



Carers' experiences of timely access to and use of dementia care services in eight European countries

Jelley, Hannah; Kerpershoek, Liselot ; Verhey, Frans; Wolfs, Claire ; de Vught, Marjolein; Bieber, Anja ; Stephan, Astrid ; Meyer, Gabriele; Michelet, Mona ; Selbaek, Geir; Sjölund, Britt-Marie; Skoldunger, Anders ; Hopper, Louise; Irving, Kate ; Marques, Maria J.; Conceição Balsinha, Maria; Gonçalves-Pereira, Manuel; Portolani, Daniel Michael; Zanetti, Orazio; Woods, Robert

Ageing and Society

DOI:

[10.1017/S0144686X19001119](https://doi.org/10.1017/S0144686X19001119)

E-pub ahead of print: 16/09/2019

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Jelley, H., Kerpershoek, L., Verhey, F., Wolfs, C., de Vught, M., Bieber, A., ... Woods, R. (2019). Carers' experiences of timely access to and use of dementia care services in eight European countries. *Ageing and Society*. <https://doi.org/10.1017/S0144686X19001119>

Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Title: Carers' experiences of timely access to and use of dementia care services in eight European countries.

Authors: Hannah Jelley¹, Liselot Kerpershoek², Frans Verhey², Claire Wolfs², Marjolein de Vugt², Anja Bieber³, Astrid Stephan³, Gabriele Meyer³, Mona Michelet^{4, 5, 6}, Geir Selbaek^{4, 5, 7}, Britt-Marie Sjölund^{8, 9}, Anders Sköldunger⁸, Louise Hopper¹⁰, Kate Irving¹⁰, Maria Marques¹¹, Maria Conceição Balsinha^{11, 12}, Manuel Gonçalves-Pereira¹¹, Daniel Michael Portolani¹³, Orazio Zanetti¹³, Bob Woods¹, and the Actifcare Consortium.

Authors affiliations:

Hannah Jelley, DSDC Wales, Bangor University¹ (UK), h.jelley@bangor.ac.uk

Liselot Kerpershoek, Alzheimer Centre Limburg, Maastricht University² (NL),

liselot.kerpershoek@maastrichtuniversity.nl

Frans Verhey, Alzheimer Centre Limburg, Maastricht University² (NL),

f.verhey@maastrichtuniversity.nl

Claire Wolfs, Alzheimer Centre Limburg, Maastricht University² (NL),

claire.wolfs@maastrichtuniversity.nl

Marjolein de Vugt, Alzheimer Centre Limburg, Maastricht University² (NL),

m.devugt@maastrichtuniversity.nl

Anja Bieber, Martin Luther University Halle-Wittenberg³ (DE), [anja.bieber@medizin.uni-](mailto:anja.bieber@medizin.uni-halle.de)

[halle.de](mailto:anja.bieber@medizin.uni-halle.de)

Astrid Stephan, Martin Luther University Halle-Wittenberg³ (DE),

astrid.stephan@medizin.uni-halle.de

Gabriele Meyer, Martin Luther University Halle-Wittenberg³ (DE),

gabriele.meyer@medizin.uni-halle.de

Mona Michelet, Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tonsberg, Norway⁴, Faculty of medicine, University of Oslo, Oslo, Norway⁵, Department of Geriatric Medicine, Oslo University Hospital, Norway⁶ (NO), mona.michelet@aldringoghelse.no

Geir Selbaek, Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tonsberg, Norway⁴, Faculty of medicine, University of Oslo, Oslo, Norway⁵, Centre for Old Age Psychiatric Research, Innlandet Hospital Trust, Ottestad, Norway⁷ (NO), geir.selbaek@aldringoghelse.no

Britt-Marie Sjölund, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden⁸, Department of Health and Caring Services, University of Gävle, Gävle, Sweden⁹ (SE), bresjd@hig.se

Anders Sköldunger, Department of Neurobiology, Care Sciences and Society, Karolinska Institute, Stockholm, Sweden⁸ (SE), anders.skoldunger@ki.se

Louise Hopper, Dublin City University¹⁰ (IE), louise.hopper@dcu.ie

Kate Irving, Dublin City University¹⁰ (IE), kate.irving@dcu.ie

Maria Marques, CEDOC, Nova Medical School | Faculdade de Ciências Médicas, Universidade Nova de Lisboa¹¹ (PT), maria.marques@nms.unl.pt

Maria Conceição Balsinha, CEDOC, Nova Medical School | Faculdade de Ciências Médicas, Universidade Nova de Lisboa¹¹, USF Marginal¹² (PT), maria.balsinha@nms.unl.pt

Manuel Gonçalves-Pereira, CEDOC, Nova Medical School | Faculdade de Ciências Médicas, Universidade Nova de Lisboa¹¹ (PT), gpereira@nms.unl.pt

Daniel Michael Portolani, Alzheimer Research Unit, Memory Clinic - IRCCS Istituto Centro San Giovanni di Dio Fatebenefratelli, ¹³ (IT), dportolani@fatebenefratelli.eu

Orazio Zanetti, Alzheimer Research Unit, Memory Clinic - IRCCS Istituto Centro San Giovanni di Dio Fatebenefratelli, ¹³ (IT), ozanetti@fatebenefratelli.eu

Bob Woods, DSDC Wales, Bangor University¹ (UK), b.woods@bangor.ac.uk

Postal addresses:

Dementia Services Development Centre (DSDC) Wales, Bangor University, Ardudwy,
Normal Site, Holyhead Road, Bangor, Gwynedd, LL57 2PZ, United Kingdom.¹

Maastricht University, Department of Psychiatry and Neuropsychology, PO Box 616
(location Drt 12) 6200 MD P.O. Maastricht, Netherlands.²

Martin Luther University Halle-Wittenberg, Medical Faculty, Institute for Health Care and
Nursing Science, Magdeburger Str. 8, D-06112 Halle (Saale), Germany.³

National advisory unit on Ageing and Health, Oslo University hospital, Ullevaal, Bygn. 37,
0407 Oslo, Norway.⁴

Karolinska Institutet, SE-14186 Stockholm, Sweden.⁸

School of Nursing and Human Sciences, Dublin City University, Dublin 9, Ireland.¹⁰

NOVA Medical School|Faculdade de Ciências Médicas, Campo Mártires da Pátria, 130,
1169-056, Lisboa, Portugal.¹¹

Alzheimer's Research Unit-Memory Clinic, IRCCS Centro S.Giovanni di Dio,
Fatebenefratelli, Via Pilastroni, 4 25123, Brescia, Italy.¹³

Abstract

Timely access to care services is crucial to support people with dementia and their family carers to live well. 390 carers of people with dementia recruited from eight countries, completed semi-structured interviews about their experiences of either accessing or not using formal care services over a 12-month period in the ‘Access to Timely Formal Care’ (Actifcare) study. Participant responses were summarised using content analysis, categorised into clusters and frequencies calculated. Less than half of participants (42.3%) reported service use. Of those using services, 72.8 per cent reported timely access and of those not using services 67.2 per cent were satisfied with this situation. However, substantial minorities either reported access at the wrong time (27.2%) or feeling dissatisfied or mixed feelings about not accessing services (32.8%). Reasons for not using services included use not necessary yet, the carer provided support, or refusal. Reasons given for using services included changes in the condition of the person with dementia, the service’s ability to meet individual needs, not coping or the opportunity to access services arose. Facilitators and barriers to service use included whether participants experienced supportive professionals, the speed of the process, whether the General Practitioner was helpful, participant’s own proactive attitude and the quality of information received. To achieve timely support, simplified pathways to use of formal care services are needed.

Keywords: carers, dementia, service access, formal care, Europe

Background

Dementia is considered to be one of the largest global challenges the public health and social care sectors face today (World Alzheimer Report 2015) and with increasing numbers of carers worldwide providing care (Harwood, Sayer and Hirschfield 2004), it is critical that

supportive services receive increased priority. A global action plan (World Health Organisation 2017) and increasing numbers of countries developing dementia strategies indicates the international realisation of the growing impact of dementia. As part of the global action plan, the World Health Organisation (World Health Organisation 2017) envisions people with dementia and their carers receiving the care and support they need to be able to lead a life that they feel is meaningful. To achieve this ambition, it is important that we optimise services offering care and support by listening to the perspectives of people with dementia and their carers to understand their experiences with these services.

There has been great interest in understanding and predicting the use of general healthcare services for some time. The Andersen behavioural model of health service use is frequently utilised to describe the complex relationship between environmental factors, population characteristics and health behaviours when accounting for use of services (Andersen 1968). The model considers a variety of predisposing, enabling, and needs factors relevant when analysing reasons for service use (Andersen 1995) and has been applied, for example, to home care use by older people (Kempen and Suurmeijer 1991). Despite the increase in numbers of people affected, and presumably demand for care services, reports of those services that are available being under-utilised are common, with many barriers that prevent help-seeking for people with dementia having been identified (Lawton, Brody and Saperstein 1989; Brodaty *et al.* 2005; Robinson, Buckwalter and Reed 2005; Werner *et al.* 2014).

Carers often perceive themselves as managing and therefore “*services are not needed*”, others are “*reluctant to use services*” even if they are struggling to manage. Some carers are willing to use services but the “*service characteristics*” are not suitable for them and many carers simply “*do not know about services*” (Brodaty *et al.* 2005). Furthermore, the literature suggests that spouses might be most reluctant to use services (Robinson,

Buckwalter and Reed 2005) or that some carers do not identify themselves as carers (Brodaty *et al.* 2005; Molyneaux *et al.* 2012; Svanberg, Stott and Spector 2010); they consider their role part of their duty as a family member and therefore are reluctant to use services (Brodaty *et al.* 2005; Macleod *et al.* 2017; Winslow 2003). A lack of information was frequently reported as a barrier to service use (Bruce and Paterson 2000; Greenwood and Smith 2015; Macleod *et al.* 2017), whereas past positive encounters and supportive professionals providing information and help facilitated service access (Greenwood and Smith 2015; Macleod *et al.* 2017).

Family carers require more information and support (MaloneBeach, Zarit and Spore 1992), especially from their General Practitioners (GP) (Buono *et al.* 1999; Thyrian and Hoffman 2012; Vetter *et al.* 1998), in particular when acknowledging that as the severity of dementia progresses service use is more likely to be required (Leon *et al.* 2000). The literature suggests that carers might be more accepting of services with more flexibility and personalised support (Greenwood and Smith 2015; MaloneBeach, Zarit and Spore 1992) and it is recognised that providing access to services tailored to individual needs is essential to support the physical, mental and social demands of a caregiving role (World Health Organisation 2017). Health care professionals can play an important role in empowering people with dementia and their carers by ensuring that they are aware of what options are available to them (Wolfs *et al.* 2010; MaloneBeach, Zarit and Spore 1992). Even when satisfaction with service use is reported, a need remains for clearer care pathways and management to improve appropriate and timely interventions (Górska *et al.* 2013).

Often, the timing of service intervention is reactive to a sudden change in the situation of the carer or the person with dementia, which results in a formal care intervention occurring in a crisis situation (Stephan *et al.* 2018). In contrast, formal care interventions in a timely fashion might assist in preventing future crises. To enable a more proactive and needs driven

approach to service use, a European research collaboration on the Access to Timely Formal Care (Actifcare) project across Germany (DE), Ireland (IE), Italy (IT), The Netherlands (NL), Norway (NO), Portugal (PT), Sweden (SE), and the United Kingdom (UK) aimed to better understand experiences of service use and explore facilitating factors that enabled service access as well as reasons for not using services for people with dementia and their carers in Europe. This large-scale project employed a mixed methods approach utilising a broad range of research methodology, including the interviews with carers that form the basis for this report.

Aims

The aim of this paper is to explore experiences of timely access of formal care services from the perspectives of carers of people with dementia from the cohort study of the Actifcare project. We addressed the following specific research question: ‘What experiences do carers of people with dementia have with regard to timely access to formal dementia care services, and what were their views on facilitators/ barriers to use of services?’

Methods

Sample

Participants in the Actifcare project were people meeting the diagnostic criteria for dementia outlined by the DSM IV TR, with a Clinical Dementia Rating (CDR) score of one or two or a Mini-Mental State Examination (MMSE) score ≤ 24 indicating mild to moderate dementia. Participants were community dwelling when recruited into the study, however during the study period some of the people with dementia moved into care homes. For each person with dementia an unpaid carer (family, friend or neighbour) participated, who had contact with the person with dementia at least once a week, and in this paper it is the carers’ perspective

that is reported. For detailed inclusion and exclusion criteria of the Actifcare study, please see the project protocol reported by Kerpershoek *et al.* (2016).

Procedure

In the Actifcare cohort study participant dyads were interviewed at baseline, six months and twelve months. At all stages participants' service use was recorded using a 'service use checklist' developed for this project (Kerpershoek *et al.* 2016). To expand further on this record of service use, the final follow-up included a semi-structured interview to retrospectively explore experiences of service (non)-use over the year. A proportion of the interviews were conducted jointly with the dyad, while others were conducted separately. In each dyad interview, the carer's perspective was specifically recorded. As the extent of information provided by people with dementia proved more limited than that from the carer's viewpoint, this paper focuses specifically on the carers' perspective. The interview questions included descriptive, exploratory and open-ended questions about service use. Interviews were audio-recorded for note taking purposes, and the data includes verbatim descriptions or annotations of services, as well as the researchers' summary of carers' responses.

Analysis

Content analysis (Mayring 2014) descriptively explored common experiences of (non)-use of services and identified frequencies of occurrence. The interview responses were collated into an excel database with responses categorised into separate spreadsheets containing either participants that were receiving services or those that were not using services. Although within the Actifcare project, the primary focus has been on formal care services involving personal care for the person with dementia, for the purposes of the current analysis, a broader definition of care was used in order to capture the wide range of experiences of services

discussed in the carer interviews. Participants accessing any formal care services in relation to dementia, including home nursing and other home services, day care, nursing home, hospital, supportive services and pharmacological and psychosocial interventions were considered to be using services. Services were grouped to include a range of different types of services accessed which is recommended for better understanding of reasons for service (non) use (Biegel *et al.* 1993).

The first and second authors (HJ and LK) reviewed the data to cluster participant answers and generated categories that described the experiences of services being reported and whether they were positive or negative. A proportion of responses were independently categorised and any disagreements were resolved by a third author (BW). The clusters of answers described the types of services accessed, service timeliness, reasons for (non)-use of services, satisfaction with service access or no access, and factors considered to facilitate or hinder service access. Once the authors were satisfied with the robustness of the descriptive categories, frequencies were calculated with SPSS (Version 22).

Results

This paper reports findings from 390 interviews in total, of which 36 were completed in the Netherlands (NL), 54 in Germany (DE), 56 in the United Kingdom (UK), 45 in Sweden (SE), 50 in Norway (NO), 40 in Ireland (IE), 57 in Portugal (PT), and 52 in Italy (IT).

The relationships of the carer to the person with dementia included 251 (64.4%) spouses and partners, 116 (29.7%) sons and daughters, and 23 (5.9%) other relationships (son/daughter-in-law, sibling, other relative, friend, or neighbour). Overall, 42.3 per cent of participants reported service use, with the proportion being similar for spouses (40%) and son /daughter (43%) carers (see Table 1).

< Insert Table 1 about here >

The range of service use reported was clustered into seven categories: (a) '*Supportive services*' which involved services that were initiated following diagnosis to provide support for the person with dementia or their carer. This included the memory clinic, mental health support, Alzheimer's cafes, and social support groups for people with dementia or carers. The most common of these was the memory clinic. (b) '*Home Social*' involved services that were designed to provide company or social activities for the person at home, such as sitting services. (c) '*Home Personal*' involved services that were designed to support personal care needs whilst at home, these included community carers providing support with washing, dressing, assisting with eating or physiotherapy for gait movement problems. (d) '*Day Care*' included all attendance (inclusive of respite) at a Day Care Centre. (e) '*Admission*' included all admissions (including respite) to nursing home, care home, and long-term hospital stays. The most common of these was care home admissions. (f) '*Home Services*' involved domestic and maintenance services that occurred at the persons home that were taken up due to the person's dementia, including gardening or cleaning services, adaptations to the home, meals on wheels (companies delivering food), and medication delivery to the person's home (not involving administering medication). The most common of these was cleaning and meals on wheels services. (g) '*Pharmacological and Psychosocial Interventions*' involved both medication for the person's memory or psychosocial interventions for people with dementia including Cognitive Stimulation Therapy (CST) and cognitive training combined with exercise. The most common of these was medication for the person's memory. One hundred and fifty three participants reported the types of services they were accessing, various combinations of services were accessed which are reflected in the total figures (see Table 2).

< Insert Table 2 about here >

The timeliness of access to formal dementia care services

Responses of 147 participants who elaborated on their use of services indicated that the majority (107 - 72.8%) considered that they had accessed services on time, whilst 4 (2.7 %) indicated that they had accessed services too early, 32 (21.8%) too late and 4 (2.7%) reported mixed feelings of some timely access and other services being accessed either too late or too early.

Amongst the majority of carers that considered services to be ‘timely’ a range of experiences were described, including services becoming available when the condition worsened or when there was an unexpected crisis. However, even when access was considered ‘timely’ some carers were still dissatisfied.

“The worsening of [person with dementia's] condition was very sudden so everything has been done very quickly and at the right time” (Timely service access/ IT daughter carer ID 8006).

“It was at the right time. Although it happened very suddenly because of the unexpected hospitalisation” (Timely service access/ UK wife carer ID 3002).

“Yes, but there should be more information available about what supports and services there are and how to access them” (Timely Service access/ IE wife carer ID 6041).

The few carers that considered service access to be ‘too early’ mostly related this to care home use and the carer’s feelings of regret or guilt, or being guided by professionals.

“At the time it felt like the timing was right. But with what we now know, we would do things differently” (Service access too early/ NO husband carer ID 5044).

“He entered a care home too soon” (Service access too early/ UK wife carer ID 3008).

“Initially felt it was too soon for [person with dementia] to attend respite and day care services- other patients there were more dependent. Encouraged to stick with it by the doctor” (Service access too early/ IE wife carer ID 6020).

Amongst the carers that considered service access ‘too late’ a range of experiences were outlined. These included accessing care following concerns arising during crisis, a lack of awareness and a lack of support resulting in service access ‘too late’.

“May have been beneficial if received care a bit sooner. Only accessed care after crisis situation- was worried that things would deteriorate rapidly” (Service access too late/ IE daughter carer ID 6002).

“If we had been more aware of what was available then services might have been accessed sooner, instead we were left alone to struggle and had to find help privately ourselves” (Service access too late/ UK wife carer ID 3039).

“I should have looked earlier, but she [person with dementia] rejects it.” (Service access too late/ DE husband carer ID 2012).

“Too late. GP should have helped more. The difference the support makes is huge. Things were very bad before the support started and it need not have become that bad” (Service access too late/ IE partner carer ID 6005).

The carers also described the challenge of finding services themselves and the difficulty in receiving the level of support required. Moreover, the slow process was also reported as a reason for late support.

“Possibly a little late but it is difficult to find services on your own” (Service access too late/ UK wife carer ID 3053).

“Too difficult to get. Basically you have to be on the phone crying to get it, even if the public health nurse requests 20 hours (she did this 3 times), you still only get 6. Getting any kinds of needs review takes 6 months, this is too long as huge amounts of change can happen in this timeframe” (Service access too late/ IE son carer ID 6034).

“Support came too late; merely due to the fact that it took a long time before the diagnosis” (Service access too late/ NL husband carer ID 1032).

Although only a small number of carers reported ‘mixed feelings’, this did serve to highlight that the perception of timeliness differed by service type.

“Memory clinic and day care were on time. Support group was too early” (mixed service access/ NL wife carer ID 1014).

“Time was right, but it was not the right service at the right moment for my husband”
(mixed service access/ DE wife carer ID 2017).

Interestingly there were very few reports of other services such as home personal care and day care being initiated before admission. Of those admitted during the year none reported receiving a combination of both home personal care and day care, and only 5/61 (8.1%) had received home personal care and 3/45 (6.6%) had received day care.

Satisfaction with service use

For those participants accessing formal care services, 144 participants elaborated on their answers when asked to what extent they were satisfied with the formal care services they were using. Responses included 98 (68.1%) participants reporting feeling satisfied with the services they were accessing, 17 (11.8%) reported feeling dissatisfied with the services they were accessing and 29 (20.1%) reported mixed feelings of satisfaction, being happy with some services but not with others.

Of those participants who were not accessing care services, 122 participants elaborated on whether they thought that formal care services should have been introduced. Two thirds of participants 82 (67.2%) were satisfied that care had not been introduced. A small proportion 21 (17.2%) was dissatisfied with their situation and felt that formal care services should have been introduced. The remaining participants 19 (15.6%) reported mixed feelings that some services should have been introduced but not others, or were satisfied with some aspects of not accessing formal care services but not with every aspect of their situation.

A variety of explanations were given for their satisfaction with not using services, such as the consideration that services were not necessary or needed yet, often because the carer

considered they were coping, or they expressed a preference not to use formal care services despite challenges.

“[Carer is] capable to take care of [Person with Dementia] and would not change anything” (Satisfied with no service use/ notes on PT husband carer ID 7007 interview)

“[the person with dementia] is better with his family” (Satisfied with no service use/ PT sister-in-law carer ID 7001).

The proportion of participants that reported that they were dissatisfied with not accessing services, indicated a range of experiences from difficulty in coping or accepting services, to a lack of information and awareness.

“Not at all satisfied, formal care should have been introduced long ago, but [her husband] refuses” (Dissatisfied with no service use/ SE daughter carer ID 4013).

“Not satisfied, not been given any information about services and we’re unaware of what services are available” (Dissatisfied with no service use/ UK husband carer ID 3076).

The remaining mixed feelings appeared to reflect either internal or external conflicts or a resilience involving coping and proactive awareness of support.

“Currently don't feel formal care services are needed as [carer] is managing well. However [carer] is looking into support groups for both [person with dementia] and [carer] as feels this might be of help” (Mixed feelings about no service use/ notes on UK wife carer interview ID 3059).

Reasons for service use

Of the 165 participants who had accessed services over the year, 150 were able to specify reasons why they sought formal care services. Often, there were multiple reasons, relating either to the person with dementia, the carer or both. A number of carers cited changes in the person with dementia including cognitive (21.3% of carers) or behavioural changes (10%).

The potential of services to meet the individual needs of the person using formal care services was also frequently reported; these included physical needs, for example relating to mobility or incontinence (34.7%), emotional (18.7%) and social (9.3%) needs. In some cases, formal care services were accessed when it was considered no longer possible to cope without a service (16.6%) or the opportunity to take up services arose (12.7%), (see Figure 1).

< Insert Figure 1 about here >

Reasons for non-use of services

Of the 225 participants not using any services over the previous 12- month period, 198 participants specified reasons for not using formal care services. Participants provided multiple reasons for non- use of services that related either to the person with dementia, the carer, or practical and service provision issues. The most common reason for not accessing services was the perception of them as not necessary yet (71.7% of carers). Other frequent reasons given included either the person with dementia (19.2% of carers) or their carer (11.1%) refusing to use a service. Less frequently reported reasons included a lack of awareness of available care services (5.1%), or the carer (12.6%) or their social support network being considered able to provide support (4%), negating the need for a formal care service. Very few carers reported not using services because they were considered not useful or worthwhile (2.5%), unsuitable (1%) or because of logistical problems (1%). Only one

carer reported disagreements within the family, or placement on a waiting list hindering service access (see Figure 2).

< Insert Figure 2 about here >

Facilitators and Barriers to service use

For all 390 participants, factors that were considered either facilitators or barriers to service use ranged from characteristics of the services and professionals involved, to personal attributes and situational factors related to the individuals. The main aspects outlined included whether they experienced supportive professionals (25.6%), the speed of the process (8.7%), whether they had a helpful GP (8.5%), or the dyad's own proactive attitude (8.2%); for example whether they investigated service availability for themselves rather than depending on professionals. Furthermore, participants reported that information (or lack thereof) (7.9%) could both facilitate or hinder service access. This included participants' discussing the amount of available information and the quality or appropriateness of information in relation to their particular situation or about a specific service (see Figure 3).

< Insert Figure 3 about here >

Discussion

To the best of our knowledge, this is the largest European study that has investigated timely service access by people with dementia and their carers. The majority of participants in this study reported timely access of services or satisfaction with not using services. However, some carers reported that they had accessed services at the wrong time or were dissatisfied with not using services. The positive experiences reported by the majority of carers in this

European sample appears to be an unusual finding in the literature which largely reports barriers to service use. Furthermore, a recent study reported a lack of timely diagnosis of dementia and carers' experiences of delays (Woods *et al.* 2018). The barriers reported in this study are in line with previous research reporting barriers to service use (Brodaty *et al.* 2005; Buono *et al.* 1999; Greenwood and Smith 2015; Vetter *et al.* 1998). This highlights the need to further refine the process of introducing formal care, to improve timely care and satisfaction with decisions of service use.

In this cohort study, most of the services were accessed to provide personal care at home or to meet physical needs, while only a limited number of services were used for companionship or social activities at home. This suggests the range of service provision requires expansion to include more services for higher-level social needs, particularly within the persons' own home in the community. These findings reflect the continued predominance of the medical model view of dementia with a primary focus on meeting physical care needs almost to the exclusion of all other needs. This is in line with previous research, establishing that services meeting social needs are often under-represented or lacking (Phillipson, Jones and Magee 2014), although the need for a biopsychosocial approach to care, that moves beyond only addressing medical needs, is recognised by political decision makers and stakeholders across Europe (Broda *et al.* 2017).

Explorations of admission, and reports of use of home personal and day care services indicated that over 75 per cent of those admitted did not report use of alternative services such as daycare or personal care at home. Furthermore, none of the participants reporting accessing a combination of daycare and home personal care services went on to admission in the 12-month period of this study. This is an interesting finding that might indicate that such a 'community care package' might prevent long-term care admission. This would support the 'balance of care' notion that suggests enhanced community services could support people

appropriately at home avoiding residential or hospital placement (Tucker *et al.* 2008). Further research is needed to determine whether this finding was simply a reflection of where this sample were in relation to their journey with dementia, or whether indeed the right combination of community care services is able to reduce the likelihood of long-term care admission.

Many of the reasons outlined for accessing services support the suggestion in previous research of the increased likelihood of service use with dementia progression (Leon *et al.* 2000) and service uptake during crisis situations (Stephan *et al.* 2018; Vroomen *et al.* 2013). An interesting finding of the current study was how access was frequently described as opportunistic: services were taken up as the opportunity was presented to participants. This suggests that although some carers may not proactively seek services, they are open to service use when the possibility is presented to them. This novel finding might be considered fitting when considered within the context of research reporting challenges faced in help seeking (Werner *et al.* 2014).

The reasons provided for not using services support previous research reporting no need for services or reluctance to use services (Brodaty *et al.* 2005; Winslow 2003) and a preference for specifically tailored services (Buono *et al.* 1999). Our results are consistent with research describing factors that prevent help seeking, such as a lack of sufficient information and knowledge of services (Brodaty *et al.* 2005; Bruce and Paterson 2000; Buono *et al.* 1999; Greenwood and Smith 2015; Macleod *et al.* 2017; Vetter *et al.* 1998).

Surprisingly, the results provide only very limited support for previous research describing logistical challenges (Blackstock *et al.* 2006; Buono *et al.* 1999) and a sense of withdrawal or resignation to the situation and low expectations (Walters, Iliffe and Orrell 2001). This might be a reflection of this sample's considerable contentment with service (non) use or perhaps attitudes to service use are changing. Furthermore, the long process of

applying to access services (Brodaty *et al.* 2005) was reported in this sample, in addition to the suggestion that a faster process can facilitate service use. Our findings on reasons for service use are in line with research suggesting the likelihood of service use increases when carers are no longer able to cope alone without support (Vetter *et al.* 1998) or where there have been positive previous experiences facilitating service access and increased familiarity (Greenwood and Smith 2015). It was clear that many preferred to seek support from close relatives and trusted primary healthcare professionals (Werner *et al.* 2014). Our findings also support research advocating a collaborative partnership between carers and healthcare professionals to support the care of people with dementia (Brodaty and Donkin 2009; Keady, Clarke and Adams 2003; MaloneBeach, Zarit and Spore 1992) and highlight the important support role of front line healthcare professionals (Buono *et al.* 1999; Greenwood and Smith 2015; Werner *et al.* 2014).

It is interesting to note that the only care professional explicitly referred to by participants was the GP. This might be considered problematic due to the various constraints of primary care provision (Franz *et al.* 2010; Hinton *et al.* 2007; Stewart *et al.* 2014) and highlights the need for a specialist key contact person in dementia care (Macleod *et al.* 2017; Stephan *et al.* 2018). The National Institute for Health and Care Excellence: NICE guideline (2018) published in the UK recently recommended that a single named professional should be responsible for coordinating care, such developments in policy make improvements to dementia service provision vital.

Overall, there is a need to improve access to services. We identified that a proactive attitude is a facilitator to service access, perhaps because information about services is not readily available. In future carers will increasingly make use of the internet to seek information, presenting a challenge to service providers to ensure that accurate, relevant and up to date information is available. The support of professionals may be needed to assist

carers in navigating the wide range of information available on the internet. Although a proactive attitude of those using services is a facilitator to service access, it is important to acknowledge that this would not be needed if there was more easily obtainable service information. The perception of services is of key importance (MaloneBeach, Zarit and Spore 1992), and increased familiarity was considered beneficial. Services could, perhaps consider offering trial sessions for individuals to discover the service and become more familiar to enable an informed decision of whether to take up a service. The findings in this study support recommendations for tailored services with more flexibility (Buono 1999; Macleod *et al.* 2017). Services might consider reflecting on the suitability and need of a service to allow for adaptation and improvements to match individuals more appropriately. If the perceived value of services can be improved through better information and exposure then this might facilitate timely access of services and reduce reactive uptake during crisis situations.

The findings from this study also highlight the need to accept that many people with dementia and their carers do not feel the need of support from services. It is important to recognise the value of autonomy (Menne and Whitlatch 2007) and respect decisions of whether or not to use formal care services. Regardless of diagnosis, every person experiencing dementia is an individual and not all services are suitable nor required, but when they are, it is important for this transition into service use to be made as easy as possible. The experiences of timely access and use of dementia care services reported here indicate a positive outlook, suggesting that many people with dementia and their carers in Europe experience both timely access and satisfaction with their (non)-use of services. However, the findings also highlight the need for continual developments for improved experiences for the substantial minority who are less satisfied.

A limitation of the current study might be that the presence of people with dementia in many of the interviews has constrained the ability of the carers to communicate openly.

Furthermore, it is important to recognise that this paper presents data from the carers' perspective only and is limited to the 12-month period. Although at times the carers' answers suggested a joint representation, the researchers could only assume this to be an accurate view of the carer, regardless of any suggestion that the carer was able to answer on behalf of the person with dementia. The researchers had planned to collect more extensive data from the perspective of the person with dementia but particularly in cases where the person with dementia was in the more advanced stages, this proved challenging. The experiences presented in this study are informative for both service providers and those considering accessing dementia care services. There is a need for more large-scale studies on service utilisation among carers of people with dementia (Robinson, Buckwalter and Reed 2005) to build on these findings and develop empirically based interventions and improve practice. Although this study draws on carers' experiences in eight European countries and differences in culture and service structures and availability are undoubtedly relevant, areas of consistency have been indicated with studies from outside Europe e.g. Australia (Brodaty *et al* 2005) and North America (Greenwood and Smith 2015). Future research requires investigation of dementia care service experiences in a variety of countries, to achieve a full understanding of the influence of cultural and structural factors.

Conclusion

These results highlight that timing remains essential for appropriate formal care service use. There is a need for more simplified service access pathways that are easier for carers to understand, and that consider the difficult balance between planning ahead to avoid crisis situations and preventative strategies. Barriers preventing service access must be addressed and insights into facilitators embraced. These findings can help service providers and health and social care professionals to empower people with dementia and their carers to make

informed decisions about service use to enable satisfaction with appropriate and timely support.

Ethical Approval

The authors confirm adherence to ethical guidelines and legal requirements of the study countries. This study was subject to Ethical approval, a favourable ethical review was provided in the following ethics committees: Germany: Ethics committee of the Medical Faculty, Martin Luther University Halle-Wittenberg 2014-89 (DE)., Ireland: Dublin City University Research Ethics Committee 2014_070 (IE)., Italy: Comitato Etico, IRCCS San Giovanni di Dio “Fatebenefratelli” 44/2014 (IT)., Netherlands: Medische Ethische Toetsings Commissie NL49382.068.14 / METC 143038 (NL)., Norway: Regional Committee for Medical and Health Research Ethics, South-East B 2014/862 (NO)., Portugal: Ethics Committee of the Nova Medical School/ Faculdade de Ciências Médicas, Universidade Nova de Lisboa 22/2014/CEFCM (PT)., Sweden: the Regional Ethics Review Board Dnr 2014/863-31/5 (SE)., United Kingdom: Wales Research Ethics Committee 5, Bangor 14/WA/1040 (UK).

Funding

The research reported in this study was an EU Joint Programme- Neurodegenerative Disease Research (JPND) project (grant 733051001). The project is supported through the following funding organisations under the aegis of JPND – www.jpnd.eu: Germany: Bundesministerium für Bildung und Forschung (BMBF) (01ED1401)., Ireland: Health Research Board (HRB) (grant ref: JPND-2013-2)., Italy: Italian Ministry of Health., Netherlands: The Netherlands Organization for Health Research and Development.,

(ZonMW)/ Alzheimer Netherlands (733051001), Norway: The Research Council of Norway., Portugal: Fundação para a Ciência e a Tecnologia (FCT-JPND-HC/0001/2012), Sweden: Swedish Research Council (SRC), & United Kingdom: Economic and Social Research Council (ESRC) grant ref: ES/L008831/1. The funders played no role in this study.

Contributions of authors

All authors contributed to the design, analysis or interpretations of the data and preparation of the manuscript.

Conflicts of interest

The authors declare no conflict of interests.

Acknowledgements

The authors would like to thank all of the participants for their invaluable contributions to this study.

The Actifcare consortium partners include the coordinator: Maastricht University (NL): Frans Verhey (scientific coordinator, WP1 leader) and the Consortium members: Maastricht University (NL): Marjolein de Vugt, Claire Wolfs, Ron Handels, Liselot Kerpershoek. Martin-Luther University Halle-Wittenberg (DE): Gabriele Meyer (WP2 leader), Astrid Stephan, Anja Bieber, Anja Broda, Gabriele Bartoszek. Bangor University (UK): Bob Woods (WP3 leader), Hannah Jelley. Nottingham University (UK): Martin Orrell (WP3 leader). Karolinska Institutet (SE): Anders Wimo (WP4 leader), Anders Sköldunger, Britt-Marie Sjölund. Oslo University Hospital (NO): Knut Engedal, Geir Selbaek (WP5 leader), Mona Michelet, Janne Rosvik, Siren Eriksen, Sverre Bergh. Dublin City University (IE): Kate Irving (WP6 leader), Louise Hopper, Rachael Joyce. CEDOC, Nova Medical School,

Faculdade de Ciências Médicas, Universidade Nova de Lisboa (PT): Manuel Gonçalves-Pereira (National PI), Maria J. Marques, Maria Conceição Balsinha, Ana Machado, on behalf of the Portuguese Actifcare team (FCT-JPND- HC/0001/2012). Alzheimer's Research Unit-Memory Clinic, IRCCS Centro San Giovanni di Dio "Fatebenefratelli" (IT): Orazio Zanetti (National PI), Daniel Michael Portolani.

References

Andersen, R. 1968. *A behavioural model of families' use of health services*. Chicago: University of Chicago.

Andersen, R. M. 1995. Revisiting the behavioural model and access to medical care: does it matter? *Journal of health and social behaviour*, **36**, 1-10.

Biegel, D. E., Bass, D. M., Schulz, R. and Morycz, R. 1993. Predictors of in- home and out- of- home service use by family caregivers of Alzheimer's disease patients. *Journal of Aging and Health*, **5**, 419-38.

Blackstock, K. L., Innes, A., Cox, S., Smith, A. and Mason, A. 2006. Living with dementia in rural and remote Scotland: diverse experiences of people with dementia and their carers. *Journal of rural studies*, **22**, 161-76.

Broda, A., Bieber, A., Meyer, G., Hopper, L., Joyce, R., Irving, K., Zanetti, O., Portolani, E., Kerpershoek, L., Verhey, F., de Vugt, M., Wolfs, C., Eriksen, S., Røsvik, J., Marques, M. J., Gonçalves-Pereira, M., Sjölund, BM., Woods, B., Jelley, H., Orrell, M., Stephan, A. and the Actifcare Consortium. 2017. Perspectives of policy and political decision makers on access to

formal dementia care: expert interviews in eight European countries. *BMC Health Services Research*, **17**, 1-14.

Brodaty, H., Thomson, C., Thompson, C. and Fine, M. 2005. Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, **20**, 537-46. doi: 10.1002/gps.1322.

Brodaty, H. and Donkin, M. 2009. Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, **11**, 217-28.

Bruce, D. G. and Paterson, A. 2000. Barriers to community support for the dementia carer: A qualitative study. *International Journal of Geriatric Psychiatry*, **15**, 451-7.

Buono, M. D., Busato, R., Mazzetto, M., Paccagnella, B., Aleotti, F., Zanetti, O., Bianchetti, A., Trabucchi, M. and De Leo, D. 1999. Community care for patients with Alzheimer's disease and non-demented elderly people: use and satisfaction with services and unmet needs in family caregivers. *International Journal of Geriatric Psychiatry*, **14**, 915-24.

Franz, C. E., Barker, J. C., Kim, K., Flores, Y., Jenkins, C., Kravitz, R. L. and Hinton, L. 2010. When help becomes a hindrance: mental health referral systems as barriers to care for primary care physicians treating patients with Alzheimer's disease. *The American Journal of Geriatric Psychiatry*, **18**, 576-85.

Górska, S., Forsyth, K., Irvine, L., Maciver, D., Prior, S., Whitehead, J., Flockhart, J., Fairnie, J. and Reid, J. 2013. Service- related needs of older people with dementia: perspectives of service users and their unpaid carers. *International Psychogeriatrics*, **25**, 1107-14.

Greenwood, N. and Smith, R. 2015. Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. *Maturitas*, **82**, 162-69.

Harwood, R. H., Sayer, A. A. and Hirschfield, M. 2004. Current and future worldwide prevalence of dependency, its relationship to total population, and dependency ratios. *Bull. World Health Org*, **82**, 251- 8.

Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L. and Barker, J. C. 2007. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *Journal of General Internal Medicine*, **22**, 1487-92.

Keady, J., Clarke, C. L. and Adams, T. (eds), 2003. *Community mental health nursing and dementia care: practice perspectives*. Maidenhead: Open University Press.

Kempen, G. I., and Suurmeijer, T. P. 1991. Professional home care for the elderly: an application of the Andersen-Newman model in The Netherlands. *Social Science & Medicine*, **33**, 1081-89.

Kerpershoek, L., de Vugt, M., Wolfs, C., Jelley, H., Orrell, M., Woods, B., Stephan, A., Bieber, A., Meyer, G., Engedal, K., Selbaek, G., Handels, R., Wimo, A., Hopper, L., Irving, K., Marques, M., Gonçalves-Pereira, M., Portolani, E., Zanetti, O., Verhey, F. and the

Actifcare Consortium. 2016. Access to timely formal dementia care in Europe: protocol of the Actifcare (ACcess to Timely Formal Care) study. *BMC health services research*, **16**, 1-7.

Lawton, M., Brody, E. and Saperstein, A. 1989. A controlled study of respite service for caregivers of Alzheimer's disease patients. *The Gerontologist*, **29**, 8-16.

Leon, J., Neumann, P. J., Hermann, R. C., Hsu, M. A., Cummings, J. L., Doraiswamy, P. M. and Marin, D. 2000. Health- related quality- of- life and service utilization in Alzheimer's disease: A cross- sectional study. *American Journal of Alzheimer's Disease*, **15**, 94- 108.

Macleod, A., Tatangelo, G., McCabe, M. and You, E. 2017. "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study. *International Psychogeriatrics*, **29**, 765-76.

MaloneBeach, E. E., Zarit, S. H. and Spore, D. L. 1992. Caregivers perceptions of case management and community- based services: Barriers to service use. *The Journal of Applied Gerontology*, **11**, 146-59.

Mayring, P. 2014. *Qualitative content analysis: theoretical foundation, basic procedures and software solution*. Klagenfurt. Available online at <http://nbn-resolving.de/urn:nbn:de:0168-ssoar-395173> [Accessed 08.06.2018].

Menne, H. L. and Whitlatch, C. J. 2007. Decision- making involvement of individuals with dementia. *The Gerontologist*, **47**, 810-9.

Molyneaux, V. J., Butchard, S., Simpson, J. and Murray, C. 2012. The co-construction of couplehood in dementia. *Dementia: The International Journal of Social Research and Practice*, **11**, 483-502.

NICE guideline 2018. Dementia: assessment, management and support for people living with dementia and their carers. Available online at <https://www.nice.org.uk/guidance/ng97> [Accessed 20.01.2019].

Phillipson, L., Jones, S. C. and Magee, C. 2014. A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health & social care in the community*, **22**, 1-12.

Robinson, K. M., Buckwalter, K. C. and Reed, D. 2005. Predictors of use of services among dementia caregivers. *Western Journal of nursing Research*, **27**, 126- 40.

Stephan, A., Bieber, A., Hopper, L., Joyce, R., Irving, K., Zanetti, O., Portolani, E., Kerpersheroek, L., Verhey, F., de Vugt, M., Wofls, C., Eriksen, S., Røsvik, Marques, M. J., Gonçalves-Pereira, M., Sjölund, B. M., Jelley, H., Woods, B., Meyer, G. and on behalf of the Actifcare Consortium. 2018. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC Geriatrics*, **18**, 1-16.

Stewart, T. V., Loskutova, N., Galliher, J. M., Warshaw, G. A., Coombs, L. J., Staton, E. W., Huff, J. M. and Pace, W. D. 2014. Practice Patterns, Beliefs, and Perceived Barriers to Care

Regarding Dementia: A Report from the American Academy of Family Physicians (AAFP) National Research Network. *Journal of the American Board of Family Medicine*, **27**, 275-83.

Svanberg, E., Stott, J. and Spector, A. 2010. "Just helping": Children living with a parent with young onset dementia. *Aging & Mental Health*, **14**, 740-51.

Thyrian, J. R and Hoffmann, W. 2012. Dementia care and general physicians – a survey on prevalence, means, attitudes and recommendations. *Central European Journal of Public Health*, **20**, 270-5.

Tucker, S., Hughes, J., Burns, A. and Challis, D. 2008. The balance of care: Reconfiguring services for older people with mental health problems. *Aging & Mental Health*, **20**, 81-91.

Vetter, P., Steiner, O., Kraus, S., Moises, H., Kropp, P., Moller, W. D. and Kohler, O. 1998. Factors affecting the utilization of homecare support by caregiving relatives of Alzheimer patients. *Dementia and Geriatric Cognitive Disorders*, **9**, 111-16.

Vroomen, J. M., Bosmans, J. E., van Hout, H. P. and de Rooij, S. E. 2013. Reviewing the definition of crisis in dementia care. *BMC Geriatrics*, **13**, 1-12.

Walters, K., Iliffe, S. and Orrell, M. 2001. An exploration of help- seeking behaviour in older people with unmet needs. *Family Practice*, **18**, 277-82.

Werner, P., Goldstein, D., Karpas, D., Chan, L. and Lai, C. 2014. Help- seeking for Dementia a systematic Review of the Literature. *Alzheimer Disease and Associated Disorders*, **28**, 299-310.

Winslow, B. W. 2003. Family caregivers' experiences with community services: A qualitative analysis. *Public Health Nursing*, **20**, 341- 8.

Wolfs, C. A. G., de Vugt, M. E., Verkaaik, M., Verkade, P. J. and Verhey, F. R. J. 2010. Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *International Journal of Geriatric Psychiatry*, **25**, 1006- 12.

Woods, B., Arosio, F., Diaz, A., Gove, D., Holmerova, I., Kinnaird, L., Mátlová, M., Okkonen, E., Possenti, M., Roberts, J., Salmi, A., van den Buuse, S., Werkman, W., & Georges, J. 2018. Timely diagnosis of dementia? Family carers' experiences in 5 European countries. *International Journal of Geriatric Psychiatry*, **34**, 114- 121.

World Alzheimer report. 2015. The global impact of dementia an analysis of prevalence, incidence, cost and trends. *Alzheimer's Disease International*. Available online at <https://www.alz.co.uk/research/world-report-2015> [Accessed 08.06.2018].

World Health Organization. 2017. Global action plan on the public health response to dementia 2017–2025. Licence: CC BY-NC-SA 3.0 IGO. Available online at <http://apps.who.int/iris/bitstream/10665/259615/1/9789241513487-eng.pdf?ua=1> [Accessed 08.06.2018].

Corresponding author

Hannah Jelley, Dementia Services Development Centre (DSDC) Wales, Bangor University,
Ardudwy, Normal Site, Holyhead Road, Bangor, Gwynedd, LL572PZ. Telephone: +44
(0)1248 388498.

Table 1. Carers' relationships to the person with dementia and reports of service use

Carer relation	NL	DE	UK	SE	NO	IE	PT	IT	Males	Females	Total
<i>Carers reporting service use</i>											
Spouse/ partner	9	26	18	8	17	11	4	7	32	67	100
Son/ daughter	2	7	5	10	6	8	4	8	10	40	50
Other	0	3	1	5	2	2	1	1	1	14	15
Total	11/ 36 (30.5%)	36/ 54 (66.6%)	24/56 (42.8%)	23/45 (51.1%)	25/50 (50.0%)	21/40 (52.5%)	9/57 (15.7%)	16/52 (30.7%)	44 (26.7%)	121 (73.3%)	165 (42.3%)
<i>Carers reporting no service use</i>											
Spouse/ partner	23	16	27	17	19	10	29	10	61	90	151
Son/ daughter	2	2	5	5	6	8	15	23	20	46	66
Other	0	0	0	0	0	1	4	3	0	8	8
Total	25/ 36 (69.4%)	18/54 (33.3%)	32/56 (57.1%)	22/45 (48.8%)	25/50 (50.0%)	19/ 40 (47.5%)	48/57 (84.2%)	36/52 (69.2%)	81 (36.0%)	144 (64.0%)	225 (57.7%)

Table 2. *Types of services accessed*

Types of Service	NL	DE	UK	SE	NO	IE	PT	IT	Total
	N= 11	N= 36	N= 24	N= 23	N= 25	N= 21	N= 9	N=16	N = 153
									(12 missing data)
Supportive services	6	9	13	0	2	3	1	9	43 (28.1%)
Home Social	4	12	2	0	0	3	1	8	30 (19.6%)
Home Personal	3	7	10	9	9	15	3	6	62 (40.5%)
Daycare	2	7	9	7	8	10	5	1	49 (32.0%)
Admission	3	1	7	10	11	4	3	1	40 (26.1%)
Home Services	1	2	6	11	6	1	3	1	31 (20.3%)
Pharmacological and Psychosocial Interventions	6	3	1	7	1	0	1	1	20 (13.1%)

Why participants using services accessed formal care services

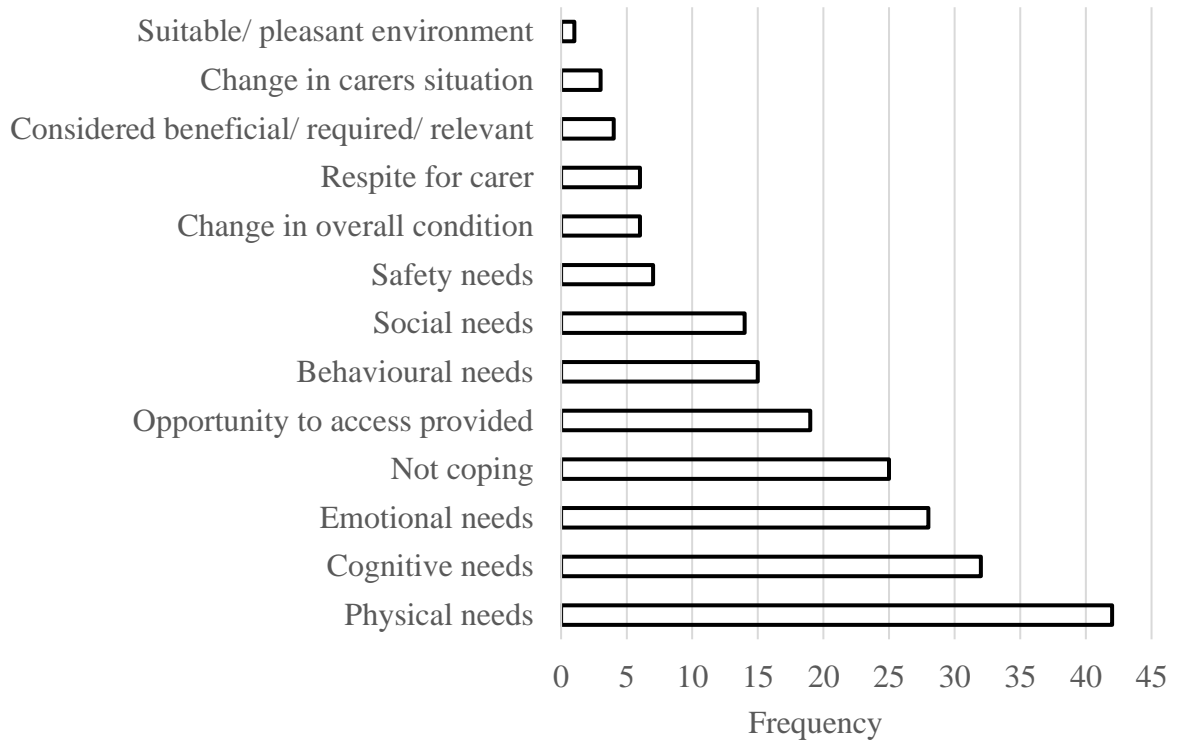


Figure 1. Reasons why participants using services accessed formal care services

Why participants not using services did not access formal care services

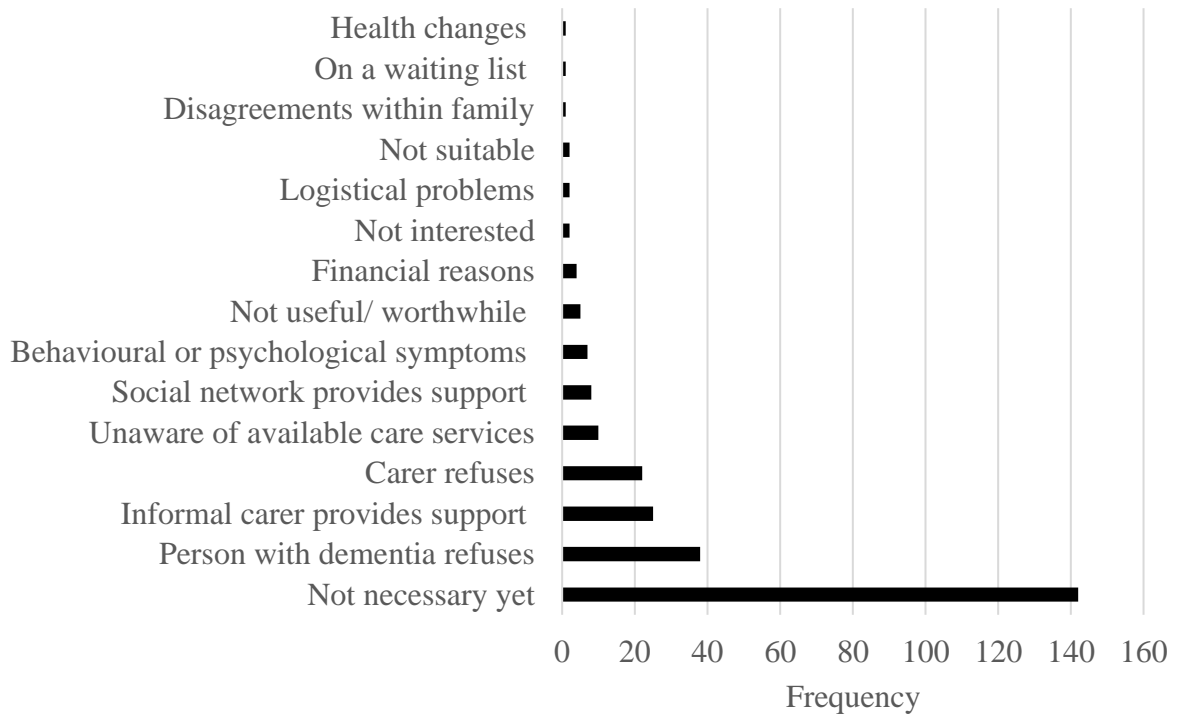
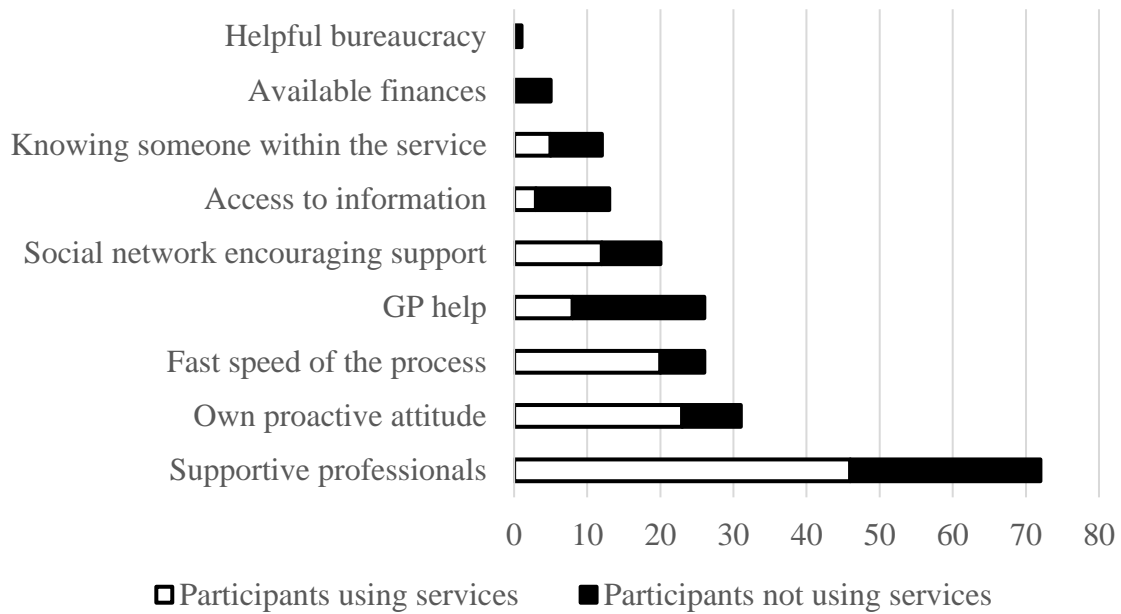


Figure 2. Reasons why participants not using services did not access formal care services

Facilitators to formal care service use



Barriers to formal care service use

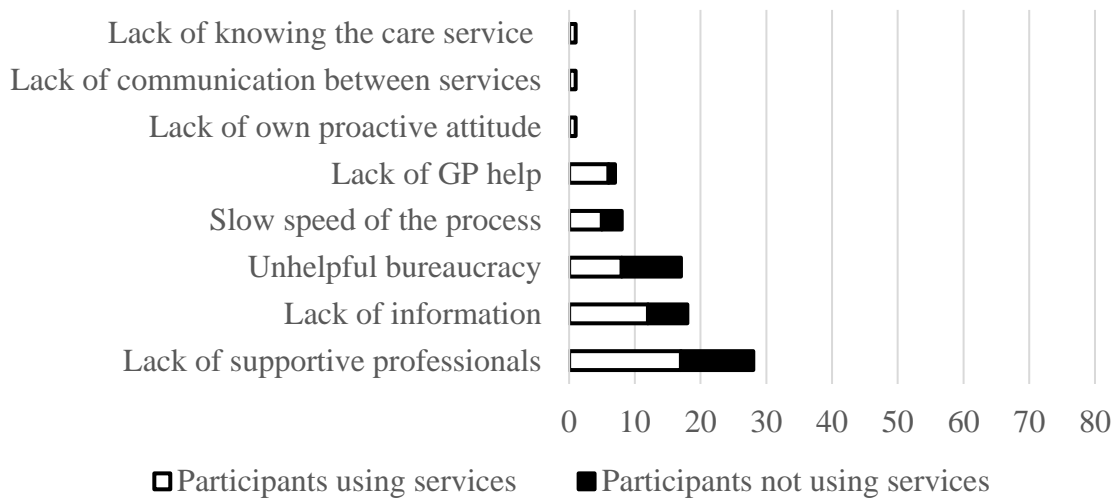


Figure 3: Factors considered facilitators or barriers to formal care service use.