# Table S1: Key characteristics of included studies.

For clarity, studies have been grouped according to the aspect of social experiences that they aimed to explore.

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| **Author, date of publication, location** | **Research aims, questions and interview topics relevant to the review** | **Sample characteristics**  (AD= Alzheimer’s Disease, MCI = mild cognitive impairment, VaD = Vascular Dementia, MID = multi-infarct dementia; FTD = frontotemporal dementia, HD = Huntington’s dementia) | **Methodological approach** |
| Langdon et al. (2007) UK  MacRae (2011) Canada | Reactions of others to person with dementia  To explore changes in participants’ perceptions of their condition and understanding of others’ reactions towards them, since dementia diagnosis. To explore what participants thought others understood by terms ‘dementia’ and ‘Alzheimer’s disease’  *Interview topics: experiences of social responses to dementia diagnosis and ways of managing changes in relationships since dementia onset*  To examine how others’ reactions to and treatment of people with dementia affect experience of dementia  *Interview topics: relationships and interactions, perception of others’ view and treatment of them* | Participants recruited through Older Adult Mental Health Unit, aged 66-87 (mean age 79)  6 men, 6 women  Dementia type not reported  Participants aged 60-85 (mean age 74) (recruitment sources varied – Memory Disability Clinic, advertisements, other professionals)  7 men, 2 women  Dementia type not reported | Semi-structured interviews  Interpretative Phenomenological Analysis  Semi-structured interview  Inductive analysis based on Coffey and Atkinson (1996), Lofland and Lofland (1995), and Taylor and Bogdan (1984), with symbolic interactionist framework |
| O’Sullivan et al. (2014) New Zealand  Katsuno, (2005) USA | The impact of societal attitudes  To explore the experience of living with dementia and the influence of social attitudes  *Interview topics not reported*  To explore quality of life, people’s experiences of dementia and the impact of negative public attitudes towards dementia  *Interview topics: social support, quality of relationships, experiences of stigma and experiences of public’s view of dementia* | Participants recruited through community groups, 59-84 (mean not reported)  6 men, 5 women, and their caregivers  5 young onset, 6 older onset dementia  Participants aged 66-91 (mean age 79)  4 male, 19 female  18 possible/probable AD, 3 MID, 2 dementia type undetermined | Semi-structured interviews with individuals and caregivers, followed by focus group discussion of findings  Critical hermeneutic analysis within action research project  Mixed methods study: Quality of Life Scales and semi-structured interview  Qualitative data analysis based on Miles and Huberman (1994) and Knafl and Webster (1988) (quantitative data not included in review) |
| Beard and Fox (2008) USA  Clare et al. (2008) UK  Orulv (2012) Sweden | Social processes within support groups  To examine Alzheimer’s Disease as a social experience, demonstrating how collective identity is formed through membership within support groups  *Interview topic: views on social interaction*  To further understanding of factors and effects involved in being part of a mutually supportive, self help movement  *Interview topic: impact of self-help group on relationships*  To explore how self-help group members construct a shared understanding of dementia, employing a citizenship perspective  *No interviews used* | Support group attendees aged 65+ (mean age 71)  28 men, 12 women  24 AD, 16 MCI  Members of self-help group (DASNI), aged 48-66 (mean age 60)  2 men, 5 women  Dementia type not reported  Members of a local initiative self-help group, aged 63-83 (mean not reported)  2 men, 5 women  3 AD, 2 VaD, 2 cognitive disability due to vascular injuries (previously misdiagnosed as dementia) | Semi-structured interviews conducted within focus groups (N=32) and individual interviews (N=8)  Constant comparison method from grounded theory  Semi-structured interviews conducted longitudinally via email (over two years)  Interpretative Phenomenological Analysis  Explorative case study, qualitative data gathered longitudinally through audio recordings of group sessions, field notes, and interviews with 3 participants  Analysis of content, discursive patterns, lines of argument, and interactions between members |
| Harris (2012) USA  Harris (2013) USA | Friendship  To examine whether remaining friendships impact on experience of dementia and what factors are critical to retaining friendship  *Interview topics not reported*  To examine the quality and nature of friendships of people with dementia, and the effects of diagnosis upon relationships  *Interview topics; defining and describing friendship, changes in relationship, the withdrawing of friends, the role of friends in coping with and adapting to dementia* | Participants recruited from Alzheimer’s Association, ages 59-85 (mean age 75)  8 women  Majority (87%) AD  10 people with dementia and 9 care partners from Alzheimer’s Association (and four friends without dementia)  Age 57-85 (mean age 72)  4 men, 6 women with dementia  Majority (90%) AD | In-depth interviews, with follow-up interviews for N = 5  Grounded theory  Focus group interviews  Individual interviews with friends without dementia (not included in review)  Phenomenological, inductive approach, also drawing on Spencer and Pahl (2006) conceptual framework of friendship |
| Tranvag et al. (2015) Norway | Dignity-preserving interactions  To explore and describe essential qualities of relational interactions preserving dignity experiences among people with dementia, while interacting with family, social network (and healthcare professionals).  *Interview topics*: *How do other people affect your experience of dignity? How can your dignity be preserved in these interactions?* | Participants recruited through hospital memory clinics. Aged 64-85 (mean not reported).  6 men, 5 women  10 with AD and 1 with MCI | Interviews with modifiable structure. Analysis using a hermeneutic approach |
| Clemerson et al. (2014) UK  Harris (2004) USA  Pipon-Young et al. (2012) UK | Younger-onset dementia as a unique experience  To explore subjective experience of young-onset AD, specifically personal, social, and psychological impact and adjustment/coping processes  *Interview topics not reported*  To explored lived experience of people with young onset dementia, specifically focusing on social dimension  *Interview topics: family and social relationships, friends’ responses, peer groups*  To further understanding of experiences of younger people with dementia - including difficulties encountered in relationships, (and their experiences of support services)  *Interview topics not reported* | Participants recruited from NHS services, aged 35-63  7 men, 1 woman  Young-onset AD  Participants from Alzheimer’s Association and DASNI internet network  Aged 43-68 (mean age 56)  10 men, 13 women  Young-onset dementia, 14 AD, 6 FTD, 1 HD, 1 MCI, 1 ‘degenerative dementia’  Participants recruited from NHS services, aged 60-67 years (mean not reported)  1 man, 7 women  7 AD, 1 mixed dementia | Semi-structured interviews  Interpretative Phenomenological Analysis  Semi-structured interviews within focus groups and individual interviews (face-to-face and online)  Analytic strategy based on Glaser and Strauss (1967)  Semi-structured interviews  Thematic analysis based on Boyatzis (1998) and Corbin and Strauss (2008)  and concept mapping from action research interpretative method |
| Mok et al. (2007) China  O’Connor et al. (2010) Canada | Socio-cultural influences  To explore lived experience of people with dementia in China, and how culture and sociological factors impact on experience of dementia  *Interview topic: Impact of forgetfulness on families*  To add to literature focusing on how socio-cultural context can shape experience of dementia  *Unstructured interviews* | Participants aged 56-80 (mean not reported)  4 men and 11 women  Dementia type not reported  1 participant aged 49 with atypical VaD  Participant’s daughter and partner also included | Guided interviews  Qualitative analysis based on Colaizzi (1978)  Longitudinal gathering of data from in-depth interviews, observations, telephone conversations, and health and social care records  Narrative and discourse analysis |
| Harris and Sterin (1999) USA  Beard (2004)  USA  Caddell & Clare (2011) UK  Hedman et al. (2012) Sweden | Self-identity  To further understand how people with dementia define their sense of self, and to explore interactions within social psychological contexts that affirm or impair sense of self  *Interview topics: reactions of others, impact of AD on relationships*  This study examined the impact of being diagnosed with early AD on identity construction. *Interview topics: participants’ opinions regarding the general public’s awareness of, or reaction to, their condition*  To explore whether people with dementia felt that they had changed as a person, what kind of person they thought they were, and how they thought identity might be affected by dementia in future. *Interview topics: whether participants felt that other people had noticed changes in them*  To use Harre’s (1998) social constructionist theory to describe how people with dementia express their sense of self  *Interview topics: social situation, and ‘self 3’ within Harre’s theory (how people position themselves and are positioned by others)* | Participants recruited through Alzheimer’s Association, aged 54-84 (mean age 70), and 15 caregivers  5 men, 12 women with AD  10 support group attendees and 3 further participants recently diagnosed. Age not reported. 7 men, 3 women with early-stage AD  Participants recruited from memory clinic records. Aged 65-88 (mean 81.1 years). 5 men, 5 women with AD or VaD  Support group attendees, aged 65-80 (mean not reported)  7 men, 5 women with AD | Semi-structured interviews  Qualitative analysis based on Glaser and Strauss (1967)  Focus group (N = 10) and individual interviews (N = 3). Grounded theory analysis.  Individual interviews.  Interpretative Phenomenological Analysis  Semi-structured interviews  Content analysis using framework of Harre’s (1998) theory of selfhood |
| Bartlett (2014a; 2014b) UK | Activism and citizenship  Bartlett (2014a): To propose social movement theory as a framework for understanding dementia activism. To explore motivations behind people with dementia taking action and tactics used  *Interview topics reported related to diary entries and photographs*  Bartlett (2014b): To inform and advance debate about the psycho-emotional dimensions of disability by highlighting the oppression and barriers experienced by citizens with dementia who campaign for social change.  *Interview topics not reported* | Activists age 55-78 (mean age 64).  11 men, 5 women.  Dementia type not reported.  Activists aged 53-74 (mean age 64)  11 men, 5 women  Dementia type not reported | Diary interview methodology and participant observation. Content and thematic analysis, techniques based on Richards (2005)  Diary interview methodology and participant observation. Content and thematic analysis, techniques based on Richards (2005) |
| MacQuarrie (2005) Canada | Awareness and coping  To find out how people in the early stages of AD experience their illness *Interview topics: Social questions around spousal, family and friend relationships, care and dependence* | Participants mainly recruited through dementia clinic.  Ages 60-89 (mean 76.5)  9 men, 4 women with possible or probable AD | Semi-structured interviews Constant comparative analysis |
| Powers et al. (2014) USA | Stress Process Model for Individuals with Dementia  To use selected components of the Stress Process Model for Individuals with Dementia to further understanding of the illness experience (including family and role strain, and social support)  *Interview topics: How has your memory loss affected your relationships with others? What about your memory loss do you wish others understood or knew?* | 114 participants aged 50-95 (mean age 77)  46% men, 54% women  50% AD, remaining = mixed dementia, VaD, ‘any type’ or ‘other’. 5.3% MCI | Interviews consisting of 5 open-ended questions  Coding process based on Strauss (1987) and interpretation of themes per question |