods like surveys, interviews, and cognitive walkthroughs. Key usability requirements included visual appearance, emphasising sophisticated design, simple colour schemes, larger fonts, and image-centric content. Navigation challenges were identified as barriers, emphasising the need

for intuitive designs. Content delivery was also an important point, with recommendations for clear, concise textual content, visual examples, and a balanced presentation. Personalisation and flexible, independent use enhanced usability. Despite tools being deemed user-friendly, additional support needs were identified. Solutions to address these needs included embedded tutorials, step-by-step guidance, and face-to-face training.

General Discussion

ACP is deemed crucial in palliative care for people with dementia, yet, at the time of this dissertation, there was a lack of consensus on its definition in this context. We sought the perspectives of a the EWGPWD to fill this gap, identifying three overarching and 16 specific recommendations for a modified, inclusive definition of ACP. These insights informed the content of an ACP support website, ensuring alignment with the preferences of people with dementia. At the end of 2023, the European Association for Palliative Care established a consensus definition of ACP in dementia (based on an international Delphi study). Our study with EWGPWD contributed to this research, through consultations with the group of authors, by emphasising key issues such as capacity or family involvement and engagement. While their approach is dementia-specific, our research underscores the preference of the EWGPWD for a dementia-inclusive adaptation of the existing ACP definition, highlighting an ongoing debate in dementia care regarding inclusive versus specific approaches.

This dissertation reveals disparities in the conceptualisation and implementation of ACP for people with dementia and their family caregivers. While existing definitions emphasise a comprehensive communication process beyond advance directives, our studies find a predominant focus on medical aspects of care in practice. Our participants expressed a desire for a broader ACP approach, incorporating social aspects of care. Accordingly, we propose a 'what matters most' approach to ACP, advocating for inclusive ACP conversations covering not only medical preferences but also current and future social care needs. Our research also underscores the significance of family involvement in ACP. Therefore, we recommend a flexible and family-focused approach that addresses both individual and relational aspects within ACP.

Our research also highlights a significant lack of comprehensive information on ACP on websites. ACP information focused predominantly on legal and medical aspects, neglecting crucial ACP themes like communication with family and health professionals, personal values, and life goals. This information gap acts as a barrier to ACP for people with dementia and their family caregivers, who express concerns about limited access to information on dementia trajectory, ACP, and available care options. Our reference framework, based on recent ACP definitions, can serve as a guide for comprehensive online

ACP information. The framework encompasses categories such as legal frameworks, preferences for care and medical treatment, communication, documentation, and personal values.

Moreover, we developed an ACP support website for people with dementia and family caregivers in the family context. This means that the website aimed to support ACP conversations between people with dementia and family caregivers outside of professional consultations. Our approach aligns with the public health perspective in palliative care, aiming to reframe ACP as a health-promoting activity. It is crucial to note that ACP within the family context and ACP with health professionals should not be seen as opposing but rather complementary approaches. The website serves as a valuable tool for people with dementia and family caregivers to facilitate ACP conversations within the family, which can provide insights into individual wishes and preferences before deciding on care and medical treatments with health professionals. While health professionals play a central role in the ACP process, particularly in medical decision-making, the website can serve as a preparatory tool for health professionals, ensuring alignment between conversations within the family context and medical decisions regarding future care and treatment.

Within the development process of the ACP support website, the content specification phase revealed that many existing web-based tools followed a step-by-step linear approach to support ACP. Such a predetermined sequence of steps, encompassing information provision, reflection stimulation, communication support, and written documentation, may not be universally suitable due to variations in individuals' readiness, barriers, and preferences toward ACP. In response, we adopted a flexible and non-linear navigation for the ACP support website, allowing people with dementia and their caregivers to engage in ACP conversations at their own pace. Recognising diverse entry points into the ACP process, we enable users to choose specific sections of the website without navigating the entire content, and pause and resume their interaction. This approach is meant to empower people to address topics aligned with their current readiness level, facilitating autonomy and personalised ACP experiences.

This dissertation emphasises the importance of usability testing in developing technology for people with dementia, involving both their perspectives and those of family caregivers. Usability testing is crucial for considering diverse user needs and experiences. While prior studies often relied on opinions of proxies for people with dementia, we used various methods to gather insights from both people with dementia and family caregivers regarding the usability of the ACP support website. Thorough usability testing led to the development of a website that was deemed as user-friendly. We also demonstrate that different people prefer using the website in different ways. For instance, people with dementia seemed to prefer using the ACP support website together with a family caregiver, leading to

family caregivers often taking a facilitating role when using the website. To reduce any potential burden associated with this facilitating role, it is crucial to address technological challenges and implementing personalised support strategies.

Finally, taking into account the digital literacy of people with dementia and family caregivers is essential. Despite the widespread use of the Internet, there are significant differences among age groups, with older people, including many people with dementia, experiencing more challenges. The results of this dissertation highlights the diverse digital skills among people with dementia and family caregivers. While some possess considerable computer experience, others have minimal skills. Our studies highlight that despite user-centred website development, support is required, particularly with the use of the web-based reflection and communication tools. Our findings stress the importance of considering digital exclusion and literacy when developing web-based tools to provide tailored support. The dissertation identifies various forms of support, such as tutorials and face-to-face training, emphasising the need for individualised approaches based on capabilities, preferences, and needs.

Recommendations for practice, policy and research

Recommendations for practice

- ACP could be introduced more as conversations about 'what matters most' for the future.

- Encourage accessible design of web-based tools according to the following criteria: visual appearance, navigation and delivery of content, and support use.

Recommendations for policy

- Raise awareness of ACP as a communication process about 'what matters most' for the future.
- Ensure that professional organisations provide comprehensive ACP information and resources and ensure that health professionals are trained on how to provide comprehensive ACP information as part of a flexible communication process.

Recommendations for research

- Further evaluate the effects of the ACP support website and study how people with dementia and family caregivers can be optimally supported when using the website.

- Further investigate ACP in the family context and its relationship with ACP with health professionals.

- Use a dementia-inclusive definition of ACP in the development of interventions.

- Facilitate and encourage the participation of people with dementia and family caregivers in research and development of technology.

- Carefully plan patient and public involvement from the start of a project and avoid tokenistic involvement of people with dementia and family caregivers.

- Involve a variety of stakeholders such as people with dementia, family caregivers, and local and regional stakeholders in research and consider diversity.

Nederlandstalige samenvatting

'Wat is voor u belangrijk?'

Ondersteuning bij vroegtijdige of voorafgaande zorgplanning voor mensen met dementie en hun familie

Algemene inleiding

Vroegtijdige of voorafgaande zorgplanning (VZP) werd door de European Association for Palliative care gedefinieerd als een proces dat "*mensen in staat stelt om doelen en voorkeuren te formuleren voor toekomstige medische behandelingen en zorg, deze doelen en voorkeuren te bespreken met familie en zorgverleners, en om eventuele voorkeuren vast te leggen en indien nodig te herzien* ".

De praktijk van VZP is in de loop van de decennia aanzienlijk geëvolueerd. Deze richtte zich aanvankelijk vooral op juridische documenten voor patiënten om specifieke medische behandelingen te weigeren. Echter, vanuit onderzoek is duidelijk gebleken dat VZP een dynamisch communicatieproces dient te zijn, tussen patiënten, hun naasten en zorgverleners waarbij de nadruk ligt op wederkerende gesprekken en gezamenlijke besluitvorming. Desondanks is de praktijk van VZP nog steeds vaak gericht op het schriftelijke documenteren van voorkeuren van patiënten in zogenaamde wilsverklaringen. De 'public health' benadering van VZP benadrukt de noodzaak om op een bredere wijze te exploreren wat belangrijk is voor mensen en om medische overwegingen af te stemmen op de prioriteiten en waarden van mensen. Terwijl VZP-gesprekken vaak plaatsvinden in een professionele setting, is er een nood om dergelijke gesprekken aan te vullen met communicatie onderling, binnen de familiecontext (en dus naast professionele consultaties), om zo een meer open en natuurlijke dialoog te bevorderen. Zowel VZP binnen de familiecontext als VZP met zorgverleners kunnen worden gezien als complementaire benaderingen, waarbij zorgverleners een cruciale rol spelen in het afstemmen van zorgdoelen op de voorkeuren van de patiënt en de familie.

Dementie is een progressieve neurologische aandoening die gekenmerkt wordt door cognitieve achteruitgang die invloed heeft op het geheugen, het denken, het gedrag en dagelijkse taken. Het is een overkoepelende term voor verschillende aandoeningen, met de ziekte van Alzheimer als meest voorkomende vorm. Wereldwijd neemt de prevalentie van dementie toe, met naar schatting 55

miljoen patiënten in 2021 en dit zal naar verwachting verdubbelen in 2030 en verdrievoudigen in 2050. VZP kan belangrijk zijn voor mensen met dementie, omdat het kan helpen bij de voorbereiding van besluitvorming, en mantelzorgers kan ondersteunen naarmate hun rol prominenter wordt. Ondanks aanbevelingen voor een vroegtijdige start, wijst onderzoek uit dat de betrokkenheid van personen met dementie en hun families in VZP laag blijft, wat de noodzaak benadrukt voor meer bewustzijn en deelname aan discussies in deze populatie.

Belemmeringen voor VZP bij dementie zijn onder andere moeilijkheden met betrekking tot het bespreken van de dood en de onzekere toekomst, omdat mensen met dementie vaak liever in het heden leven en mogelijk informatie missen over het ziektetraject. Culturele factoren, familiedynamiek en beperkte kennis over behandelingen en rollen in de besluitvorming kunnen de betrokkenheid bij VZP verder verhinderen. Specifieke behoeften voor VZP bij dementie zijn onder andere een duidelijk begrip van het ziektetraject, de toenemende betrokkenheid van familie of vrienden naarmate de cognitieve vaardigheden afnemen, en de erkenning van de behoefte aan een vertegenwoordiger. Een vroegtijdige start van VZP lijkt echter cruciaal, gezien de geleidelijke progressie van dementie. Ook een aanpak op maat die de nadruk legt op persoonlijke zorg, de mate waarin mensen bereid zijn om na te denken over later, en de gewenste wijze waarop men wil praten, lijken essentieel bij dementie. Informele gesprekken binnen de familiecontext kunnen een belangrijke rol spelen bij VZP en waardevolle inzichten verschaffen in de wensen en voorkeuren van mensen. Zowel mensen met dementie als hun naasten kunnen echter problemen ondervinden bij het voeren van gesprekken over VZP, waardoor ondersteuning nodig is om effectief over VZP te communiceren.

Eerdere VZP-interventies, zoals professionele trainingen of documentatieboekjes, waren voornamelijk gericht op het vergemakkelijken van het nemen van beslissingen over toekomstige zorg en behandeling in coördinatie met zorgprofessionals, en waren voornamelijk gericht op andere patiëntengroepen of zorgprofessionals, met beperkte aandacht voor mensen met dementie. Bestaande onderzoeken vonden een schaarste aan studies die zich specifiek richten op VZP voor mensen met dementie, en de beschikbare studies hadden vaak betrekking op mantelzorgers in plaats van directe betrokkenheid van de persoon met dementie. Een uitdaging op dit gebied is onder andere het gebrek aan consensus over een op maat gemaakte definitie van VZP voor mensen met dementie. Een andere uitdaging is de ontoereikende theoretische onderbouwing van VZP-interventies voor mensen met dementie, aangezien de meeste interventies impliciet of niet gevalideerd zijn voor deze populatie. Ook legt de huidige literatuur vooral de nadruk op VZP binnen medische contexten, waardoor er een opvallend gebrek is aan richtlijnen om VZP te ondersteunen binnen de familiale context.

Digitale gezondheid (de ontwikkeling en het gebruik van digitale technologieën om de gezondheid te verbeteren) biedt voordelen zoals autonomie, ondersteuning op maat, en toegankelijkheid zonder geografische beperkingen. Binnen de dementiezorg hebben digitale gezondheidsinterventies, die toegankelijk zijn via diverse apparaten (bijvoorbeeld computers of tablets), aanzienlijk terrein gewonnen. Deze interventies spelen in op uiteenlopende behoeften en bevorderen de onafhankelijkheid van mensen met dementie. Ondanks mogelijke moeilijkheden voor oudere mensen, waaronder degenen met dementie, wijst onderzoek op een groeiend internetgebruik en een toenemende bereidheid om digitale ontwikkelingen te omarmen. Voortbouwend op positieve evaluaties in andere medische contexten, zijn online hulpmiddelen veelbelovend bij het ondersteunen van VZP voor mensen met dementie en hun mantelzorgers. Bestaande online VZP-hulpmiddelen zijn echter niet specifiek gericht op of getest met mensen met dementie, wat een opvallend hiaat in de literatuur is.

Vanwege veranderingen die mensen met dementie ervaren (bijv. verlies van cognitieve functies), zijn dementie-inclusieve interfaces belangrijk. Binnen het dynamische domein van digitale gezondheid zijn een gebruikersgericht ontwerp en de participatie van patiënten en het publiek (bekend als Patient and Public Involvement - PPI) van essentieel belang. Dit geldt met name voor mensen met dementie, aangezien zij specifieke behoeften hebben bij het gebruik van digitale gezondheidsinterventies. Gebruikersgericht ontwerp geeft prioriteit aan de behoeften van eindgebruikers en zorgt voor de ontwikkeling van intuïtieve en gebruiksvriendelijke hulpmiddelen. PPI benadrukt de actieve betrokkenheid van mensen met dementie bij het vormgeven van digitale gezondheidsoplossingen en draagt bij aan het creëren van oplossingen die zijn afgestemd op hun unieke behoeften en voorkeuren. Deze inclusieve aanpak heeft als voordeel dat het kan zorgen voor een betere adoptie, omdat het de noden van mensen met dementie weerspiegelt, wat de bruikbaarheid, tevredenheid en acceptatie van digitale gezondheidsinterventies in deze populatie verbetert.

Onderzoeksdoelen

Het hoofddoel van dit proefschrift is om meer inzicht te krijgen in de manier waarop mensen met dementie ondersteund kunnen worden bij vroegtijdige of voorafgaande zorgplanning (VZP) binnen de familiecontext. Dit proefschrift is gestructureerd rond drie kerndoelen, die elk verschillende specifieke doelstellingen omvatten.

Het eerste kerndoel richt zich op het verkennen van de huidige definities van VZP en het geven van aanbevelingen vanuit het perspectief van mensen met dementie en hun mantelzorgers. Dit omvatte het verkrijgen van inzicht in de VZP-inhoud op websites van dementieverenigingen in Europa (doelstelling 1). Daarnaast omvatte het de verzameling van de perspectieven van de Europesen werkgroep voor mensen met dementie en hun mantelzorgers over hoe VZP gedefinieerd is en het ontwikkelen van aanbevelingen voor veranderingen in de definitie van VZP (doelstelling 2).

Het tweede kerndoel richt zich op het ontwikkelen van een VZP-ondersteuningswebsite voor mensen met dementie en hun familie en het evalueren van gebruikerservaringen. Dit omvatte het beschrijven van het protocol voor een onderzoek gericht op het ontwikkelen en tegelijkertijd testen van de bruikbaarheid van een gebruikersgerichte ondersteuningswebsite voor VZP, ontworpen voor en samen met mensen met dementie en hun naasten (doelstelling 3). Doelstelling 4 is de effectieve ontwikkeling en het testen van een op bewijs- en theorie-gebaseerde website om mensen met dementie en hun mantelzorgers te ondersteunen in VZP binnen de familiecontext (doelstelling 4). Ten slotte omvatte het de evaluatie van het gebruik en de ervaringen van mensen met dementie en hun mantelzorgers met twee interactieve online hulpmiddelen voor reflectie en communicatie over VZP (doelstelling 5).

Het derde doel was het opstellen van aanbevelingen voor toekomstige online hulpmiddelen gericht op communicatie en besluitvorming voor mensen met dementie. Dit omvatte het identificeren van bruikbaarheidseisen, bruikbaarheidstestmethoden en designsuggesties (in English: usability requirements, usability testing methods, and design suggestions) uit onderzoeken die zich richtten op online hulpmiddelen voor communicatie en ondersteuning van besluitvorming in de dementiezorg (doelstelling 6).

Methoden

Om het eerste kerndoel van dit proefschrift te bereiken, gebruikten we verschillende methodologieën. Ten eerste voerden we een inhoudsanalyse uit van VZP-informatie op websites van Europese dementieverenigingen. Websites die in aanmerking kwamen, werden in meerdere talen beoordeeld en gescreend op VZP-inhoud gericht op een breed publiek. Alle VZP inhoud, waaronder webpagina's en PDF-documenten, werd van de websites geëxtraheerd. Kwalitatieve inhoudsanalyse werd toegepast om thema's te identificeren, met behulp van een referentiekader gebaseerd op internationale VZP-definities. De toegankelijkheid en leesbaarheid van de websites werd ook beoordeeld, op basis van specifieke criteria uit de DEEP-gidsen voor het maken van dementievriendelijke websites en informatie. Ten tweede werd een kwalitatieve studie uitgevoerd met focusgroepen en interviews om perspectieven op de definitie van VZP te onderzoeken bij een

multinationale groep mensen met dementie en hun mantelzorgers, met name leden van de Europesen werkgroep voor mensen met dementie en hun mantelzorgers. De gegevensverzameling omvatte online focusgroepen en individuele interviews. De discussies hadden betrekking op de presentatie van de consensusdefinitie van VZP, ondersteund door de European Association for Palliative Care. De gegevens werden geanalyseerd aan de hand van een thematische analyse. De analyse identificeerde thema's en subthema's, wat leidde tot de ontwikkeling van aanbevelingen voor veranderingen in de definitie van VZP.

Om het tweede onderzoeksdoel te bereiken, gebruikten we een gebruikersgerichte aanpak om een ondersteuningswebsite voor VZP te ontwikkelen voor mensen met dementie en hun mantelzorgers. We volgden Elwyn et al.'s proceskaart voor het ontwikkelen van webgebaseerde beslissingsondersteunende interventies en het Medical Research Council (MRC) framework voor complexe interventies. Onze ontwikkelingsaanpak omvatte gebruikersgerichte ontwerpprincipes en voortdurende betrokkenheid van belanghebbenden, verdeeld over twee fasen: contentspecificatie en creatief ontwerp. De basis voor de contentspecificatie werd gevormd door behoeftebeoordelingen en een synthese van bewijsmateriaal. Tijdens de creatieve ontwerpfase werden iteratieve prototypes gemaakt en bruikbaarheidstesten uitgevoerd

Verschillende prototypeversies van de website werden geëvalueerd door personen met dementie en hun naasten door middel van 'think-aloud'-sessies en semigestructureerde interviews, met iteratieve aanpassingen op basis van gebruikersinput en feedback van een adviesgroep. Framework analysis werd toegepast op aantekeningen van think-aloudsessies en op interviewtranscripties. Dit omvatte fasen van data familiarisatie, thematische raamwerkontwikkeling, indexering, in kaart brengen en interpretatie. Vervolgens gebruikten we gegevens van een acht weken durend, convergent, parallel en mixed-method evaluatieonderzoek om een overzicht te geven en twee online reflectie- en communicatiemethoden te evalueren die deel uitmaakten van de VZP-ondersteuningswebsite. De gegevensverzameling bestond uit webloggegevens die interacties vastlegden en semigestructureerde interviews met duo's of individuele mantelzorgers. Beschrijvende statistieken analyseerden sociodemografische kenmerken en R werd gebruikt voor de analyse van loggegevens. Getranscribeerde interviews ondergingen een framework analysis, waarbij in eerste instantie vooraf vastgestelde codes werden gebruikt en nieuwe codes werden geïntroduceerd voor opkomende thema's.

Ten slotte hebben we, om het derde kerndoel aan te pakken, een systematische review uitgevoerd om bruikbaarheidseisen, testmethoden en ontwerpsuggesties te identificeren van onderzoeken die zich richten op online hulpmiddelen voor communicatie en ondersteuning bij besluitvorming in de

dementiezorg. Er werd gezocht in MEDLINE, Embase, PsychINFO, Web of Science en Scopus. De gegevensextractie had betrekking op studie-informatie, demografische gegevens van de deelnemers, beschrijvingen van de hulpmiddelen, methoden voor bruikbaarheidsevaluatie en resultaten. Vervolgens werd een narratieve synthese uitgevoerd om patronen in de geïncludeerde onderzoeken te rapporteren.

Belangrijkste bevindingen

In hoofdstuk 2 analyseerden we 26 websites van dementieverenigingen in Europa, waarvan er 16 het topic VZP bespraken. Slechts drie daarvan behandelden alle VZP-thema's die we hadden geïdentificeerd in ons referentiekader, dat de definitie van VZP, juridische en medische aspecten, en de levenskwaliteit, sociale en praktische aspecten van VZP omvatte. VZP werd op vier websites expliciet gedefinieerd, en op alle websites met inhoud over VZP lag de nadruk vooral op juridische en medische aspecten, met name wilsverklaringen. Er werd minder aandacht besteed aan thema's rond levenskwaliteit, sociale en praktische aspecten van VZP. Daarnaast kwamen specifieke behoeften van dementie naar voren, zoals geleidelijk verlies van beslissingsbevoegdheid en moeilijkheden in VZP-gesprekken. Hoewel de meeste websites een duidelijke opmaak en structuur hadden, waren essentiële functies zoals printopties en tekst-naar-spraak functionaliteiten minder gebruikelijk, en het gebruik van ondersteunende beelden zoals foto's en video's was niet consequent geïmplementeerd.

In hoofdstuk 3 verzamelden we via online focusgroepen en individuele interviews inzichten over de definitie van VZP van de Europesen werkgroep voor mensen met dementie en hun mantelzorgers. Terwijl de leden van de Europesen werkgroep voor mensen met dementie hun steun uitspraken voor belangrijke aspecten van de huidige VZP-definitie, zoals de nadruk op het feit dat het een continu proces is en het bevorderen van communicatie en documentatie van beslissingen, drongen ze aan op een meer inclusieve benadering, waarbij ook mensen met afnemende beslissingscapaciteit aan bod komen, de rol van families erkend wordt en de sociale aspecten van zorg benadrukt worden. De Europesen werkgroep voor mensen met dementie en hun mantelzorgers pleitten voor een bredere definitie die van toepassing is op zowel mensen met als zonder aandoeningen die de cognitieve capaciteiten beïnvloeden, en adviseerden om de huidige definitie aan te passen om deze perspectieven beter te weerspiegelen.

In hoofdstuk 4 en 5 richtten we ons op de ontwikkeling van een VZP-ondersteuningswebsite voor mensen met dementie en hun naasten. In hoofdstuk 4 beschreven we het studieprotocol van het ontwikkelings- en bruikbaarheidsonderzoek van de VZP-ondersteuningswebsite. In hoofdstuk 5 presenteren we de resultaten van het ontwikkelings- en bruikbaarheidsonderzoek. Door gebruik te

maken van een 'wat is belangrijk voor u'-benadering, bevordert de website VZP-gesprekken door uitgebreide informatie te bieden, waaronder de definitie van VZP, voordelen, richtlijnen, wettelijke kaders en communicatietips. Twee online hulpmiddelen, Levenswensenkaarten (een kaartentool met vooraf geformuleerde uitspraken) en een reflectietool, vergemakkelijken de betrokkenheid van de gebruiker. De flexibele, niet-lineaire navigatie van de website, samen met functies zoals lettergrootteverandering, tekst-naar-spraak en contrastopties, komt tegemoet aan verschillende gebruikersbehoeften. Bruikbaarheidstests met 17 mensen met dementie en 26 mantelzorgers brachten factoren aan het licht die de bruikbaarheid beïnvloeden, wat leidde tot verbeteringen zoals verkorte en vereenvoudigde tekstuele inhoud, minder afkortingen en aangepaste navigatie. Er werden instructievideo's geïntegreerd om de moeilijkheden aan te pakken die mensen met dementie ervaren bij het gebruik van de twee online reflectie- en communicatie- hulpmiddelen.

In hoofdstuk 6 beschrijven we in detail de twee online reflectie- en communicatiehulpmiddelen, namelijk het hulpmiddel "Nu denken over later" en de Levenswensenkaarten. We onderzochten hoe mensen met dementie en hun mantelzorgers twee online hulpmiddelen voor reflectie en communicatie gebruikten en ervoeren. We namen 52 deelnemers (21 met dementie en 31 mantelzorgers) op in het onderzoek. 22 deelnemers gebruikten de hulpmiddelen actief. Van degenen die de hulpmiddelen gebruikten, vonden we dat ze gesprekken over voorkeuren en wensen voor huidige en toekomstige zorg vergemakkelijkten. Zowel mensen met dementie als mantelzorgers waardeerden het gestructureerde kader dat de online reflectie- en communicatiehulpmiddelen boden. Deelnemers ondervonden enkele barrières bij het gebruik van de hulpmiddelen, waaronder een gebrek aan concrete stappen na het invullen van de hulpmiddelen. Mensen met dementie hadden ook moeite met het zelfstandig gebruiken van de hulpmiddelen. Mantelzorgers speelden vaak een faciliterende rol door technische, emotionele en cognitieve ondersteuning te bieden en uitten bezorgdheid over het onafhankelijk gebruik van online hulpmiddelen door mensen met dementie.

Tot slot presenteren we in hoofdstuk 7 de bevindingen van een systematisch onderzoek naar bruikbaarheidseisen voor online hulpmiddelen die gericht zijn op communicatie en besluitvorming voor mensen met dementie en hun mantelzorgers. Onze zoektocht in vijf databases leverde zeven onderzoeken op die voldeden aan de inclusiecriteria, waarbij gebruik werd gemaakt van methoden zoals enquêtes, interviews en cognitieve walkthroughs. De belangrijkste bruikbaarheidseisen hadden betrekking op het visuele uiterlijk, waarbij de nadruk werd gelegd op verfijnd design, eenvoudige kleurenschema's, grotere lettertypen en beeldgerichte inhoud. Navigatieproblemen werden geïdentificeerd als barrières, waarbij de nadruk werd gelegd op de behoefte aan intuïtieve ontwerpen. De levering van inhoud kreeg aandacht, met aanbevelingen voor duidelijke, beknopte tekstuele inhoud, visuele voorbeelden en een evenwichtige presentatie. Personalisatie en flexibel, onafhankelijk

gebruik verbeterden de bruikbaarheid. Ondanks het feit dat de tools gebruiksvriendelijk werden bevonden, werd aanvullende ondersteuning geïdentificeerd, waaronder ingebouwde tutorials, stapsgewijze begeleiding en persoonlijke training.

Algemene discussie

Ten eerste wordt VZP cruciaal geacht in de palliatieve zorg voor mensen met dementie, maar ten tijde van dit proefschrift was er een gebrek aan consensus over de definitie ervan in deze context. We zochten de perspectieven van de Europesen werkgroep voor mensen met dementie om deze leemte op te vullen en identificeerden drie overkoepelende en 16 specifieke aanbevelingen voor een aangepaste, inclusieve definitie van VZP. Deze inzichten vormden de basis voor de inhoud van een website om VZP te ondersteunen, die afgestemd is op de voorkeuren van mensen met dementie en hun families. Eind 2023 stelde de European Association for Palliative Care een nieuwe consensusdefinitie op (o.b.v. een internationale Delphi studie) van VZP bij dementie, waarin de focus ligt op van wederkerende communicatie over voorkeuren, waarden en doelen. Onze studie met de EWGPWD heeft bijgedragen aan dit onderzoek, door in overleg met de auteursgroep te benadrukken wat belangrijke thema's omtrent VZP bij dementie zoals de capaciteit van de persoon met dementie en de betrokkenheid en inzet van de familie. Hoewel de European Association for Palliative Care een definitie maakte die specifiek is voor dementie , onderstreept ons onderzoek de voorkeur van de EWGPWD voor een dementie-inclusieve aanpassing van de bestaande VZP-definitie, hetgeen een lopend debat in de dementiezorg over inclusieve versus specifieke benaderingen benadrukt.

Daarnaast onthult dit proefschrift verschillen in de conceptualisatie en implementatie van VZP voor mensen met dementie en hun mantelzorgers. Terwijl bestaande definities de nadruk leggen op een uitgebreide communicatieproces dat verder gaat dan wilsverklaringen die medische beslissingen aan het levenseinde regelen in geval van wilsonbekwaamheid, blijkt uit ons onderzoek dat er in de praktijk een overheersende focus is op medische aspecten bij VZP. Deelnemers aan onze studie uitten de wens voor een bredere VZP-benadering, die ook sociale aspecten van de zorg omvat. We stellen daarom een 'wat is belangrijk voor u'-benadering voor, die pleit voor inclusieve VZP-conversaties die niet alleen medische voorkeuren omvatten, maar ook huidige en toekomstige sociale zorgdoelen en activiteiten. Ons onderzoek onderstreept het belang van betrokkenheid van familie bij VZP en beveelt een flexibele en patiëntgerichte, familiegerichte benadering aan die zowel individuele als relationele aspecten behandelt.

Ons onderzoek wijst ook op een groot gebrek aan uitgebreide informatie over VZP op websites. VZP-informatie richtte zich voornamelijk op juridische en medische aspecten en verwaarloosde cruciale VZP-thema's zoals communicatie met familie en zorgverleners, persoonlijke waarden en levensdoelen. Deze informatiekloof vormt een barrière voor VZP voor mensen met dementie en hun mantelzorgers. Zij geven aan een beperkte toegang tot informatie over het dementietraject, VZP en beschikbare zorgopties te hebben. Ons referentiekader, gebaseerd op recente VZP-definities, kan dienen als een gids voor uitgebreide online VZP-informatie. Het raamwerk omvat categorieën zoals wettelijke kaders, voorkeuren voor zorg en medische behandeling, communicatie, documentatie van beslissingen, persoonlijke waarden en toegankelijkheidskenmerken.

Uit de fase van contentspecificatie van de ontwikkeling van de VZP-ondersteuningswebsite bleek dat veel bestaande online hulpmiddelen een stapsgewijze lineaire benadering volgden om VZP te ondersteunen. Deze vooraf bepaalde volgorde, die informatieverstrekking, stimulering van reflectie, communicatieondersteuning en schriftelijke documentatie omvat, is mogelijk niet universeel geschikt vanwege variaties in de bereidheid, belemmeringen en voorkeuren van mensen ten aanzien van VZP. Daarom hebben we gekozen voor een flexibele niet-lineaire navigatie voor de ontwikkeling van het VZP-ondersteuningsinstrument, zodat mensen met dementie en hun verzorgers in hun eigen tempo deel kunnen nemen aan VZP-gesprekken. We erkennen daarmee de verschillende ingangspoorten in het VZP-proces en stellen gebruikers in staat om specifieke secties van de website te kiezen zonder door de volledige inhoud te navigeren, en om hun interactie te pauzeren en te hervatten. Deze aanpak stelt mensen in staat om onderwerpen aan te pakken die aansluiten bij hun huidige bereidheid, wat autonomie en gepersonaliseerde VZP-ervaringen mogelijk maakt.

Bovendien ontwikkelden we een VZP-ondersteuningswebsite voor mensen met dementie en mantelzorgers in de familiecontext. Dit betekent dat de website gericht was op het ondersteunen van ACP-gesprekken met mensen met dementie en mantelzorgers buiten de professionele consulten om. Onze benadering sluit aan bij het perspectief van volksgezondheid en palliatieve zorg, met als doel VZP te herdefiniëren als een gezondheid bevorderende activiteit door middel van publieke voorlichting en betrokkenheid. Het is cruciaal om op te merken dat VZP binnen de familiecontext en VZP met zorgverleners niet gezien moeten worden als tegengestelde, maar eerder als complementaire benaderingen. De website dient als een waardevol hulpmiddel voor mensen met dementie en mantelzorgers om VZP gesprekken binnen de familie te faciliteren, die inzicht kunnen geven in individuele wensen en voorkeuren voordat beslissingen worden genomen over zorg en medische behandelingen met zorgverleners. Hoewel zorgverleners een centrale rol spelen in het VZP-proces, met name in de medische besluitvorming, kan de website dienen als een voorbereidend hulpmiddel

voor zorgverleners, om te zorgen voor afstemming tussen gesprekken binnen de familiecontext en medische beslissingen over toekomstige zorg en behandeling.

Dit proefschrift benadrukt het belang van bruikbaarheidstesten bij het ontwikkelen van technologie voor mensen met dementie, waarbij zowel hun perspectief als dat van mantelzorgers wordt betrokken. Testen van bruikbaarheid is cruciaal om rekening te houden met verschillende gebruikersbehoeften en -ervaringen. Terwijl eerdere studies vaak vertrouwden op de mening van proxy's voor mensen met dementie, gebruikten wij verschillende methoden om inzichten te verzamelen van zowel mensen met dementie als mantelzorgers met betrekking tot de bruikbaarheid van de VZP-ondersteuningswebsite. Grondige bruikbaarheidstesten leiden tot de ontwikkeling van een website die als gebruiksvriendelijk werd beschouwd. We tonen ook aan dat verschillende mensen de website op verschillende manieren willen gebruiken. Mensen met dementie gaven er bijvoorbeeld de voorkeur aan om de VZP-ondersteuningswebsite samen met een mantelzorger te gebruiken, waardoor mantelzorgers vaak een faciliterende rol op zich namen bij het gebruik van de website. Om de mogelijke last van deze faciliterende rol te verminderen, is het cruciaal om technologische uitdagingen aan te pakken en gepersonaliseerde ondersteuningsstrategieën te implementeren.

In de context van de groeiende belangstelling voor digitale gezondheid is het essentieel om rekening te houden met de digitale geletterdheid van mensen met dementie en mantelzorgers. Ondanks het wijdverbreide gebruik van het internet bestaan er aanzienlijke verschillen tussen leeftijdsgroepen, waarbij oudere mensen, waaronder veel mensen met dementie, achterblijven bij jongere generaties. Het proefschrift belicht de uiteenlopende digitale vaardigheden onder mensen met dementie en mantelzorgers. Terwijl sommigen aanzienlijke computerervaring hebben, hebben anderen minimale vaardigheden. Het onderzoek onderstreept dat ondanks gebruikersgerichte websiteontwikkeling ondersteuning nodig is, met name bij online reflectie- en communicatiemiddelen. De bevindingen onderstrepen het belang om digitale uitsluiting en geletterdheid in overweging te nemen bij het ontwikkelen van online hulpmiddelen om ondersteuning op maat te bieden. Het proefschrift identificeert verschillende vormen van ondersteuning, zoals tutorials en face-to-face training, en benadrukt de behoefte aan een geïndividualiseerde aanpak op basis van capaciteiten, voorkeuren en behoeften.

Aanbevelingen voor praktijk, beleid en onderzoek

Aanbevelingen voor praktijk

- VZP zou geïntroduceerd moeten worden als gesprekken over 'wat is belangrijk voor u' voor de toekomst.
- Stimuleer een toegankelijk design van online hulpmiddelen volgens de volgende criteria: visueel uiterlijk, navigatie, levering van inhoud en ondersteunend gebruik.

Aanbevelingen voor beleid

- Maak VZP meer bekend als een communicatieproces over wat het belangrijkst is voor de toekomst.
- Zorg ervoor dat beroepsorganisaties uitgebreide VZP-informatie en hulpmiddelen aanbieden en zorg ervoor dat gezondheidswerkers worden getraind in het bieden van uitgebreide VZP-informatie.

Aanbevelingen voor onderzoek

- Evalueer verder de VZP-ondersteuningswebsite en onderzoek hoe het gebruik van online hulpmiddelen voor mensen met dementie het best kan worden ondersteund.
- Verricht verder onderzoek naar VZP in de familiecontext en de relatie met VZP in de medische context.
- Gebruik een dementie-inclusieve definitie van VZP bij de ontwikkeling van interventies.
- Faciliteer en stimuleer de participatie van mensen met dementie en naasten in onderzoek en ontwikkeling van technologie.
- Plan de betrokkenheid van patiënten en het publiek zorgvuldig vanaf het begin van een project en vermijd symbolische betrokkenheid van mensen met dementie en mantelzorgers.
- Betrek diverse belanghebbenden zoals mensen met dementie, mantelzorgers en lokale en regionale belanghebbenden in onderzoek en neem diversiteit in overweging.

Curriculum Vitae

About the author

Fanny Monnet was born on 29 September 1996 in Monthey, Switzerland. She obtained her bachelor's degree in European Public Health in 2018 and her Master's degree in Health Education and Promotion in 2019 also at Maastricht University in the Netherlands. During her bachelor's degree, she went on an exchange semester at the University of Adelaide in Australia and on a research internship abroad at the University of Otago in New Zealand. During her master's degree she also completed a research internship at the Department of Health Promotion at Maastricht University. During her studies she worked as a nursing aide in a psychogeriatric hospital in Switzerland.

After obtaining her Master's degree, Fanny joined the End-of-Life Care Research Group at the Vrije Universiteit Brussel (VUB) in December 2019. She has been working on the DISTINCT project (H2020-MSCA-ITN-2018) as a doctoral researcher (Early Stage Researcher) developing an advance care planning website for people with dementia and their family caregivers using a participatory and user-centred approach. This project was funded by the Marie Skłodowska-Curie Innovative Training Network, which is a prestigious and competitive doctoral programme that aims to train a new generation of creative, entrepreneurial and innovative early-stage researchers across Europe. Within this programme, she had the opportunity to conduct 2 secondments abroad with the department of Psychiarty of Amsterdam University Medical Centres, location VU medical centre (Netherlands) and the NIHR MindTech MedTech Co-operative (United Kingdom). During her PhD, Fanny was supervised by Prof. Dr. Lieve Van den Block and Prof. Dr. Lara Pivodic. All findings reported and discussed in her dissertation were published in or submitted to international journals and presented at international conferences.

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Academic presentations

2024   *Dementia friendly communities.* Dementia, palliative care, and living environments workshop HETSL. Lausanne, Switzerland. [Invited speaker]

2022   *Developing an advance care planning website for dementia: Integrating a user-centred approach and patient and public involvement*. 32nd Alzheimer Europe Conference. Bucharest, Romania. [Oral presentation]

Main findings of the DISTINCT projects on technology to promote social health. 32nd Alzheimer Europe Conference. Bucharest, Romania. [Symposium presentation]

Developing an advance care planning website for dementia: Integrating a user-centred approach and patient and public involvement. 7th Public Health Palliative Care International Conference. Bruges, Belgium. [Poster presentation]

Defining advance care planning from the perspective of people with dementia: focus groups with the European Working Group of People with Dementia. Alzheimer's Association International Conference. Virtual, San Diego, USA. [Poster presentation]

Development of an advance care planning website for and with people with dementia and their family caregivers. Centre for Dementia seminars. Institute of Mental Health, University of Nottingham, UK. [Invited speaker]

2021   *Information provided to people with dementia and their carers on advance care planning: a content analysis of dementia associations' websites in Europe.* 31st Alzheimer Europe Conference. Virtual, Utrecht, The Netherlands. [Quick oral presentation]