D3.1.4

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Community Areas of Sustainable Care and Dementia Excellence in Europe

CASCADE

D 3.1.4 Survey of international experts to build consensus about optimum care standards, educational programmes, care environments & technological developments

for people living with dementia

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Contents

Acknowledgements

Executive Summary

This report describes the results and implications of D3.1.4, CASCADE Delphi study. The original Delphi study approach proved to be less successful than expected, with recruitment of participants the most challenging aspect. As a result of the low participation rate the Delphi study was proportionately modified to one round of an electronic survey. Twenty three experts shared their views about optimum care standards, care environments, educational standards and technological innovations they would provide the best future support for people living with dementia (PLWD) but many of their recommendations are applicable to any person requiring support for their health and wellbeing so are potentially transferable across contexts.

The findings did not present any new or ground breaking ideas around innovations not already known or identified in current practice or in the literature. Participants from countries considered to be leading the field on policy and practice were unsurprisingly more sophisticated in their ideas and those from countries where family centered models of practice feature heavily in health care focused on this as an important aspect of person centered relationship focused care. Those from the Netherlands and Belgium shared their innovative models of assisted living and neighbourhood case management models already widely endorsed by the UK as being something to aspire to.

The findings did present at times a rather troubling discourse that indicated a stigma and bias towards people living with dementia, that they somehow were not "human", needed surveillance and containing in care facilities concerned with treating their medical conditions. There were a number of assumptions underpinning these responses. However these were limited to a smaller sample of the participants and did not appear to be the conclusions of the whole group.

The report concludes with recommendations around how the project team as a whole need to consider further work around evidencing best practice models and looking further for evidence in different formats to underpin development of the CASCADE model. It also presents a challenge for the project team going forwards in terms of the way it presents the outcomes of the social innovation project in order to overcome the biomedical view of dementia.

Introduction

D3.1.4 was originally designed as a 3 stage electronic (e-) Delphi study using a survey of international experts to build consensus about what care standards, educational programmes, care environments & technological developments will provide optimum care for people living with dementia in the future for the Community Areas of Sustainable Care and Dementia Excellence in Europe (CASCADE) Project. The ethics clearance and survey distribution was carried out by the CASCADE project partners based in the Netherlands.

The round 1 survey was sent out to 77 identified experts working worldwide in the field of dementia between the months of March and May 2018. The intention is to use the data to inform the building of two new dementia care facilities in Kent UK, based on a new care model intended to be more oriented to the needs of people with dementia and their families or others who are important to them. By obtaining the views of all those involved in caring for and commissioning and developing dementia care services and facilities, it is hoped that the new premises will be centres of excellence in which the highest possible architectural, technical and care standards possible are delivered.

Methodology and Methods

A Delphi study is a consensus building method based on the results of questionnaires sent to a panel of experts. Several rounds of questionnaires are sent out, and the anonymous responses are aggregated and shared with the group after each round. This Delphi study aimed to consist of 3 rounds. International experts that we could invite to participate in completing the survey were chosen on the basis of a review of peer reviewed scientific publications in the field of dementia care, including a review of university websites to identify those actively involved in dementia care research. These were approached in the first instance and asked to snowball the link to the survey to others.

Round 1 of the Delphi study was distributed as an online survey in March 2018. By April 2018 it had become apparent that the survey responses were low at n=18, which constitutes a 23% response rate. A strategy was put in place to widen the number of potential participants the survey was sent to, thereby boosting participation. Along with reminder emails to the original 77 experts, the PP7 partners in Belgium distributed the survey by emailing it to their networks. Colleagues outside the project, but known to have associated networks in Germany and Switzerland also emailed the survey out.

In Mid-May 2018 n=23 people had participated in completing the survey. At this point it was decided a full Delphi Study was not tenable and that just a single survey analysis would be taken forward.

At the close of the survey on 14th May 2018, the total number of survey participants was n=23. Not all participants answered all questions.

Survey Results

Descriptive Statistics

The descriptive statistics from the survey summarised in this section of the report provide some context and background information around the participants who completed it.

Whilst 23 participants completed the survey, 2 responses were incomplete and therefore could not be included. Of the 21 remaining participants 10 (47.6%) identified as female and 11 (52.4%) identified as male.

Ten participants came from Belgium, 4 from the UK, and 7 from other countries in the EU.

Table 1

Responses	Countries
9	Belgium
1	Flanders (Belgium region)
Subtotal 10	
2	UK
1	England (UK region)
1	Scotland (UK region)
Subtotal 4	
2	Netherlands
1	Germany
1	Malta
1	Luxemburg
1	Switzerland
1	Turkey
Total responses n=21	

The majority of participants came from academic or research fields in health care (with expertise in working with dementia) and identified as either nurses, allied health professionals or from a managerial background.

Table 2

Responses	Work/ profession
3	Management (healthcare)
1	Commissioners
3	Nursing
1	Education & consultancy in elderly care
7	Academic/ researcher (healthcare & dementia)
4	Allied health professionals (including GPs, speech therapists, occupational therapists, psychologists)
2	Other (undeterminable)
Total responses n= 21	

Participants were asked to identify with a set of 7 groups. They could identify with 1 or more of the groups. Once they identified with a group participants were asked the significance of being a member of that group using a scale of 1-8, with 1 being most significant and 8 being less significant. The results for each group are reported below.

Nine responses to the statement 'I have been diagnosed with dementia' selected 8 on the scale, meaning that they did not have a diagnosis of dementia.

Eleven participants identified that they were not a family member living with dementia or in an unpaid carer role for someone diagnosed with dementia.

Table 3

Responses	Scale no.
2 (18.2%)	3
1 (9.1%)	5
8 (72.2%)	8
Total response n=11	

The majority of 14 participants identified that they were a health or social care professional providing care to people with dementia.

Table 4

Responses	Scale no.
6 (42.9%)	1
3 (21.4%)	2
2 (14.3%)	3
1 (7.1%)	4
2 (14.3%)	8
Total responses n=14	

Ten out of 12 participants identified that they have a role in planning or commissioning of dementia care services.

Table 5

Responses	Scale no.
4 (33.3%)	1
5 (41.7%)	2
1 (8.3%)	3
2 (16.7%)	8
Total responses n=12	

Fifteen out of 17 participants identified they there had a role in developing local, national, international policy about dementia care.

Table 6

Responses	Scale no.
7 (41.2%)	1
3 (17.6%)	2
3 (17.6%)	3
2 (11.8%)	4
2 (11.8%)	8
Total responses n=17	

Six out of 10 participants identified strongly that they have a role as an architect, builder, designer or creator of premises for the care of people with dementia or technologies intended to assist them in their daily lives.

Table 7

Responses	Scale no.
1 (10%)	2
1 (10%)	4
1 (10%)	6
1 (10%)	7
6 (60%)	8
Total responses n=10	

Fifteen out of 17 participants identified that they have an educational role working with people who provide care for people with dementia.

Table 8

Responses	Scale no.
5 (29.4%)	1
5 (29.4%)	2
4 (23.5%)	3
1 (5.9%)	4
1 (11.8%)	8
Total responses n=17	

Eleven out of 16 participants identified that they are actively researching fields relevant to dementia care.

Table 9

Responses	Scale no.
8 (50%)	1
1 (6.3%)	2
1 (6.3%)	3
1 (6.3%)	4
1 (6.3%)	5
1 (6.3%)	6
1 (6.3%)	7
2 (12.5%)	8
Total responses n=16	

Nine participants had been actively researching field related to dementia care for between 1 and 10 years,7participants working in the field for between 11 and 20 years and 5 participants identified as having more than twenty years' experience in the field.

Table 10

Responses	No. of years
4 (19%)	1-5 years
5 (23.8%)	6-10 years
7 (33.3%)	11-20 years
5 (23.8%)	More than 20 years
Total responses n=21	

In summary, the largest group of participants come from Belgium, and the second largest group of participants coming from the UK. One third (n=7) of participants come from an academic background, with the other two thirds (n=14) coming from a range of different healthcare professions. There was an almost even split between males and females participating in the survey.

In terms of the groups people identified as belonging to, the largest numbers identified as active researchers working in a field relevant to dementia care and/ or as family or other unpaid carer for someone diagnosed with dementia. The next set of groups that people identified with were as healthcare professionals caring for people with dementia, and/ or as developers of local, national, and international policy about dementia, and/ or as architects, builders, designers, or creator of premises or technologies for the care of people with dementia.

Regarding the length of time people had been associated with the group they identified as most significant to them, the largest number responded that they had been associated for between 11-20 years, although there is a fairly even spread of experience ranging across 1-more than 20 years.

The answers to questions 7-18 were analysed by members of the team and grouped into themes were there was consensus. These are presented here at the core areas that the Delphi intended to explore in detail namely the **ideal care environment, priorities of care, who should deliver care, level and kind of training, technical aids and devices, retaining links with the community** and **additional services that might be provided by the care environment.** The findings are interspersed with excerpts from participants' statements to illustrate the points raised.

The Ideal Care Environment

Participants were asked to identify the ideal care environment for people living with dementia. The majority identified that the preference would be to provide care for people in their own home with the support of carers who are appropriately trained.

> "*It would be ideal that people living with dementia could stay at home as long as possible with as much help as possible (health care, social care, psychological care) and for the people taking care of them*".

> "*People could be cared for in their own environment by people with enough time, competence and trust to provide a safe place for the person with dementia*".

Participants identified that where this is not possible they would prefer to see the development of small care neighbourhood or village schemes that provide housing for small groups of residents to live together.

> "*Normal housing for small groups, integrated in the neighbourhood. The living environment is rich and interesting for the residents, it stimulates them to be active and promotes thinking so that they retain contact with who they are*".

While integration is key to this theme, there is an emphasis on ensuring people are safe and that the environment is designed around their needs to promote as normalised a living concept as possible with connection to their family, community or neighbourhood being key.

Several participants identified that people living with dementia should be "*admitted to a care facility*" when they are no longer able to live at home. This view identified that the care facility would provide supported living "*including closed wards as a last resort*". The emphasis identified by 4 participants appears to be on safety, management of risk, and reducing the potential for loneliness and isolation. Whilst these participants appeared to be making assumptions about what is good or in the best interests of people living with dementia, they do emphasize that large scale facilities are not beneficial.

> "*A world without big nursing homes, just small facilities in the area where people did live. Important issues are participation and emancipation*".

> "*They would live in a small house with only a few people together and someone to care for them. There must also be a garden and only a ground floor*".

Participants identified a number of important or essential ingredients that the ideal care environment should have which emphasized the principles of inclusion and participation, respect, positive regard, holistic focus on the person and their family, freedom to move around and participate in everyday activities, space for meeting others, and an environment that is relaxing and varied.

When asked to identify the ideal number of people living in residential settings in an ideal care environment, participants identified groupings of 6-12 residents as the mean with several identifying as few as 3. Whilst there is no ideal number identified in the literature, one participant was clear that for them small houses should have 6-8 residents, whilst group homes would have 10-12 residents "*dependent on the characteristics of the person living with dementia*", going onto say,

> "*Depends on the way residences are structured. The best I have seen are quite small and look like true homes allowing enjoyment and contribution to life. But this could be modular*".

One participant identified the importance of facilitating the ability to live with spouses in the care setting.

> "*The environment should not make a mass impression, but the number of residents is not crucial/not limited to a small number. The presentence of professional carers and specialists would favour a large population, but the building should have a number of homelike units, making it possible for the spouse to live with the person with dementia.*"

Three participants identified specifically larger numbers of people living together and these numbers varied between 20-30 and 80-100 but the focus here was on quantifying numbers for care homes. One participant emphasized that "nursing homes and getting old have a bad reputation" mentioning that it is viewed "*very negatively by society and this should perception should change*".

Priorities of Care

When asked about the key priorities of care for people living with dementia and their families the over-riding theme was quality of life, achieved through person centred holistic care, positive relationships and being included in community activities.

> "*Person centred and individualised care (not one size fits all)*".

> "*A holistic approach should prioritise all areas. The priority of care would be dependent on the individual/carer. For example some individuals would prioritise social care needs over spiritual needs and vice versa*".

A focus on positive relationships was considered to be key to quality of life. This participant summarizes:

"*The basis of everything is the quality of the relationship between the professional carer and the person with dementia and important people in their network. It is important to be attentive and understand what counts. There is too much therapeutic/interventionistic/medical thinking in dementia care*".

Several participants emphasized the importance of connection with loved ones and carers.

"*To be as near to their previous life as is possible, with familiar carers and who see care are being carried out along with the person themselves and friends and family*".

"*They must be able to make their own choices. Family and friends could help to care if they want*".

One participant identified the importance of family centred models of care in responding to this question.

"*Care and support that is timely, relevant to the needs of the person and the family members/friends and that is person and family centred*".

The concept of inclusion was seen to be essential also to quality of life so that people are "*integrated in communities*", "*feeling accepted and not excluded by their social environment*". This must however be driven by the person's choice and preferences.

Who should deliver optimal care

Participants were asked to identify who or what combination of people would be best able to deliver their vision for optimal care. Two participants identified that this should be driven by the person and their history, needs and choices determined by a holistic assessment.

"*This will depend on the person, their history and state, culture and social environment.*"

"*In my view it very much depends on the needs of the person with dementia and their family members. Once a thorough comprehensive assessment is done it will be possible to identify whose expertise is needed according to the needs of the person*".

Most participants identified that a mixed combination of professional and non-professional carers determined by the needs of the person to provide formal and informal care would be the optimal model, citing doctors, nurses, speech therapists, occupational therapists, and physiotherapists. One participant mentioned the importance of having community nurses in the neighbourhood specifically citing the benefits of the Buutzorg model.

"*Neighbourhood nurses e.g. Buurtzorg in the Netherlands, with autonomy to make care decisions on a low level in the organisation, little administrative burden. Medical specialists for the elderly at the office of the family doctor (first line)*".

Emphasis was placed on the carer having empathy, competence and appropriate training and education.

Level and Kind of Training

When asked about the level and kind of training care givers should receive in order to be effective in their role, participants identified that everyone should have a foundation level of training that would provide a "*good knowledge of what dementia is but more importantly of the cared for".* The emphasis here being on person centred practice.

> "*Training in human and personalised centred care with a vision on human functioning that is positive and rewarding*".

One participant identified the importance of generic training with specific content on "*how to deal with the dementia and relate to persons with dementia and their relative*s".

The key areas identified in this foundation level of training appear to be on a basic level of knowledge skills and competence in dementia care for all persons in direct contract with people living with dementia.

Participants then emphasized the importance of having a scalable model of learning and development tailored to the needs of care givers, their contexts and specific professional needs, and those of their care delivery teams. One participant emphasized the important of a case management approach to be flexible enough to meet the needs of different people at any one time.

> "*We need much more training on a long term basis and integrated in the care policy of the care organisation. But most of all there is a clear need to be intervision in teams. Professional carers should be much more involved in interdisciplinary meetings about individual care receivers".*

The scalable model of learning and development would provide longitudinal support for career progression and specialisation in the field with Masters, specialist and advanced programmes.

Technical Aids and Devices

When asked what technical aids and devices would enable the person living with dementia to live an optimal life, four groups of aids emerged. These were smarthomes, robotic assistance, walking and mobility aids and devices to support cognitive stimulation, eating and drinking. However, the specific detail of useful products were not identified. There was a big emphasis on tracking and surveillance devices to track and trace people, promote safety, minimise risk from harm such as falls, and prevent wandering. Several participants acknowledged caution when using technology that it should be "*non-stigmatising, as less intrusive as possible, and facilitate communication, sensory and functional processes*". One participant identified the

need to ensure that "*devices must support people with dementia to let them live as long as possible in their own safe environment*".

Retaining links with the community

Participants were asked to identify how the care environment could help people to retain links with their local community or wider social circle. Specific activities identified as being potentially most beneficial and helpful included tourism, memory cafes, singing groups, intergenerational activities through clubs and kindergartens, arranging school children to visit care homes, inviting neighbours into care homes, support groups and advisors and buddies. The emphasis was on enabling people to remain connected with the community "*being in the middle of it and not sealed off*", "*by binging the community into the house for activities*". The theme of small scale living units re-emerged here as being the most enabling model for supporting people to live meaningful lives at the heart of their community. However, there was also a negative discourse that focused on "*making them normal and accepted*", "*just be normal*", "*staying normal*" "*people as insufficient*".

When delving deeper into how the care environment might best encourage people to participant in social and creational activities in the wider community this negative discourse was also evident. One participant identified the importance of "*being as normal as possible*" whilst another identified that there should be,

> "*Court appointed personal guardians or volunteers to support and assist activities and make sure that people with dementia attend*".

This discourse undermines the majority view of personal choice and independence and has an underlying assumption that people should be forced to participate in community activities for their own good.

The majority of participants identified that the care environment, regardless of setting and context, should enable and empower people to participate in activities that are connected with their families and communities in some way with the community at the heart of the model. These activities should be adapted to the person's needs and interests and supported by staff who are trained to make the most of opportunities for social and recreational activities.

Additional Services that might be offered by the care environment

When asked what additional services might be offered by the care environment to support people as their condition progresses there were some key themes that focused mainly on the individual and their family. One participant emphasized the importance of having a case management approach to facilitate best use of additional services.

> "*Mixed economy of inputs. Case management coordinated by one service/discipline/team and then mobilising other stakeholders can be effective in ensuring resources are targeted appropriately.*"

Focusing at the individual level, participants mentioned the importance of promoting choice, having a one to one care ratio, having an approach that visits everyone over the age of 70, focusing on environmental design, technology and adapted housing, advanced care planning and having palliative specialists to support people to live well regardless of context. There was no one theme that prevailed. However, the suggestions were laden with assumptions that because people are increasingly diagnosed with dementia at a younger age visiting everyone over 70 would not only be economically unviable, but would also miss many people living in our communities who may require support.

Suggestions made with a focus on the family included family home management programmes, employing more admiral nurses (a model used in the UK context), and appointing family coaches or buddies to offer support in the home. There were no suggestions for services for friends which might indicate that participants do not value the fact that people living with dementia have friends, or just that this is not significant in their thinking about additional services. However, in modern day society people are increasingly living without the support of extended families and rely on the support of friends and neighbours in their communities, so this should not be overlooked.

When asked about what combination of people might provide these additional services the responses were very diverse, but at their core had a holistic case management approach combining support from informal carers and family, community volunteers and professionally trained staff in a network of support.

When considering how the staff in the care environment might help others living in the community to learn more about dementia, there were a range of suggestions given. These were labelled "dementia friendly activities" and included having community reference persons or champions, dementia awareness programmes facilitated by Admiral Nurses using a networked case management model, media and public awareness campaigns including use of social media, neighbourhood activities such as drop in events – coffee mornings, care boot sales, regular talks and discussions facilitated by family doctors and care givers, and events laid on by care facilities for the community, bringing the community in. Colleagues from Switzerland cited the dementia bus model that is used to go out into communities to raise awareness and offer support.

The importance of staff facilitating awareness and spreading their knowledge and expertise to others was emphasized in supporting the development of student practitioners. Here role

modelling was cited as being important in facilitating learning about how to support people to live well with dementia, challenging attitudes and breaking down stereotypes.

Finally participants were asked to identify anything further they wanted to add that they felt had not been addressed elsewhere. There were some interesting responses including:

> *"Nurses and carers need to be free of mental diseases and issues and need to have a balanced personality".*

Whilst this statement appeared to be value laden the participant did go on to clarify that *"nurses and professional carers need to look after themselves well to be able to care well".*

One participant from the UK cited several published reports about the important role that Admiral Nurses play in the case management approach, citing best practice examples from Norfolk and Sutton. The emphasis on effective team working was made by several participants with acknowledgement of the importance of team culture:

> "*You must create a team where everybody is motivated. A bad switch can pull the whole team down*".

One participant summarised a key message that:

> "*No standard solution will fit. One of the characteristics is that dementia presents itself in a unique way in each person and it progresses also in a sometimes unpredictable way. All caregivers need to be very flexible and open minded, searching each time for the optimal quality of life and quality of care*".

The findings from the survey are now followed by a discussion of the implications for the broader CASCADE project and for partners other deliverables.

Discussion

The survey has not revealed any new or ground-breaking insights into best practice models for dementia care that shed light on possibilities for the CASCADE model of care currently being developed by PP9 and partners.

The results indicate that policy is more advanced in the UK countries where participants emphasized person centred case management approaches with increasing numbers of Admiral Nurses to provide family support. The family centred care approach featured heavily in the responses from the one participant from Malta because this is the prevalent model of care both in hospital and community settings. Neighbourhood models of care with a focus on smaller living units unsurprisingly were the focus of participants in the Netherlands and Belgium where these models are more developed by the UK. The emphasis on technology and surveillance bears some cross over with the themes derived from a literature review of technology enabled care services (TECS) reported in deliverable 3.3.1, with a concern over

the ethical and moral foundation for increasing surveillance to prevent harm, and the cost that technologies for the home might bring to bear on families with limited budgets. Whilst technologies should be designed to enable independent living, the flip side is that it could contradict a person's human right to privacy and dignity.

There was a negative discourse running through some of the participant responses that indicated strong underlying assumptions that stereotype and stigmatise people living with dementia. In these responses the focus on the biomedical model and treating people "*as though they are human*" was strongly evident. Placing people in care facilities to be surveilled and made to engage in activities for their greater good were also evident in these responses. Whilst unhelpful to the CASCADE project it is nonetheless important to identify that these stereotypes need to be challenged by any model that the project team develop.

In summary the themes derived from this survey echo findings already reported in deliverable reports 3.1.1,3.1.2 and 3.1.4.

Limitations

The survey was limited by the low response rate in both the initial call for participants, and the subsequent wider call. A full Delphi study had to be abandoned, and as a consequence the survey is unable to provide a systematically concluded consensus about what kinds of environments would provide optimal care for people living with dementia in the future. This limitation was compounded by the fact that not all participants answered all the survey questions. Whilst the survey had 23 participants the largest number of responses for any one question was only 21, meaning there is missing data. However, the demographic data do give some important information about the background of the participants and have been helpful in providing some context behind the qualitative comments that participants contributed.

Recommendations

Consideration needs to be given by all partners to how we revisit a Delphi approach in the future to extend our exploration of best practice models in year 2 of the project so that we can build on this initial disappointing response. We would recommend that a scoping review of best practice models is undertaken to expand our understanding of what currently works, and what ideas are ground-breaking and having positive impact at community, family and individual levels.

Conclusions

The response rate was disappointing despite the attempts to garner support from a wider network across the EU to help with dissemination. At this point it is not possible to draw any

concrete conclusions from the data as the sample is too small, but it does provide some insight into the challenges that this social innovation faces in terms of the gaps, and the stereotypes in place that dominate the world view of dementia as a condition that needs medical treatment, surveillance and specialist treatment. It does indicate that the CASCADE team have many challenges ahead in designing the social innovation outcomes intended in the project plan.