The perceived care and support needs as articulated by carers and people living with dementia.

A scoping overview of the international research literature to inform the Dementia Standards Working Group (July 21, minor update June 22). Gill Windle g.windle@bangor.ac.uk

Rationale

The Dementia Care Standards for Wales (published 23 3 21) sets out twenty standards to improve dementia care for individuals and their carers, alongside a pathway towards effective implementation. Standard 1 requires community engagement to understand what people with dementia, their families and services that support them have identified they need, and what support is currently provided.

The working group discussed a number of challenges facing the regions regarding this first step in engagement, such as consultation fatigue, variable methods in consulting, difficulties reaching some populations etc., which could affect the level of engagement and subsequent service growth.

Whilst not necessarily reflecting the ‘voice’ of people living with dementia and their families in Wales, a scope of the international literature may highlight some common themes from the voices of others living elsewhere in the world. These could be a useful starting point in conversations with local communities; for example as prompts to help people consider their own needs, and the extent to which they may feel these are relevant to their needs.

Question

What are the self-perceived needs of community dwelling people living with dementia and the (informal) carers?

Starting point – understanding care needs from the ‘lived experience’ perspective

A systematic review of 12 qualitative studies explored the self-perceived needs of partner and/or offspring caregivers who were caring for community-dwelling older adults with dementia. Four of the studies were based in the United Kingdom; 2 in the United States; and 1 respectively in Australia, Canada, Ireland, Norway, Sweden, and Hong Kong China. The focus was research that included caregivers of community-dwelling people living with dementia who are aged 65 or older (aged 60 or older if from a developing country or aged 50 or older if indigenous people by referring to the situation in Australia).

The following unmet needs were identified.

Caregiver Needs Related to Managing Care Recipients

- Information and knowledge needs about dementia and how to manage
- Support needs in managing care recipients’ ADL, instrumental activities of daily living (IADL), and Behavioural and Psychological Symptoms of Dementia (BPSD)
- Care support needs from professional services
- Informal care support needs from families, friends and peers

Caregivers’ personal needs

- The need to address caregivers’ physical and psychological health conditions
- The need to manage caregivers’ own lives
The perceived care and support needs as articulated by carers and people living with dementia.

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Aim

This work builds on the previous review by McCabe et al (2016), and undertake a systematic scoping search of the international published research literature to identify:

- New literature relating to carers (family or friends, of any age) published since September 2015 (updating the searches of McCabe et al.).
- New literature that reflects the voices of people living with dementia

The methods for the review are described in the appendix. The process led to the inclusion of 21 research articles reflecting the voices of carers (14 papers), people with dementia and carers together (5 papers) and people with dementia (2 papers).

Table 1 summarises each research article and highlights the key points in relation to the perceived needs articulated in the research.
Table 1: Perceived care and support needs as articulated by carers and people living with dementia

<table>
<thead>
<tr>
<th>Source</th>
<th>Population</th>
<th>Key points in relation to perceived needs</th>
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</table>
• Need for information about the role of hospice care resources  
• Support for carer to access community resources (e.g. unable to leave the person they care for alone) |
Unmet needs or challenges included:  
• Patient/caregiver education  
• Education of non-specialist clinicians and community care providers  
• Scheduling difficulties  
• Caregiver support  
• Financial concerns  
• Assistance with advance care planning  
• Finding local resources, and effective treatments for DLB symptoms. |
| Dam, A., Boots, L., van Boxtel, M., Verhey, F., & de Vugt, M. E. (2018). A mismatch between supply and demand of social support in dementia | 10 spousal carers (70% female, mean age 75). | Spousal caregivers need:  
• Emotional support  
• Practical support |
| | | |

<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Needs</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Care: a qualitative study on the perspectives of spousal caregivers and their social network members. <em>International psychogeriatrics</em>, 30(6), 881–892. <a href="https://doi.org/10.1017/S1041610217000898">https://doi.org/10.1017/S1041610217000898</a></td>
<td>The Netherlands.</td>
<td>The authors first had two focus group interviews with 13 professionals to explore carers’ support needs as observed by professionals. Then three focus group interviews with 18 carers to explore their various support needs in the past and present, followed by in depth interviews with 5 carers.</td>
<td>Denmark.</td>
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<tr>
<td>• Need for support to get knowledge on caring</td>
<td></td>
<td>• Need for support to get help for myself</td>
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<td>• Need for support to talk about difficult issues</td>
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<td>• Need for support to handle emotional burden</td>
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<tr>
<td>• Need for support to achieve physical well-being</td>
<td></td>
<td>• Need for support to communicate and interact with family, network and professionals</td>
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<tr>
<td>Cottrell, L., Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Ghosh, S., Holroyd-Leduc, J. M., Nekolaichuk, C., Forbes, D., Paragg, J., &amp; Swindle, J. (2020). Using focus groups to explore caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes. <em>Aging &amp; mental health</em>, 24(2), 227–232. <a href="https://doi.org/10.1080/13607863.2018.1531369">https://doi.org/10.1080/13607863.2018.1531369</a></td>
<td>Canada.</td>
<td>9 family/friend carers who were predominantly female (89%), married (78%), not employed (78%), and caring for their spouse or life partner (89%). Length of post-placement caregiving ranged from five to 55 months (mean 24 months; SD 17.67). Mean age for was 67.57 (SD 5.97).</td>
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<td>Caregivers need a range of support following their family member’s move to a full time care facility. These include:</td>
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<td>• Clear information to help caregivers better navigate a complex health care system</td>
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<td></td>
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<td>• Support with building relationships with the facility staff</td>
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<td>• Emotional support with guilt, grief and loss</td>
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<tr>
<td>Reference</td>
<td>Description</td>
<td>Support with</td>
<td></td>
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</table>
- Connecting with and supported by others  
- Need to balance their own needs and health with those of the individual  
- Maintaining control and being the co-ordinator of their relative’s care (navigating the care system and accessing practical support). |
| Gottschalk, S., Neubert, L., König, H. H., & Brettschneider, C. (2021). | Balancing care demands and personal needs: A typology on the reconciliation of informal dementia care with personal life based on narrative interviews. *Dementia (London, England)*, 14713012211008306. Advance online publication. | - The carers needs are shaped by the caring context (e.g. relationship quality; distribution of care tasks between the members of the care network; being the primary or secondary carer).  
- Self-care by participating in activities outside care should be promoted as it is crucial for achieving a balance between care and personal life. |
In relation to support in managing changes in behavior and mood of their relatives with dementia, the carers need:  
- Information about dementia and its symptoms |
<table>
<thead>
<tr>
<th><strong>Reference</strong></th>
<th><strong>Participants</strong></th>
<th><strong>Findings</strong></th>
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</table>
| Gill Windle. Scoping overview of the international research literature to inform the Dementia Standards Working Group (July 21) [g.windle@bangor.ac.uk](mailto:g.windle@bangor.ac.uk) minor update June 22 |  | • Tips and advice on managing changes in behavior and mood  
• Opportunities to discuss experiences and feelings  
• Appreciation and acknowledgement of caregiving |
| Hynes, S. M., Field, B., Ledgerd, R., Swinson, T., Wenborn, J., di Bona, L., Moniz-Cook, E., Poland, F., & Orrell, M. (2016). Exploring the need for a new UK occupational therapy intervention for people with dementia and family carers: Community Occupational Therapy in Dementia (COTiD). A focus group study. *Aging & mental health*, 20(7), 762–769. [https://doi.org/10.3928/19404921-20180216-01](https://doi.org/10.3928/19404921-20180216-01) | 18 people living with dementia (13 males, age not reported). 21 carers (14 females, age not reported). England. | [This study focussed on how an OT intervention could help specific needs, so the research is tailored towards that, but there are one or two general findings to extrapolate]:  
• The need for continuity of support throughout the dementia pathway and also for consistency of approach.  
• Support with adjustment to loss of role and aspects of life before dementia  
• More support to be provided post-diagnosis and signposting to relevant services. |

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**Notes:**
- **Tips and advice on managing changes in behavior and mood**
- **Opportunities to discuss experiences and feelings**
- **Appreciation and acknowledgement of caregiving**
- **The need for continuity of support throughout the dementia pathway and also for consistency of approach.**
- **Support with adjustment to loss of role and aspects of life before dementia.**
- **More support to be provided post-diagnosis and signposting to relevant services.**
- **Responding to care needs requires high-quality needs assessments. Moving beyond a superficial ‘tick-box’ assessment, people with dementia and their carers need encouragement through in-depth explorations to articulate their underlying needs and preferences.**

<table>
<thead>
<tr>
<th>Purposeful sample of:</th>
<th>Results highlighted the difficulties experienced by this patient group and underscores the crucial role of informal caregivers in decision-making at all stages.</th>
</tr>
</thead>
</table>
| • 10 patients with a diagnosis of cancer–dementia (50% female, mean age=73.6±15.4 (range 39–93)) | Four themes were identified:  
(1) leading to the initial consultation  
(2) communicating clinically relevant information—informal caregivers are relied on to provide patient information, advocate for the patient and support decision-making  
(3) adjustments to cancer care—patients with dementia get through treatment with the help of their family  
(4) following completion of cancer treatment—there are continuing information needs. |
| • 9 informal caregivers (44% female, mean age=63.8±12.3 (range 47–77, relationship: 56% spouse, 44% son/daughter) |  |
| • 12 oncology HCPs. |  |
| North West England, U.K. |  |


| 82 family carers, majority female (91.50%) mean age (years) 58.3. Spain. | • Practical help (instrumental support) from other family members  
• Practical help (instrumental support) from paid/professional caregivers  
• Respite support to enable time out/self-care  
• Timely diagnosis  
• Training in care oriented towards meeting the basic needs of the care recipient  
• Training to manage special care situations and behavioural problems  
• Free time for leisure and socialising |
<table>
<thead>
<tr>
<th>Source</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peterson, K., Hahn, H., Lee, A.J. <em>et al.</em> (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers’ education needs, barriers, and preferences. <em>BMC Geriatr</em> 16, 164. <a href="https://doi.org/10.1186/s12877-016-0338-7">https://doi.org/10.1186/s12877-016-0338-7</a></td>
<td>27 family carers, mostly female (70%), mean age =58.5 years. adult children (55.2%) or spouses (30.0%). USA.</td>
<td>Carers need health care professionals to ‘recommend, endorse, and guide’ them to specific sources of care and information (e.g. referrals to other healthcare professionals, print material, and community and internet resources).</td>
</tr>
</tbody>
</table>
| Rabanal, L. I., Chatwin, J., Walker, A., O’Sullivan, M. & Williamson, T. (2018). Understanding the needs and experiences of people with young onset dementia: a qualitative study. *BMJ Open* 2018;8:e021166. doi:10.1136/bmjopen-2017-021166 | Semi-structured, in-depth interviews with 14 people with a diagnosis of Young Onset Dementia. They were aged between 57 and 67 years. UK. | Four superordinate themes are reported on ‘process of diagnosis’, ‘the impact of living YOD’, ‘needs of people with YOD’ and ‘living well with YOD’. Key issues that emerging included:  
- a lack of general awareness of YOD; how this can delay help seeking  
- commonalities in prediagnosis trajectories  
- retrospective understanding of prediagnosis symptom patterns  
- the difficulties of obtaining a firm diagnosis  
- the importance of face-to-face support  
- difficulties associated with daily living. Participants also described the emotional and psychological impact of the condition and the importance of formal and informal support networks. |
| Ramirez, M., Duran, M. C., Pabiniak, C. J., *et al.* (2021). Family Caregiver Needs and Preferences for Virtual Training to Manage Behavioral and Psychological Symptoms of Dementia: Interview Study. *JMIR Aging*, 4(1):e24965 | 15 semi-structured interviews with family caregivers of people with dementia. Mostly female (67%) and spouse/partner (67%), mean age =72. | Carers said health care providers did not provide adequate education in the early disease stages about the personality and behavior symptoms that can affect people with dementia, leaving them unprepared to manage these symptoms. Caregivers expressed a strong desire for the health care organization to offer virtual training early in the disease course. |
1. Knowing the person, 
2. Process of decision making, 
3. Maintaining normalcy and quality of life 
4. Out of their control. |
- Worries and concerns were about ability to adequately care for their partner 
- Need emotional support 
- Maintaining healthy diet and exercise 
- Personal time away from caring role |
| Telenius, E. W., Eriksen, S. & Rokstad, A. M. M. (2020). I need to be who I am: a qualitative interview study exploring the needs of people with dementia in Norway. *BMJ Open*, 10(8), e035886. | 35 participants diagnosed with dementia (19 women, 16 men, aged 59-92) were interviewed. 16 lived at home and used no services, 14 received services in the community and 5 were severely affected and lived in nursing homes. | Offspring caregivers: 
- Mental health needs (feeling depressed, hopeless, anxious, lonely, isolated, overwhelmed, and having low self-worth). 
- Need emotional support 
- Maintaining healthy diet and exercise 
- Personal time away from caring role |
| Three main categories of needs that emerged from the interview analysis were: 
(1) to stay connected – the importance of close relationships, dependence on others and dealing with shifting social networks. 
(2) to be active and participate – to experience joy and enthusiasm and to experience mastery and meaning in everyday life. |
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title and Details</th>
</tr>
</thead>
</table>
| Vaitheswaran, S., Lakshminarayanan, M., Ramanujam, V., Sargunan, S., & Venkatesan, S. (2020). Experiences and Needs of Caregivers of Persons With Dementia in India During the COVID-19 Pandemic: A Qualitative Study. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 28(11), 1185–1194. [https://doi.org/10.1016/j.jagp.2020.06.026](https://doi.org/10.1016/j.jagp.2020.06.026) | Norway. 31 dementia carers; mean age = 54.06 years (SD 15.04) and 16 (51.6%) were women. Chennai, India. Immediate needs (during the pandemic)  
- Need for consultation with a specialist  
- Access to medicines for dementia  
- Assistance and extra help at home for the person with dementia  
- Flexible implementation of policies (e.g. not forcing a person with dementia who needs to get out of the house to be confined at home)  
Long term needs  
- Trained home care support for persons with dementia,  
- Caregiver training  
- Respite services  
- Improved awareness about dementia in society  

Wang, M., Shao, S., Li, J., Liu, Y., Xu, X., & Du, J. (2018). The needs of informal caregivers and barriers of primary care workers toward dementia management in primary care: a qualitative study in Beijing. *BMC Family Practice*, 19(1), 201. [https://doi.org/10.1186/s12875-018-0890-7](https://doi.org/10.1186/s12875-018-0890-7) | China. 10 family carers; 9 females, mean age=66. 29 primary care professionals, mean age=38.9. NOTE: these findings were derived by synthesising the perspectives of both participant groups (family carers and professional carers). Carers need:  
- Knowledge and skills to help them with caring  
- Psychological support for stress  
- Respite care for leisure and social activities  
Primary care professionals need:  
- More training for knowledge and skills in dementia care  
- A team based approach to care management |
Methods

Inclusion criteria (carers)

- English language publications since September 2015 (to follow on and update McCabe et al.)
- Published qualitative studies that use interviews, focus groups/group discussions, or observations (studies using mixed research methods if the qualitative data meet the inclusion criteria)
- No age restrictions
- Studies primarily focused on caregiver needs or those that reported findings that included caregiver needs
- Caregiver needs must be from the caregivers’ perspectives (not a third party).
- Caregivers must be family members, spouse or partner, friend/close contact.
- The joint perspectives of dyads (people living with dementia and their carers) included.

Exclusion criteria

- Opinion-based studies/commentaries, literature reviews/essays without a replicable methodology, study protocols;
- Studies including mixed participants (different types of caregivers, care recipients, and/or care professionals) that do not differentiate between each of their perspectives (e.g. pools the data for analysis)
- Studies including caregivers who care for older people with memory loss or impaired cognitive functioning that was not related to a dementia.

Inclusion criteria (people living with dementia)

- English language publications since September 2000
- Published qualitative studies that use interviews, focus groups/group discussions, or observations (studies using mixed research methods if the qualitative data meet the inclusion criteria)
- No age restrictions
- Studies primarily focused on the needs of people living with dementia, or those that reporte findings that included their needs from their perspective (but proxy reporting included if capacity is an issue)
- The needs of people living with dementia from their own perspectives (not a third party, but proxy reporting included if capacity is an issue)
- The joint perspectives of dyads (people living with dementia and their family/friend/informal carers) included

Exclusion criteria
Opinion-based studies/commentaries, literature reviews/essays without a replicable methodology, study protocols
- Studies reporting on memory loss or impaired cognitive functioning that is not related to a dementia.
- Studies that report the perspectives of professional carers only.

**Searches**
Title and abstract searches in Medline, PsycINFO and Web of Science Core Collection.

**Table 2: Search 1**

<table>
<thead>
<tr>
<th>Key search term</th>
<th>Modes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care</td>
<td>care OR caring OR caregiving or carer* or caregiver*</td>
</tr>
<tr>
<td>Qualitative</td>
<td>qualitative * or interview* or focus group* or observation&quot; or group discussion*</td>
</tr>
<tr>
<td>Needs</td>
<td>need OR needs OR require* OR expect* OR want* or demand* or wish</td>
</tr>
<tr>
<td>Dementia</td>
<td>Dementia OR Frontotemporal Dementia OR Alzheimer’s Disease OR vascular dementia OR PPA OR PCA OR familial Alzheimer’s Disease OR mild cognitive impairment OR MCI</td>
</tr>
</tbody>
</table>

**Table 23: Search 2**

<table>
<thead>
<tr>
<th>Key search term</th>
<th>Modes</th>
</tr>
</thead>
</table>
| Lived experience| "lived experience*" OR "person with" OR "people with" OR "lived perspective*"
| Qualitative     | qualitative * or interview* or focus group* or observation" or group discussion* |
| Needs           | need OR needs OR require* OR expect* OR want* or demand* or wish |
| Dementia        | Dementia OR Frontotemporal Dementia OR Alzheimer’s Disease OR vascular dementia OR PPA OR PCA OR familial Alzheimer’s Disease OR mild cognitive impairment OR MCI |

**Results**
Search 1 abstract searches in WoS produced 1,650 results (24/06/21). Given this was an initial rapid scope of the research literature, the searches were restricted to the title only. This yielded 24 results, 10 of these were found not to meet the inclusion criteria leaving 14 articles. After duplicates were removed a further 3 articles were identified in Medline, none in PsychInfo and 1 article found when searching reference lists of the included papers (20 research papers). On
14 paper did not meet the inclusion criteria, leaving 19 papers. Title searching for search 2 led to 18 results, 14 did not meet the inclusion and exclusion criteria. On full appraisal 2 further papers were excluded, leaving a combined total of 21 papers.
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minor update June 22