

## G.2 Involving people with dementia in decision about care

### G.2.1 Barriers and facilitators to involvement in decision making for people living with dementia

- What barriers and facilitators have an impact on involving people living with dementia in decisions about their present and future care?
- What barriers and facilitators have an impact on how people living with dementia can make use of advance planning?

#### G.2.1.1 Barriers to decision making

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Patient level - Denial of problem							
3 (Goodman, Livingston, Poppe)	Focus groups, interviews	If the person with dementia is unreconciled to the severity of their needs, this is a barrier to accepting care. The main barrier to advance planning on the part of the people with dementia and carers was difficulty for some people with dementia or carers to accept the diagnosis.	Not serious	High	High	High	High
Patient level - Rejection of help							
1 (Livingston)	Focus groups, interviews	People will often reject help, either because they feel they do not need it or because accepting help would involve psychologically acknowledging the severity of their problems.	Not serious	High	High	High	High
Patient level – Deference to authority							
1 (Goodman)	Interviews	Having dementia combined with living in a care home meant the older people often accepted that staff and visiting healthcare professionals would make decisions on their behalf.	Very serious <sup>1</sup>	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Very low
1 (Goodman)	Interviews	Knowing that they had dementia affected confidence in expressing opinions, self-esteem and whether they thought their views were worth listening to.	Very serious <sup>1</sup>	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Very low
Patient level – Poor relationship with formal or informal carers							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Goodman)	Interviews	If the person with dementia has a poor relationship with the carer(s), this could be a barrier to expressing a wish regarding care.	Very serious <sup>1</sup>	High	Moderate <sup>2</sup>	Moderate <sup>3</sup>	Very low
Patient level – one partner more dominant							
1 Denning (2017)	Semi-structured interviews	Often there was one partner more dominant in decision-making.	Not serious	High	Moderate <sup>2</sup>	High	Moderate
Professional – Not recognising problems							
1 (Livingston)	Focus groups, interviews	Healthcare professionals may not recognise people need additional assistance to be involved in decision-making particularly when people are not open about difficulties they are having.	Not serious	High	High	High	High
Professional – Late diagnosis							
1 (Livingston)	Focus groups, interviews	If the diagnosis of dementia is delayed, this can make it difficult for all the necessary advance discussions to be had before capacity issues start to occur.	Not serious	High	High	High	High
Professional – Timing and quantity of information given							
2 (Livingston, Lord)	Focus groups, interviews	Feelings of guilt and distress for carers were often exacerbated by a perceived lack of support and information.	Not serious	High	High	High	High
Professional - Confidentiality and data protection							
1 (Livingston)	Focus groups, interviews	Carers felt they could not get the necessary information to help support decision-making because of confidentiality issues.	Not serious	High	High	High	High
Professional – Bureaucracy and rigidity (sticking to protocols)							
1 (Livingston)	Focus groups, interviews	People felt discussions were not sufficiently individualised due to a reliance on following pre-specified protocols.	Not serious	High	High	High	High
Carer – Role conflict							

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
2 (Livingston, Lord)	Focus groups, interviews	Many carers reported the decision was against the care recipient's wishes, and signalled a major carer role transition. Carers report a shift in the dynamic to a "mother/child" type relationship. They struggled with being expected to relinquish their caregiver role and that friends and family perceived the dyadic relationship to be over.	Not serious	High	High	High	High
Carer – Relationship to person living with dementia							
1 (Samsi)	Interviews	Friend carers often felt they were less able to make decisions on behalf of individuals than family carers.	Serious <sup>4</sup>	High	High	Moderate <sup>3</sup>	Low
Carer – Carer guilt							
2 (Livingston, Lord)	Focus groups, interviews	Feelings of anguish and guilt over decisions made. Journey towards a decision was directed by a mixture of fatigue and a lack of obvious or available alternatives. Feelings of guilt and failure were particularly strong for people obliged to cope alone.	Not serious	High	High	High	High
Carer – Family conflict							
2 (Livingston, Samsi)	Focus groups, interviews	When the person with dementia was involved in decision-making, they usually expressed reluctance to move to a care home. This often led the carer either to delay the decision or exclude the person with dementia from decision-making.	Not serious	High	High	High	High
Carer – Rigidity of system							
1 (Livingston)	Focus groups, interviews	People felt that once a decision was reached, it was then difficult to change this decision if circumstances changed, and this led to a reluctance to make initial decisions.	Not serious	High	High	High	High
Carer – Cultural issues							
2 (Lord, Mackenzie)	Interviews	Cultural issues may place a particular strain on decision-making around future places of care. In South	Not serious	Moderate <sup>5</sup>	High	High	Moderate

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		Asian communities, there may be a tendency to want to protect the person with dementia from ridicule by keeping them away from other people.					
Structural – Inability to plan							
2 (Lord, Poppe)	Interviews	Struggle with knowing when to seek care home placement due to dementia being unpredictable and wait lists of institutions. Some patients find discussing the future difficult without knowing what the future will bring.	Not serious	High	High	High	High
<ol style="list-style-type: none"> <li>1. Theme only identified in studies at high risk of bias</li> <li>2. Theme does not consistently emerge from all relevant studies</li> <li>3. Insufficient data to develop a full understanding of the phenomenon of interest</li> <li>4. Theme only identified in studies at moderate or high risk of bias</li> <li>5. Unclear how the groups included in this study generalise to the population at large</li> </ol>							