“Who to tell, how and when?”

The qualitative exploration of the experiences of people living with dementia and their supporters attending a newly developed dementia disclosure support programme.

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: [blank]

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Date: 29.11.2019
Overview

This three-part thesis provides a systematic meta-review of reviews evaluating dyadic interventions for community-dwelling people living with dementia and their carers. It details the development of a dyadic intervention for this population, and critically appraises the process of conducting research in this area.

Part 1: Stand Alone Paper. A systematic meta-review and narrative synthesis of reviews evaluating dyadic interventions for community dwelling people living with dementia and their carers. Material was drawn from 6 systematic reviews of dyadic psycho-social interventions for community dwelling people living with dementia and their carers. There is a good theoretical and evidence-based rationale for the use of a dyadic approach. Improvements have been made in the direct assessment of the person living with dementia and interventions have been shown to be acceptable and beneficial for both members of the dyad. However, interventions fail to consider the interpersonal landscape when assessing efficacy. Further research needs to be done to create a dyadic model of stress which includes the impact of interpersonal factors which can be used to guide the development and evaluation of interventions in this area.

Part 2: Empirical paper. The development of a dementia disclosure support programme for people living with dementia and their supporters is detailed. The intervention was piloted with seven people living with dementia and their seven supporters. A semi-structured interview was conducted after the intervention to explore participants’ experience of the group and the impact of the group on their experience of living with dementia. Four themes were generated: “a cross on my back”; “denial and acceptance”, a “safe space”; and “wanting more” from the group. Participants in this study were aware of the public stigma that surrounds this
diagnosis, and this was found to inform their attitudes towards dementia disclosure. The group not only afforded them a safe space to discuss dementia disclosure, but it also increased communication within dyads. The findings also highlighted participants’ unmet needs regarding the wider issue of diagnostic adjustment and support afforded to the dyad post-diagnosis.

**Part 3: Critical Appraisal.** Reflections on the challenges of adapting an intervention for dementia dyads were considered along with a review of the study design, recruitment methods used, challenges faced in the administration of study materials and reflections on the process of thematic analysis. Future implications for research and practice were also considered.
Impact Statement

The systematic meta-review conducted as part of this thesis highlights that over the last ten years, studies of dyadic psychosocial interventions for people living with dementia and their supporters have improved in the direct assessment of the person living with dementia. However, most have focused on assessing the cognitive, functional and affective aspects of the condition for the person living with dementia and stress and burden in carers. Few have actively sought to explore the relational aspects of the diagnosis or looked at how this affects dyadic appraisals within the illness despite evidence highlighting the importance of these domains on the experience of living with dementia. None have considered the position of the dyad in the intervention in terms of its effects on outcomes.

Although increasing numbers of interventions seek to use a dyadic approach most continue to treat the dyad as two separate individuals and ignore the relationship in dementia. This may be due in part to a lack of a standardised conceptualisation of “dyadic intervention” but also due to the individualised models of stress that underly psycho-social interventions in this area. Researchers working in this field would benefit from a standardised conceptualisation of what is meant by a dyadic intervention. Further research needs to be conducted which can develop a dyadic model of stress which adequately considers the relational factors at work in the experience of living with dementia. Additionally, clinicians would benefit from using standardised measures to assess the quality of the relationship before treatment as a way of identifying the most effective interventions for dementia dyads. Further research is needed to identify the active mechanisms at work in effective dyadic interventions to determine what works for whom and when and evaluate the impact
of the positions the dyad is placed in within the intervention in terms of its effects on outcomes.

The results of this empirical study, which involved the adaptation of a disclosure support intervention for dementia dyads, show that the diagnosis and disclosure of dementia are more nuanced topics than is reflected in the current NICE guidelines (NICE, N.G. 97, 2018). Results highlighted the limitations of current models of disclosure (Chaudoir & Fisher, 2010; Greene et al., 2009) in terms of their individualised focus and assumption that people have autonomy and control over disclosure of a concealable, stigmatising diagnosis which is often not the case with dementia. These models do not address the issues at work when a diagnosis, such as dementia, is held by multiple individuals, or over time becomes less concealable. They do not speak to process issues at work in the dementia dyad where supporters may have to weigh up risks and benefits of disclosing or not disclosing the diagnosis for their loved one. Future research should consider the development a dyadic model of disclosure of stigmatised conditions which considers these issues.

People living with dementia and their supporters may benefit from access to a disclosure support intervention, such as the “Who to tell, how and when?” intervention developed as part of this thesis, around the time of diagnosis within a broader intervention focussed on helping the dyad adjust to the diagnosis, paying particular attention to the interpersonal needs of these dyads and providing the dyad with adequate post-diagnostic support.
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Part 1: Stand Alone Paper

The dyad in dementia.

A systematic meta-review of reviews evaluating dyadic interventions for community-dwelling people living with dementia
Abstract

Aims: To provide a meta-review of systematic reviews of psycho-social interventions conducted with community-dwelling people living with dementia and their carers.

Method: PsycINFO was searched using terms related to dementia, Alzheimer’s, intervention, treatment and psychosocial. Only peer-reviewed full text reviews in English which stated, a priori a research question pertaining to the evaluation of dyadic psycho-social interventions conducted with human populations were selected. Six systematic reviews met eligibility criteria. Review characteristics were extracted and summarised. An overlap analysis was conducted to determine the level of overlap between included reviews. A MeaSurement Tool to Assess Systematic Reviews (AMSTAR) was used to assess methodological quality. The individual studies included in these reviews were analysed to determine the ways in which the person living with dementia and their carer were positioned in the intervention. The measurement tools used to assess dyadic interpersonal constructs were extracted and summarised, along with the result of the impact of these interventions on the dyad.

Results: There is no consistent definition of “dyadic” in the context of interventions for people living with dementia and their carers. Dyadic interventions are heterogenous and the positioning of each member of the dyad varies across and within interventions. Despite evidence that stresses the importance of interpersonal factors in the experience of living with dementia, few studies evaluate these domains. Nevertheless, reviews of interventions that involve both members of the dyad have found that such approaches are acceptable and effective but there is some evidence to suggest that they may not outperform carer-focussed approaches.
Conclusions: This review highlights the challenges associated with conceptualising, assessing, and treating the dyad in dementia. Although interventions are increasingly targeted at “the dyad” and the direct assessment of people living with dementia has improved, “the dyad” is generally conceptualised as two separate individuals with the relationship in dementia being ignored. Researchers working in this field would benefit from a standardised conceptualisation of dyadic interventions and psychometrically tested measures evaluating stigma in this population. The development of a dyadic model of stress would also be of benefit, for example in highlighting the importance of assessing interpersonal domains when working with dementia dyads.
Introduction

This standalone paper provides a meta-review and narrative synthesis of systematic reviews evaluating dyadic psychosocial interventions for community-dwelling people living with dementia and their carers.

What is dementia?

Dementia, also known as Major Neurocognitive Disorder in the Diagnostic Statistics Manual (DSM-5, American Psychiatric Association, 2013), is the overarching term for a set of symptoms which lead to the chronic and progressive deterioration of a person’s cognitive function more than would be expected from normal ageing. There are many different causes of dementia, the most common of which is Alzheimer’s disease. Dementia is characterised by progressive deficits in two or more cognitive domains; memory, comprehension, orientation, calculation, learning, language or judgement, and results in complex needs. Increasingly the time from diagnosis to death can cover many years and has a notable impact on the quality of life of both the person living with dementia (PLwD, which in this case is the person with the diagnosis), and their carer (Brodaty, Seeher & Gibson, 2012).

The prevalence of dementia

Worldwide, dementia affects approximately 50 million people and this is predicted to increase to 152 million by 2050 (Prince et al., 2015, World Health Organisation, 2017). In 2018 there were 537,097 people with a diagnosis of dementia in the United Kingdom (Alzheimer’s Research UK, 2018). This number is set to rise to over one million by 2025 and double again by 2051, due in part to population ageing (Prince et al., 2013). The World Alzheimer Report identified dementia as a major cause of disability and dependency amongst the older population (Batsch et al., 2012).
The global position and national guidelines

The 2013 G7 (United Kingdom, United States, Canada, Japan, Germany, France and Italy) “Global Action Against Dementia” increased funding for dementia research and aims to identify a cure or a disease modifying therapy for dementia by 2025. Along with research highlighting the increasing incidence, prevalence and projected impact of dementia (Prince et al., 2013, 2015), this initiative has led to a concerted effort to raise awareness and encourage earlier diagnosis and treatment. The Department of Health (2009, 2012, 2015) and the National Institute for Clinical Excellence (NICE, N.G. 97, 2018) have published guidelines to support this effort.

Currently the Department of Health and Social Care (2015) aims for the diagnosis of two thirds of the estimated number of PLwD, and delivery of appropriate post-diagnostic support.

The impact of dementia on the individual and their carers

The symbiotic relationship between the PLwD and their carer (often their spouse but sometimes their child), has been well documented, in terms of the effects on the physical and mental health of both members (Ablitt, Jones & Muers, 2009; Braun et al., 2009; Quinn, Clare & Woods, 2009). There is evidence that carers of PLwD experience burden, increased stress, higher levels of depression and anxiety, a reduced quality of life and an increased risk of physical health problems and morbidity (Schulz & Martire, 2004). Increased memory and behavioural problems have also been documented in PLwD where carers are experiencing high levels of burden and stress (Braun et al., 2009). There is evidence that a lower quality of relationship before diagnosis leads to increased depression, burden and emotional reactivity in carers and lower self-efficacy post diagnosis. The quality of relationship prior to diagnosis also predicts the psychological wellbeing and the functional ability of
of the PLwD post diagnosis (Ablitt et al., 2009). Qualitative reviews examining the impact of dementia on marriage have identified the multiple transitions that couples are forced to face, in terms of the relationship, the roles taken on by each spouse, levels of intimacy and the challenging and frightening shared journey they are required to go on. For spousal carers, this takes place in the context of managing the gradual loss of a partner and the loss of a marriage (Evans & Lee, 2014). Wadham, Simpson, Rust and Murray’s qualitative meta-synthesis (2015) noted that for spousal dyads being connected and attuned to one another was of most importance as this was viewed as the basis from which they could cope with the changes in power, identity and affect inherent in the experience of living with dementia.

**Stress and dementia**

Hall and Buckwalter’s Progressively Lowered Stress Threshold model (PLST, 1987) argues that dementia reduces a person’s stress threshold, thus stress and distress are more easily triggered for those living with dementia. There are multiple dynamic stressors caused by dementia, and individual stress process models have been developed to help understand this process (Pearlin et al., 1990; Judge, Menne & Whitlach, 2010).

According to Pearlin et al’s, Stress Process Model for carers (1990) stressors include; the cognitive status of the PLwD, the challenge of managing the behavioural and psychological symptoms of dementia, the level of dependence of the PLwD on the carer regarding activities of daily living (ADLs), the level of PLwD resistance to carer support regarding ADLs, the loss of intimacy, shared goals and activities with the PLwD, conflict with the wider system regarding the care of the PLwD, economic strains, job and care giving conflicts, the loss of social activities as a result of the caregiving role and the psychological and emotional consequences of this new role.
for the carer’s self-concept. Mediators of these stressors include the support system available to the carer, the carer’s appraisals of the PLwD’s symptoms and the coping skills they can use to manage the practical and affective challenges inherent in caring for someone living with dementia (Pearlin et al., 1990).

According to Judge et al.’s, Stress Process Model for PLwD (2010) stressors include; managing the symptoms of dementia and the emotional and psychological consequences of these symptoms, adjusting to and managing changes in life and relationship roles, and dealing with the impact of this condition on views of the self. Mediators include the PLwD’s personality, life orientation, resilience and formal and informal sources of support (Judge et al., 2010). Theories of caregiving, such as the Social Contextual Model (SCM, Berg et al., 1998) emphasize the interactive influence between partners in social roles, such as caregivers and care receivers in dementia dyads. Although dementia stress process models acknowledge stress within the dyad no models have been developed which consider the specific ways stress interacts and impacts on the caregiver-care recipient relationship and on the experience of living with dementia.

The Binding Ties theory (Townsend & Franks, 1995), the Enrichment Process theory (Cartwright, Archbold, Stewart & Limandri 1994) and the Scaffolding Process theory (Cavanaugh et al., 1989) argue that sharing pleasurable activities (Cartwright, et al., 1994) and providing cognitive support to the PLwD (Cavanaugh et al., 1989) serves to enrich the relationship thus increasing the closeness between the members of the dyad, reducing carer stress and burden and improving the quality of life and wellbeing of both the PLwD and their carer (Townsend & Franks, 1995). Using a dyadic approach is indicated when working with PLwD and their carers and has the potential to provide benefits for both members of the dyad.
Psychosocial interventions and dementia

For many years, psycho-social interventions in dementia care focussed on reducing carer stress and burden through providing carer support. Psychoeducation and skills building, counselling, multi-component interventions (interventions that provide, for example, psycho-education and training in behavioural strategies to manage challenging behaviours) and technology-based interventions have been found to be effective for carers in reducing levels of depression and burden and increasing levels of social support and well-being (Elvish, Lever, Johnstone, Cawley & Keady, 2013; Pusey & Richards, 2001).

Another longstanding approach, often based on principles of behaviour modification, are interventions which intend to bring about changes in the PLwD via the carer. For example, carers have been trained to deliver exercise interventions to the PLwD in the community and these interventions have been effective in increasing activity levels of PLwD and reducing levels of depression (Logsdon, McCurry & Teri, 2005). In contrast to “indirect” interventions, such as the carer focussed ones detailed above, the development, evaluation, widespread uptake and efficacy of Cognitive Stimulation Therapy (CST; Spector et al., 2003) has also served to change perceptions about whether interventions can and should be provided directly to PLwD without family involvement.

Currently recommended psycho-social interventions for PLwD include tailored activities to promote wellbeing, cognitive stimulation, reminiscence therapy, cognitive rehabilitation, occupational therapy interventions, psychological treatments for the behavioural and psychological symptoms of dementia (BPSDs) and a personalised multicomponent sleep management approach, plus psychoeducation and tailored skills training interventions for carers (NICE, N.G. 97, 2018). These
recommended interventions address a range of individual needs for the PLwD and their carer. However, few interventions specifically assess and target the interpersonal needs of the dementia dyad.

Four meta reviews have been conducted that bring together systematic reviews of psychosocial interventions for PLwD and their carers (Abraha et al., 2016; Gilhooly et al., 2016; Laver, Dyer, Whitehead, Clemson & Crotty, 2016; McDermott et al., 2018). They have looked at non-pharmacological interventions to treat behavioural disturbances in dementia (Abraha et al., 2016), considered stress and coping in the context of dementia interventions (Gilhooly et al., 2016), reviewed interventions which aim to delay functional decline in people with dementia (Laver et al., 2016) and provided an evaluation and overview of psychosocial interventions for PLwD (McDermott et al., 2018). These reviews have concluded that the dyad needs to be considered when conducting interventions in this area and that interventions are effective when delivered to the dyad together.

The dyad in dementia; evaluating interpersonal dyadic domains

According to Ablitt et al.’s., (2009), framework for understanding wellbeing and relationships in dementia, the pre-diagnostic relationship determines the form that the caring relationship takes post diagnosis. This form has the potential to either maintain or decrease the quality of the relationship which in turn determines the emotional wellbeing of the dyad and the experience of living with dementia. There are several measures that can be used to assess the quality of the relationship. For example, quantitative measures such as the Miller Social Intimacy Scale (Miller & Lefcourt, 1982), the Caregiver Reciprocity Scale (Carruth, 1996) and the Dyadic Marital Adjustment Scale (Spanier, 1976) can be used to assess changes in intimacy, reciprocity, communication and overall happiness within the marriage and the
Quality of Prior Relationship (Williamson & Schulz, 1990) can be used to assess the pre-diagnostic relationship.

**Research question**

This systematic meta-review and narrative synthesis aims to answer the following research question: What do reviews evaluating dyadic psychosocial interventions reveal about the ways the dyad is positioned in the intervention, the domains assessed and the impact of these interventions on the PLwD, their carer, and the dyadic relationship?

**Method**

The Preferred Reporting Items for Systematic reviews and Meta-Analyses was used in the writing of this review (PRISMA, Liberati et al., 2009; Moher, Liberati, Tetzlaff & Altman, 2009). Although a protocol was not established and the systematic review was not registered before conducting this review the PRISMA checklist was followed (Liberati et al., 2009; Moher et al., 2009, see Appendix A for the PRISMA checklist).

**Eligibility criteria**

For this review the following definitions were used to determine review eligibility.

**Participants:**

- Person living with dementia (PLwD); the person who has received a formal diagnosis of dementia.
- Carers: partners, un-paid carers, adult children, friends.

**Intervention:**

- Psychosocial dyadic intervention: a non-pharmacological facilitated intervention that addresses the interaction between social factors and
symptoms, thoughts, feelings and/or behaviours and which aims to address the needs of both the PLwD and their carer.

**Reviews:**

- Systematic review; a review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant primary research and to extract and analyse data from the studies that are included in the review. (NHW Centre for Reviews and Dissemination, 2001).

Quantitative or qualitative systematic reviews, published in English in peer reviewed journals between 2010 and 2019, which include the evaluation of non-pharmacological, psycho-social community-based interventions that recruit both the PLwD and their carer were included. Reviews were eligible for inclusion if they stated, a priori, a research question pertaining to the evaluation of dyadic psycho-social interventions for PLwD and their carers and included community-based interventions. Individual studies, overviews and meta-reviews, or reviews evaluating only pharmacological or non-community-based non-dyadic interventions were excluded as well as reviews where the research question did not pertain to the evaluation of such interventions.

**Search strategy and review selection**

PsycINFO was used to conduct a database search in January 2019 using the subject heading (MeSH) term “dementia” or “Alzheimer*” in combination with “intervention” or “treatment” and “psychosocial”. Database filters were set such that only peer-reviewed full text articles in English evaluating interventions conducted with human populations were selected. Duplicates were removed and a “review” filter was applied. Reference lists and forward and backward citation searches were
used to identify additional reviews. Finally, recommendations were made by experts on the research team and a search of Google Scholar was conducted. A full text search took place to determine which reviews specifically focussed on the dyad and a final list of eligible reviews was established independently by the author.

Data analysis and synthesis

Review characteristics and overlap analysis

The characteristics of eligible reviews were extracted. Reviews were read to identify whether authors had provided a definition of a dyadic intervention. Table one details the authors, number of studies included, number of dyadic studies included, characteristics of participants, an overview of the dyadic interventions included in the review, an overview of the areas evaluated in the study as they relate to the carer, the PLwD and the dyad, and the level of definition of “dyadic” used in the review.

Individual studies included in these reviews were extracted for the overlap analysis. This analysis was conducted using Pieper, Antoine, Edmund, Neugebauer and Eikermann’s (2014) “Corrected covered area” index. Using this method, a table was created of the dyadic interventions in the included reviews. These were listed in the rows and the reviews were listed in the columns. An entry of “1” in the table indicated that a given source was in a given review and an entry of “0” indicated that a given source was not in a given review. The “Corrected covered area” index formula (see figure one, Pieper et al., 2014) was used to determine the percentage of study overlap between reviews. Scores of 0-5% are interpreted to be of slight overlap, 6-10% moderate overlap, 11-15% high and more than 15% very high (Pieper et al., 2014).
CCA (Corrected covered area) = \frac{N - r}{(r^c) - r}

**Figure 1. Corrected covered area (CCA) index formula.** Where N is the total number of included publications including double counting and where r is the number of individual publications and where c is the number of systematic reviews (Pieper et al., 2014).

**Assessment of the methodological quality of included reviews**

AMSTAR was used to assess the methodological quality of the included reviews to inform the risk of bias assessment within reviews (PRISMA checklist item 19). AMSTAR is an 11-item psychometrically validated measurement tool (Shea et al., 2007; Shea et al., 2009). AMSTAR items are scored as ‘Yes’ (1 point), ‘No’ (0), ‘Can’t Answer’ (0), or ‘Not Applicable’ (0). Methodological quality is judged as ‘high’ (score ≥9), ‘medium’ (score 5–8) or ‘low’ (score≤4) based on the overall score (maximum score 11) (see table two). Discrepancies over AMSTAR scores were resolved by discussion in supervision.

**What do reviews evaluating dyadic psychosocial interventions reveal about the ways the dyad is positioned in the intervention, the domains assessed and the impact of these interventions on the PLwD, their carer, and the dyadic relationship?**

A review of the details of the intervention provided in the original studies included in eligible reviews established the ways in which the intervention positioned the dyad in each session. Individual studies were reviewed to determine whether sessions were delivered to the PLwD alone with the aim of modifying carer behaviour, whether sessions were delivered to the carer alone with the aim of modifying PLwD behaviour, whether sessions were delivered to both the carer and the PLwD at the same time but were conducted separately, whether sessions were delivered to the PLwD and carer at the same time, whether carers were trained to deliver the sessions, and finally whether there was a mix of the above in session
delivery. A table listing the interpersonal outcome measures used by the individual studies included in these systematic reviews is provided (see table three). A narrative synthesis of findings related to the impact of these interventions from the included systematic reviews is provided.

**Results**

**Study Identification**

An initial search of PsycINFO identified 1274 articles. Duplicates were removed (n=808), and a title search was conducted on 466 articles. All individual studies, overviews and meta-reviews, or reviews evaluating only pharmacological or non-community-based interventions were removed (n=426). The screening of the remaining 40 abstracts resulted in the removal of 18 articles which did not evaluate or failed to provide information on the evaluation of the dyadic psycho-social interventions included in the review. A full text search was conducted on 22 reviews and the further 14 reviews which were added as a result of expert recommendations, forward and backwards citations and reference searching. Of these six reviews had as the evaluation of dyadic community-based psycho-social interventions for PLwD and their carers as the focus of their review and met the eligibility criteria for inclusion in this meta-review (see figure two).
Review characteristics

The six reviews evaluating dyadic psycho-social interventions varied in their a priori research focus. Beilsten and Hellström’s review (2017a, 2017, b), attempts to identify what types of interventions have been conducted for couples living with dementia and the objectives and outcome measures of these interventions. Lamotte et al., (2017) reviewed the clinical evidence for dyadic exercise interventions. Laver et al., (2017) conducted a comparison of carer focused and dyadic multi-component
interventions. Moon and Adams (2012) evaluated the effectiveness of dyadic interventions for PLwD and their carers. Rausch et al., (2017) explored what types of psychosocial interventions had been provided for PLwD and their carers together and analysed the effectiveness of these interventions and Van’t Leven et al., (2013) reviewed the effects of dyadic psychosocial interventions for PLwD and their carers in the community.

Two reviews included individual studies that applied a randomised controlled trial design (Laver, Milte, Dyer & Crotty, 2017; Van't Leven, Prick, Groenewoud, Roelofs, de Lange & Pot, 2013). Two reviews included both randomised controlled trials and case-controlled trials (Lamotte, Shah, Lazarov & Corcos, 2016; Rausch, Caljouw & van der Ploeg, 2017). One review included randomised controlled trials and single group studies (Bielsten & Hellström, 2017) and one included experimental and quasi-experimental studies, evaluations of feasibility and acceptability, qualitative studies and case studies (Moon & Adams, 2012). All reviews applied a narrative analysis and synthesis of findings and two reviews supplemented this with a quantitative meta-analysis using a random effects model (Laver et al., 2017; Van’t Leven et al., 2013).

The number of individual studies included in these reviews ranged from five to 23 dyadic studies with participant numbers in these studies ranging from two to 4130 participants. Carers were predominantly female and spouses. Reviews reported that dyads were mixed in nature, being comprised of spouses and parents and children. However, the majority of interventions were conducted with spousal dyads. Table one provides an overview of the characteristics of the systematic reviews included in this meta-review.
Table 1: Review characteristics

<table>
<thead>
<tr>
<th>Review</th>
<th>Dyadic interventions (total interventions)</th>
<th>Participant characteristics</th>
<th>Interventions interpreted as “dyadic” by review authors.</th>
<th>Domains assessed for PLwD, Carer and Dyad</th>
<th>Dyadic definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moon &amp; Adams (2012)</td>
<td>14 (14)</td>
<td>Sample sizes ranged from 2-142 dyads (m=45.08, s.d.=41). Carers were predominantly female, white and spouses. PLwD were in the early stage of dementia living at home.</td>
<td>Counselling (n=4); CST (n=2); Psychoeducation and support groups (n=4); Support group and skills training (n=2); Skills training (n=2).</td>
<td>PLwD: cognition, activities of daily living, quality of life, depression, knowledge. Carer: marital needs, cognition, stress, strain, self-efficacy, quality of life, knowledge, coping, adjustment. Dyad: qualitative evaluation of their experience of the intervention.</td>
<td>UD</td>
</tr>
<tr>
<td>Van't Leven et al., (2013)</td>
<td>23 (23)</td>
<td>Sample size ranged from 30-4130 participants (m=305.49, s.d.=957.22). Mean MMSE scores for PLwD ranged from 11-24 (m=17.72, s.d.= 3.49). No other details regarding</td>
<td>Dementia case management (n=3); sleep intervention (n=1); support group (n=1); multicomponent programmes involving psycho-ed, skills training (communication, stress management,) environmental adaptations, assistive devices, activities and some additionally had talking therapy and exercise components (n=10); carer psycho-ed</td>
<td>PLwD: BPSDs, cognition, mood, activities of daily living, sleep, reducing time to institutionalisation, and quality of life of the person. Carer: mood, burden, competence, and quality of life.</td>
<td>CD</td>
</tr>
<tr>
<td>Study</td>
<td>Participant demographics reported.</td>
<td>Group and PLwD activity group (n=2); exercise intervention with psycho-education and activities (n=1); advice service (n=1); reality orientation therapy and carer psychoeducation (n=1). The details of 3 interventions were not reported.</td>
<td>Dyad: none reported.</td>
<td></td>
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<tr>
<td>Lamotte, Shah, Lazarov &amp; Corcos (2016)</td>
<td>Sample sizes ranged from 32-210 dyads (m=91.33, s.d.=52.35). PLwD (mild to severe) and their carers (72.1% of total sample were female). Other demographics not reported.</td>
<td>Home based dyadic exercise programme (n=3); Group based dyadic exercise programme (n=2).</td>
<td>PLwD: cognition, BPSDs, general health, physical functional performance, activities of daily living. Carer: burden, mood, stress. Dyad: none reported.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bielsten &amp; Hellström (2017) part A and B</td>
<td>Sample sizes ranged from 4-488 dyads (m=70.79, s.d.=109.83). PLwD (mild to moderate dementias of all types) and their carers, 60% of PLwD were male</td>
<td>Couples counselling (n=2); Music therapy (n=4); Skills training (n=2); Exercise (n=2); Cognitive rehabilitation (n=5); One each for Cognitive behavioural therapy (n=1); Cognitive stimulation (n=1); Psychoeducation (n=1); Group reminiscence activities (n=1).</td>
<td>PLwD: cognition, depression, anxiety, quality of life, coping, activities of daily living and neuropsychiatric symptoms. Carer: burden, depression, anxiety, general health, coping, quality of life. Dyad: none reported.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
and 70% of carers were female.


<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Sample Description</th>
<th>Interventions</th>
<th>PLwD</th>
<th>Carer</th>
<th>Dyad</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laver, Milte, Dyer &amp; Crotty (2017)</td>
<td>23 (40)</td>
<td>Sample sizes ranged from 13-330 carers (m=129.65, s.d.=85.42). Mean age = 65 years (s.d. 10.11). Carers were predominantly female. PLwD symptom severity was from mild to severe across studies but most had MMSE scores in the mild to moderate range.</td>
<td>Multi-component skills training for memory loss, ADLs, meaningful shared activities (n=7); Counselling (n=1), BPSD* management (n=6), Dementia case management (n=3); Cognitive rehabilitation with psychoeducation (n=2); Support group (n=2); Cognitive stimulation plus psychoeducation, skills training and BPSD management (n=1) and joint completion of a research advance directive (n=1).</td>
<td>PLwD: activities of daily living, BPSDs. Carer: depression, quality of life, burden, distress. Dyad: none reported.</td>
<td>UD</td>
<td></td>
</tr>
<tr>
<td>Rausch, Caljouw &amp; van der Ploeg (2017)</td>
<td>6 (6)</td>
<td>Sample sizes ranged from 6-360 dyads (mean=73, s.d.=123.68). Most dyads were spouses</td>
<td>Art intervention (n=2). Couples counselling (n=2); Joint reminiscence group (n=1); Tailored activities programme (n=1).</td>
<td>PLwD: cognition, quality of life, depression, anxiety, general health. Carer: burden, depression,</td>
<td>ND</td>
<td></td>
</tr>
</tbody>
</table>
and other dyads were a PLwD and their son or daughter.

Dyad: semi-structured qualitative interviews.

* BPSD = behavioural and psychological symptoms of dementia. ** Definition of dyadic; ND = no definition, UD = unclear definition, CD = clear definition.
Across the six reviews there were 63 unique studies, giving a CCA of 4.44% which implies a slight overlap between the individual studies included in the systematic reviews included in this meta-review (Pieper et al., 2014). See figure three for CCA calculation.

\[
\text{CCA (Corrected covered area)} = \frac{63 - 77}{(63 \times 6) - 63} = 4.44\%
\]

**Figure 3. “Corrected covered area” (CCA) index calculation (Pieper et al., 2014).**

Of the six reviews that met the eligibility criteria of this meta-review the operationalisation of a “dyadic” intervention differed across reviews. Two reviews provide a clear definition of what the authors conceptualised as a “dyadic” intervention in their write up (Beilsten & Hellström, 2017; Van’t Leven et al., 2013). Beilsten and Hellström (2017) defined dyadic interventions as *interventions where the PLwD and their carer jointly participate throughout the intervention*. In contrast, Van’t Leven et al. (2013) defined dyadic interventions as *programmes that involved face-to-face contact between a consistent health care professional and the dyad but where sessions do not have to be held together*. Three reviews referred to the involvement of the dyad in the intervention in their eligibility criteria but provide unclear definitions regarding the dose or intensity of the joint involvement of the dyad. “Applied to both” (Lamotte et al., 2017, p.365), “work with both” (Laver et al., 2017, p.1309), and “should be for both” (Moon & Adams, 2012, p.823) were not defined in any of these reviews. One review (Rausch, Caljouw & van der Ploeg, 2017) described interventions which could be regarded as dyadic, in that it evaluated interventions which involved both members of the dyad and referred to dyads in the review but failed to provide a definition of how they operationalised a dyadic intervention.
Methodological quality of included reviews

The AMSTAR checklist was used to identify the methodological quality of the reviews included in this meta-review and assess the risk of bias within individual reviews (see table two).

Table 2: AMSTAR scores

<table>
<thead>
<tr>
<th>Review</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moon &amp; Adams (2012)</td>
<td>Y</td>
<td>CA</td>
<td>CA</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>5</td>
</tr>
<tr>
<td>Van't Leven et al. (2013)</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>6</td>
</tr>
<tr>
<td>Lamotte et al. (2016)</td>
<td>Y</td>
<td>CA</td>
<td>CA</td>
<td>Y</td>
<td>CA</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>6</td>
</tr>
<tr>
<td>Bielsten &amp; Hellström (2017)</td>
<td>Y</td>
<td>CA</td>
<td>CA</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>3</td>
</tr>
<tr>
<td>Laver et al. (2017)</td>
<td>Y</td>
<td>CA</td>
<td>CA</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>5</td>
</tr>
<tr>
<td>Rausch et al. (2017)</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>5</td>
</tr>
</tbody>
</table>

AMSTAR items are: (1) a priori design; (2) duplicate study selection and data extraction; (3) comprehensive literature search; (4) inclusive publication status; (5) included studies provided; (6) characteristics of included studies provided; (7) quality assessment of studies; (8) study quality used appropriately in formulating conclusions; (9) appropriate methods used to combine studies; (10) publication bias assessed; and (11) sources of support and conflict of interest stated. Scores: C, can’t answer (0 points); N, no (0 points); NA, not applicable (0 points); Y, yes (1 point). (Adapted from McDermott et al., 2018).

The methodological quality of included reviews differed, as evidenced through use of the AMSTAR checklist (Shea et al., 2007; Shea et al., 2009). The majority (n=5) were of medium methodological quality and one (Bielsten & Hellström, 2017) was of low quality (m=5, s.d. 1.10, range 3-6).

All included an a priori design (AMSTAR item one) specifying the research questions to be addressed and the inclusion criteria prior to conducting the review. Documentation of study selection and data extraction varied (AMSTAR item two). Only one review (Van’t Leven et al., 2013) stated there were two researchers independently involved in this process. One review (Rausch et al., 2017) used one data extractor but two people independently assessed the selected papers by full text, discussed differences and reached a consensus regarding study inclusion. The
remaining four reviews failed to provide enough information to answer this question. All reviews conducted electronic searches (AMSTAR item three). The majority (n=5) detailed the search strategy but there was not enough information provided to determine whether they had supplemented their search by searching references, consulting textbooks, specialized registers or experts in the field. Only one review (Lamotte et al., 2016) conducted a search of the grey literature (AMSTAR item four) and none provided a list of excluded studies (AMSTAR item five) making it difficult to determine the level of bias within reviews. All reviews provided tables of the characteristics of the included studies but provided a differential amount of information related to participant demographics or intervention characteristics (AMSTAR item six). Five reviews assessed the scientific quality of the included studies (AMSTAR item seven); and all of these reviews went on to refer to the methodological quality of the included studies when formulating their conclusions (AMSTAR item eight). Appropriate methods were used to combine studies across reviews (AMSTAR item nine). Due to the heterogeneity of the interventions included the majority of authors applied a narrative analysis and synthesis of findings and two reviews supplemented this with a quantitative meta-analysis using a random effects model (Laver et al., 2017; Van’t Leven et al., 2013). No reviews assessed publication bias (AMSTAR item ten) and none of the included reviews included conflict of interest and sources of support for both the review and the included studies (AMSTAR item eleven).
What do reviews evaluating dyadic psychosocial interventions reveal?

The position of the dyad in the intervention

After reviewing the intervention details provided in the individual studies cited in these reviews, I was able to determine the position of the dyad in 95% of cases (n=60).

Fifteen interventions were delivered to both members of the dyad at the same time. Dyadic interventions involved joint problem solving, activity scheduling, future planning, skills building, joint reminiscence, peer support, group singing, joint exercise, couples counselling and viewing and making art together. Four interventions delivered sessions to each member of the dyad separately. Across these interventions the PLwD was variously provided with cognitive stimulation, rehabilitation, and music therapy and the carer was provided with psychoeducation, skills building and support. Six interventions were delivered to the PLwD with support from the carer. These interventions involved the carer supporting the PLwD with; cognitive training, cognitive rehabilitation, cognitive behavioural therapy (CBT) for depression, CBT for anxiety, exercise, the use of supportive technologies and viewing and making art. Five interventions were delivered to the carer alone as a way of skilling up the carer so that they were better able to modify the BPSD or improve PLwD activities of daily living. Four interventions involved training the carer to deliver the intervention. Carers were variously trained to deliver a music intervention, reality orientation therapy and cognitive stimulation. However, most interventions (n=16) positioned the dyad differently throughout the intervention; conducting sessions with both members together and / or separately, utilising the carer to support the PLwD with part of the intervention (either with the carer acting
as co-therapist or co-researcher) and / or training the carer to modify PLwD behaviour.

**The dyadic interventions evaluated**

Notable across reviews was the observation that dyadic interventions are heterogenous in terms of the ways in which they position the dyad, the content, intensity, duration of the intervention, the outcome measures used and the length of follow-up. A minority (9.5%, n=6) of the included studies in these reviews used a structured assessment of interpersonal factors between the dyad (see table three for a summary of these interpersonal measures used).

**Table 3: Structured relational assessments used by studies evaluating dyadic interventions**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Authors</th>
<th>Use in evaluation of dyadic intervention</th>
<th>Psychometric properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Needs Satisfaction Scale</td>
<td>Stinnett, Collins, &amp; Montgomery, 1970</td>
<td>Quayhagen et al., 2000; Quayhagen &amp; Quayhagen, 2001</td>
<td>Designed for use with older adults; Used only with carers</td>
</tr>
<tr>
<td>Family Assessment Measure</td>
<td>Skinner, Steinhauer, &amp; Santa-Barbara, 1983</td>
<td>Logsdon et al., 2010</td>
<td>Good internal reliability in studies with people living with Alzheimer’s disease and their carers</td>
</tr>
<tr>
<td>Mutual Communal Behaviours Scale</td>
<td>Williamson &amp; Schulz, 1995</td>
<td>Baker, Grocke and Pachana (2012)</td>
<td>Used only with carers (not people with dementia)</td>
</tr>
<tr>
<td>Quality of Caregiver Patient Relationship scale</td>
<td>Spruytte, Van Audenhove, Lammertyn &amp; Storms, 2002</td>
<td>Woods et al., (2012)</td>
<td>Used with both carers and people with dementia</td>
</tr>
</tbody>
</table>
Moon and Adams (2012) review argues that dyadic interventions are acceptable and effective. Studies used a wide variety of outcome measures to variously assess psychological wellbeing, coping, knowledge about dementia, relationship quality, and cognitive function. Improvements in the psychological well-being of both partners, improved dyadic relationships, improvements in quality of life, increased knowledge about the disease and improvements in coping skills were observed for both members of the dyad. Improvements in the cognitive function of the PLwD were observed in cognitive stimulation interventions.

Of the dyadic studies included in this review only three assessed the interpersonal relationship using standardised measures, including the marital needs satisfaction scale (MNSS, Stinnett, Collins, & Montgomery, 1970 used in the Quayhagen et al., 2000 and Quayhagen & Quayhagen, 2001 studies) or qualitative semi-structured interviews designed by the study’s authors (Sørensen, Waldorff & Waldemar, 2008). Across these studies the authors report improvements in the quality of the relationship. It is notable that the MNSS, has been designed for use with older adults rather than PLwD and therefore may not be suitable for use with this population. The measure was also only used with carers in both studies (Quayhagen et al., 2000; Quayhagen & Quayhagen, 2001) so it remains to be seen whether the improvements in relationship quality were also experienced by the PLwD.

The authors note that interventions failed to acknowledge the wider social system, that the goals of interventions were often vague (“improving the well-being of dyads”, p. 835, Moon & Adams, 2012), that sample sizes were small for the majority of studies, most applied a quasi-experimental design, and only the randomised controlled trials used psychometrically tested outcomes measures. They
note that this meant comparison of the effectiveness across studies was not possible. In addition, they noted that the time of intervention evaluation was often delayed, and few studies conducted follow-up thus making it difficult to accurately ascertain intervention effectiveness over time.

It was not possible to determine whether these findings were statistically or clinically significant as this was not reported. It was also not possible to determine whether one intervention was more effective than another given the heterogeneity of interventions and outcome measures used.

Van't Leven et al., (2013) conducted a meta-analysis of studies published between 2005 to 2012; however, none of the outcomes were dyadic in nature. The authors report an increase in the number of dyadic interventions showing moderate to good effects when compared to a previous review of dyadic interventions published between 1992 to 2005 (Smits et al., 2007). They found evidence for the effectiveness of communication skills training for the caregiver. However, they note that the relationship between the efficacy of the interventions and their specific treatment components is difficult to determine within multi-component interventions. Interventions that provide skills training to both members of the dyad were found to be more effective than those that just skilled up the carer. Conducting a structured needs assessment at the beginning did not lead to better effects when compared to interventions which tailored needs within sessions.

It was notable that across the studies included in the review only one (Logsdon et al., 2010) assessed the quality of communication in the dyad and the quality of the relationship. The measure used was the communication, affective expression and involvement subscale of the Family Assessment Measure (Skinner, 1983). This measure assesses the level of interpersonal conflict between members of the dyad
and has been shown to have good internal reliability in studies with people living with Alzheimer’s disease and their carers (Logsdon et al., 2010). Significant improvements were observed around communication between the dyad in this study.

The authors note a lack of consistency regarding programme effects when interventions were delivered successively with different samples (Graff et al., 2006; Voigt-Radloff et al., 2011). They hypothesise that this could be due to the tailored nature of the interventions, differences in participant characteristics, differences in the healthcare professionals involved in delivering the intervention and differences in the healthcare systems in which these professionals are operating. However, this was not examined in the review so it is difficult to determine what it was that worked so well in the community based occupational therapy intervention evaluated by Graff et al., (2006) compared to the intervention when it was delivered in a different country (Voigt-Radloff et al., 2011) for example.

Outcomes evaluated by Lamotte et al’s., review of dyadic exercise interventions (2016) were PLwD cognition, the neuropsychiatric and behavioural symptoms of dementia, functional performance and general health and carer burden. No outcomes measures were used which assessed the relationship before or after the intervention. Results were mixed regarding adherence. Cognitive deterioration, as measured by the MMSE, was observed in the PLwD across all interventions; however, this is unsurprising given the nature of the condition. No effects were observed for neuropsychiatric and behavioural symptoms across studies. Functional performance was found to improve across all studies for the PLwD. Carer burden was observed to decrease across the three studies that measured this outcome (Canonici et al., 2012; Lowery et al., 2014; Prick et al., 2015) and no adverse effects for carers were observed in the Prick et al., (2015) study that measured these domains.
This review shows that dyadic exercise interventions are feasible and effective, both as interventions in and of themselves and as part of multi-component programmes, leading to positive results for both members of the dyad in terms of PLwD functional performance and carer burden. Although the authors suggest that the position of the carer in supporting an exercise intervention may have confounded effects no studies examined this variable or examined interpersonal factors, such as communication between the dyad or relationship quality.

Beilsten and Hellström’s (2017a; 2017b) review encompassed couples counselling, music therapy, cognitive behavioural therapy, exercise, skills training, cognitive rehabilitation, cognitive stimulation, psychoeducation and reminiscence. Of the 21 studies included, seven assessed relationship quality. Two of these (Quayhagen et al., 2000; Quayhagen & Quayhagen, 2001) have been reviewed above in the Moon and Adams review (2012). In their evaluation of couples counselling, Auclair, Epstein and Mittleman (2009) provided case examples from a couples counselling intervention and found that this approach enabled couples to take on a non-judgemental, accepting stance with the other which allowed them to “face the future together more optimistically and collaboratively” (p.145, Auclair et al., 2009). Baker, Grocke and Pachana (2012) used the Mutual Communal Behaviours Scale (MCBS, Williamson & Schulz, 1995) with both members of the dyad to assess the effects on the spousal relationship of a music intervention. It is notable that although the MCBS has been found to be a reliable measure for use with cancer populations and their carers it has not been psychometrically tested with dementia dyads. However, the authors also asked carers to complete a diary to assess the impact of the intervention on the relationship and on PLwD communication and conducted a semi-structured interview with both members of the dyad; however, questions
focussed on the feasibility and acceptability of the intervention. There were no significant increases in the quality of the relationship from a quantitative perspective which the authors state was due to the high quality of relationship pre-intervention. However, qualitative analysis of interview and diary data showed enhancements in this domain, with the intervention stimulating shared activities, reminiscence and reciprocity between the dyad (Baker et al., 2012). Judge, Yarry, Looman and Bass (2012) in their skills teaching and strengths-based intervention used the Dyadic Relationship Strain Scale (Bass, Tausig, & Noelker, 1989), which was valid and reliable when psychometrically tested with the sample used in this study. The scale was administered to carers and the intervention was found to have led to statistically significant reductions in dyadic relationship strain. However, given that the measure was only administered to carers it is not possible to determine whether these results were mirrored in the PLwD. Osman, Tischler and Schneider (2016) used a qualitative semi-structured interview in their evaluation of a singing intervention and found that the intervention provided a “meaningful activity that allows communication and connection at a different level” (p.1332, Osman et al., 2016). Woods et al., (2012) used the Quality of Caregiver Patient Relationship scale (QCPR, Spruytte, Van Audenhove, Lammertyn & Storms, 2002), a valid and reliable measure for use with this population, in their assessment of joint reminiscence groups. Results noted significant improvements in the relationship from the perspective of the PLwD but this was not reflected by the carer who experienced significant increases in anxiety and stress.

Beilsten and Hellström (2017a; 2017b argue there is evidence that dyadic interventions lead to positive effects in the cognitive domain for the PLwD, decrease depression for carers, promote the well-being of people with dementia and carers and
benefit the dyadic relationship. However, the results from the Woods et al., (2012) study suggest that some interventions, such as joint reminiscence groups, need to consider carefully the needs of carers to ensure that the intervention does no harm. A follow-up study conducted by Melunsky et al., (2015) noted the following areas need to be considered when conducting such an intervention; respite from the PLwD, carer needs (the intervention needs to ensure that both carer and PLwD needs are attended to) and the provision of sufficient support for the carer regarding the implementation of newly acquired skills.

Laver et al’s., (2017) review compared carer focussed with dyad focussed interventions. Multi-component interventions focussing on the dyad appeared to be beneficial in reducing carer depression and the behavioural and psychological symptoms of dementia (BPSDs) and in improving the activities of daily living for PLwD. However, across the meta-analysis, dyadic interventions were not found to be more effective than carer focussed interventions. Although Laver et al., (2017) did not extract data on relationship quality or any other interpersonal dimension, three of the individual studies within the review included an assessment of relationship quality (Logsdon et al., 2010; Judge et al., 2012; Quayhagen et al., 2000).

Rausch et al (2017) review identified six dyadic interventions; a reminiscence group, a psychoeducation and counselling intervention, an occupational therapy intervention and two arts interventions and narratively synthesised the results of these studies. The tailored activity programme was observed to lead to reduction in BPSDs and increased activity engagement of PLwD and showed a trend toward overall improved quality of life (Gitlin et al., 2008). A slight trend showing reduced carer burden was observed in the art interventions and qualitative evidence showed improvements in the PLwDs engagement and positive effects for carer mood,
confidence, reduced isolation and the value of a shared experience (Eekelaar, Camic & Springham, 2012; Camic, Tischler & Pearman, 2014). Individualised couples counselling was assessed as feasible and acceptable for both members of the dyad. The authors noted that there was a high risk of bias across studies so results need to be interpreted with caution.

Four studies assessed relationship quality (Camic et al., 2013; Eekelaar et al., 2012; Epstein et al., 2007; Auclair et al., 2009). Participants valued and found it beneficial to engage in arts intervention which enabled them to share an experience which went beyond dementia. The value of the counselling intervention (Epstein et al., 2007; Auclair et al., 2009) has been reviewed previously by Bielsten and Hellström (2017a, 2017b) and Moon and Adams, (2012) and the results in this review replicate findings that such an intervention was acceptable and beneficial in improving the dyadic relationship and communication within the dyad.

Discussion

Looking across the six reviews of psychosocial dyadic interventions in dementia there is a lack of conceptual clarity regarding the definition of a dyadic intervention and the measures used to evaluate the interpersonal effects of such interventions. Dyadic interventions are heterogenous in terms of the ways in which they position the dyad, their content, length, duration, outcome measurements used and length of follow-up. This poses considerable challenges when it comes to the systematic evaluation of such approaches within reviews particularly when studies use a variety of standardised and unstandardized outcome measures. It also leads to difficulties in determining which interventions are most effective for which populations.
The conceptualisation of a dyadic intervention

From the literature there is no standardised conceptualisation of a dyadic psycho-social intervention in dementia research. This means that authors conducting reviews of psycho-social interventions in this field apply their own individual understandings. This inevitably has an impact on the ways in which dyadic studies are indexed within psychological databases which then determines the studies selected for inclusion in systematic reviews.

The results of this overview highlight that studies are being missed from such reviews or differentially conceptualised across reviews. In the Laver et al., (2017) review some interventions were regarded as carer focussed interventions but involved ongoing dementia case management with the PLwD so the effects of these interventions cannot be seen in isolation apart from the dyadic framework from which they are operating. Thus, results in this field of work should be interpreted with caution.

The heterogeneity of dyadic interventions; a challenging evaluation

Cognitive interventions (reminiscence, rehabilitation, stimulation, reality orientation), multi-component interventions (dementia case management and care coordination, skills training, education, support, counselling, activity planning, aids and environmental adjustments), arts interventions (singing, art), support groups, sleep, exercise and nutritional programmes, talking therapies (CBT, counselling, life story, psychodynamic) and the joint completion of advanced directives were all conceptualised as dyadic in some form or another. Interventions attempt to target multiple psycho-social domains for both the PLwD and the carer (cognition, quality of life, affect, cost, time to institutionalisation) using a wide range of standardised
and unstandardized assessment measures most of which failed to assess the interpersonal landscape of the dementia dyad highlighted by Ablitt et al., (2009).

Most interventions attempt to meet the differing needs of the dyad by providing interventions which position the dyad in different ways throughout the intervention. Such interventions were noted to provide sessions together, separately, skill up the carer to deliver the intervention and / or modify PLwD behaviour or treat the carer as co-facilitator of the intervention supporting the PLwD with the intervention. The majority of interventions had a multi-component nature involving education, support and skills training to dyads at varying levels of intensity. The intensity and duration differed widely; however, across reviews dyadic interventions were found to be feasible and beneficial for one or both members of the dyad.

**The dyadic relationship**

On the whole the quality of the dyadic relationship was ignored in individual studies and reviews without consideration of its effect on the intervention or the effect of the intervention on the relationship. Although communication, relationship quality, and interpersonal conflict were measured by some studies the majority failed to include any assessments of these domains. In one review such domains were not presented at all despite these results being reported in the individual studies (Laver et al., 2017). This is an important finding given the potential such a variable has to mediate, moderate or confound the effects of interventions (Ablitt et al., 2009).

**Strengths and limitations**

This meta-review highlights the challenges associated with conceptualising, assessing, and treating the dyad in dementia. It notes the ways in which researchers and clinicians working in this field often fail to consider the impact of the relationship on the experience of living with dementia. However, it also highlights
that dyadic interventions are not only possible, but they are also acceptable and effective.

While this review aims to provide a transparent synthesis of findings, conclusions are limited by the search terms used, sources searched, and the eligibility criteria. Additionally, it is difficult to draw firm conclusions regarding the treatment of the dyad and the active mechanisms at work given the heterogenous nature of interventions for PLwD and their supporters and the minimal details relating to the characteristics of the participants and interventions included in these reviews.

**Research implications**

The qualitative evidence provided in these reviews suggests that dyadic interventions speak to the five psychological needs of PLwDs (comfort, attachment, inclusion, occupation and identity, Kitwood, 1997) and serve to enrich the dyadic relationship, in line with Townsend and Franks (1995) Binding Ties theory. Certainly, multi-component interventions have the potential to address the multiple dynamic stressors identified by Pearlin et al’s, Stress Process Model for carers (1990) and Judge, Menne and Whitlach’s Stress Process Model for PLwD (2010). Furthermore, in dyadic interventions using a group approach, changes may be the result of Yalom’s (1985) group processes; the installation of hope, universality of experience, the delivery of information, altruism, the development of socialising techniques and group cohesiveness. Dyadic interventions may be effective because they act on the dyad’s appraisals, reduce stress and burden, and increase coping skills and self-efficacy. Dyadic interventions, which involve modifications to the environment, engagement of either the PLwD or their carer in meaningful, supportive and educational activities, increase the opportunities for positive social contact and reduce the opportunities for stressful experiences. Thus, the distress
experienced by the PLwD and the carer is reduced, in line with Berg et al’s., SCM (1998) and Hall and Buckwalter’s PLST model (1987).

Further research is needed to separate out the specific elements of these interventions to determine what works for whom and when. Studies applying a dyadic framework need to consider the relationship, the way the intervention positions the dyad and the effects of the intervention on the relationship.

Researchers working in this field would benefit from a standardised conceptualisation of dyadic interventions. Bearing in mind the findings from the Woods et al., (2012) evaluation of joint reminiscence groups, that the needs of both members of the dyad need to be addressed, the following definition of a “dyadic intervention” may be of use to future researchers working in this field; *interventions where the PLwD and their carer jointly participate in the intervention and where the majority of sessions are conducted together.* Evaluations across studies would also benefit from the development of dyadic models of stress in dementia and the use of standardised measures of relationship quality.

**Clinical Implications**

This review highlights that “dyadic” interventions are acceptable and effective and clinically indicated. Clinicians would benefit from assessing the relationship before treatment as a way of determining where interventions would be most effective. Interventions that target interpersonal process could be used more widely, such as the couples counselling approach used in the Quayhagen et al’s., (2001) study. Additionally, clinicians could use models, such as Miller et al’s., (2007) model for modifying Interpersonal Psychotherapy (IPT) for PLwD with depression, to develop interventions that specifically target the interpersonal processes at work in the dementia dyad.
Conclusion

Over the last ten years, studies of dyadic interventions have improved in the direct assessment of the experience of the PLwD. However, most have focused on assessing the cognitive, functional and affective aspects of the condition for the PLwD and stress and burden in carers. Few have actively sought to explore the relational aspects of the diagnosis or looked at how this affects dyadic appraisals within the illness. None have considered the position of the dyad in the intervention in terms of its effects on outcomes. Although increasing numbers of interventions seek to use a dyadic approach most continue to treat the dyad as two separate individuals and ignore the relationship in dementia. Across studies there is no agreed definition of what is meant by a “dyadic” psycho-social intervention in dementia or how we go about assessing the interpersonal aspects of such interventions. Given the importance of the dyad in dementia more research needs to be done to standardise the conceptualisation and assessment of such approaches before determining their efficacy.
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Part 2: Empirical Paper

“Who to tell, how and when?”

The qualitative exploration of the experiences of people living with dementia and their supporters attending a newly developed dementia disclosure support programme.
Abstract

Aims: This study details the adaptation of the Honest, Open, Proud programme for a dementia population and was designed to support people living with dementia and their supporters with dementia disclosure decisions. A qualitative analysis of the experiences of attendees of the new developed intervention aimed to explore the impact of the intervention on participants’ views of dementia, dementia disclosure and the intervention itself and provide recommendations for the next stage of intervention development and piloting.

Method: Semi-structured interviews were used to capture the views of participants in the intervention. Observations of the groups were conducted by the author and feedback was sought from group facilitators. A thematic analysis of this data was conducted based on Braun and Clarke’s guidelines (2006).

Results: Four themes were generated: “a cross on my back”; “denial and acceptance”, a “safe space”; and “wanting more” from the group. Participants in this study were poignantly aware of the public stigma that surrounds this diagnosis, and this was found to inform their attitudes towards dementia disclosure. The group not only afforded them a safe space to discuss dementia disclosure but also increased communication within dyads (person living with dementia and supporter). The findings also highlight participants’ unmet needs regarding the wider issue of diagnostic adjustment and support afforded to the dyad post-diagnosis.

Conclusions: Results from this study provide evidence that the diagnosis and disclosure of dementia is a more emotionally nuanced topic than is reflected in current NICE guidelines. This intervention may be suitable for delivery at the time of diagnosis and as part of a broader intervention focussed on helping PLwD and their
supporters adjust to the diagnosis, paying particular attention to the interpersonal needs of these dyads.
Introduction

Dementia is a “syndrome that can be caused by a number of progressive illnesses that affect memory, thinking, behaviour and the ability to perform everyday activities” (Batsch & Mittelman, 2012, p.6). The World Alzheimer’s Association has highlighted the stigma associated with such a diagnosis and addressed ways to overcome this issue (Batsch & Mittelman, 2012). Societal level interventions, such as, high profile and large-scale campaigns like Dementia Friends (2017) and Dementia Friendly Communities (2017), have attempted to reduce the stigma of dementia by raising awareness among the public. Several higher education courses now focus on dementia, indicating rising general interest in and awareness of dementia (Dementia UK, 2016).

National Institute for Health and Care Excellence (NICE) guidelines for the assessment and treatment of people living with dementia (PLwD) in the United Kingdom, which in this paper refers to the person diagnosed with the condition, address the needs of both the PLwD and their chosen supporter (NICE, N.G. 97, 2018). Currently the Department of Health and Social Care (2015) aims for the diagnosis of two thirds of the estimated number of PLwD. PLwD are now routinely told their diagnosis as a way of ensuring timely access to help, services and support in planning for the future and respective information is often delivered with a supporter present. Early diagnosis has the potential to ensure the continued involvement of the PLwD in their own care and is in line with national guidelines recommending person-centred care (NICE, N.G.97, 2018). Such an approach makes community-based psycho-social interventions which involve both the PLwD and their supporter feasible. Interventions have been shown to improve the well-being and quality of life of both members of this dyad (Tam-Tham, Cepoiu-Martin,
Batsch et al., (2012) highlighted the stigma associated with dementia and the central role played by stigma in the experience of the condition. Stigma, according to Link and Phelan (2001), connotes a loss of status and power and results in discrimination and negative stereotyping by others. Referred to as a “spoiled identity” by Goffman (1963), it has far reaching consequences for both the PLwD and their support system (Batsch et al., 2012).

Stigma, operating at all levels of society from the individual to the institutional, can affect a person’s desire to seek a diagnosis, pursue avenues of support post-diagnosis, increase feelings of distress, shame, and burden, lead to a reduced standard of care and limit the inclusion of PLwD and their supporters in society (Burgener, Buckwalter, Perkhounkova & Liu, 2015; Swaffer, 2014). There is evidence to suggest that stigma associated with a dementia diagnosis and fears regarding the negative reactions of others, even in the early stages of the condition, leads PLwD to make concerted efforts to hide their condition from others, resulting in social isolation and a reduced quality of life and well-being (MacKenzie, 2006; Milne, 2010; Reed & Bleuthmann, 2008). Although concealment may be possible early on in the illness and may protect the individual from external stigma (unfair treatment by others), there is evidence to suggest that the effort involved may increase the psychological strain on the individual, their levels of self-stigma, and the risk of stress-related illnesses (Cole, Kemeny, Taylor, Visscher, & Fahey, 1996; Frable, Platt, & Hoey, 1998; Major & Gramzow, 1999; Pachankis, 2007; Smart & Wegner, 1999). Self-stigma, whereby the individual internalises negative attitudes and beliefs related to the stigmatised condition (Link & Phelan, 2001), may be
further amplified for PLwD and their supporters due to widespread ageism (Milne, 2010). Managing the stigma associated with dementia has been identified as one of the highest ranked unmet needs by those living with early stage dementia and their supporters (Reed & Bluethmann, 2008).

Training is given to memory service staff in the UK on how to deliver a diagnosis of dementia. However, neither those with dementia nor their chosen supporter are given advice on whether or how to share their diagnosis with those within their social network. There is evidence to suggest that the disclosure of one’s mental health condition may confer certain advantages in terms of stigma reduction (Corrigan and Rao, 2012) and protection against discrimination (e.g. in the UK via the Equality Act, 2010). Recent research suggests individual-level disclosure support interventions can be effective in addressing the potential negative consequences of mental health stigma and reduce the risk of internalised stigma (Mehta et al., 2015; Yanos et al., 2015). Chaudoir and Fisher’s (2010) disclosure process model (DPM) and Greene et al.’s (2009) disclosure decision-making model (DD-MM) highlight the multiple factors at work in the acts of disclosure or concealment, including the quality of the relationship with the disclosure target, their anticipated response, the long-term impact on the relationship, the discloser’s confidence that they can accurately anticipate the target’s response to their disclosure, the stigma associated with the condition, and the discloser’s skills in negotiating disclosure. Anticipated discrimination features prominently in dementia disclosure decisions (Henderson et al., 2012; Katsuno, 2005). There is evidence to suggest that disclosure can lead to discrimination as well as support (Reavley. Morgan & Jorm, 2017). The wish to elicit kindness and understanding, legitimise symptoms, ward off negative assumptions, challenge stigma and ensure difficulties are taken seriously, are factors
that may encourage disclosure (Beard, 2004; Hedman, Hansebo, Ternestedt, Hellström, & Norberg, 2012; Örulv, 2012).

The “Honest, Open, Proud” (HOP) programme (Corrigan, Kosyluk & Rüsch, 2013) was developed in the United States and is designed to support individuals with lived experience of mental illness with disclosure decisions. It aims to reduce conflict around disclosure decisions and reduce the distress associated with such decisions. Developed in line with models of concealment (Pachankis, 2007), this peer-led group-based programme provides attendees with space to consider and reflect on factors involved in disclosure decisions. Through discursive exercises focussed on weighing up the potential benefits and costs of disclosure, and by providing attendees with an opportunity to share their story with a small group of peers it is hoped that the experience will empower the individual to make informed disclosure decisions. The programme has been shown to reduce decisional conflict along with disclosure and stigma stress-related variables for persons with mental health problems who are considering disclosure in different settings in both Europe and the United States (Corrigan et al., 2013; Mulfinger et al., 2018; Rüsch et al., 2014).

To date no psycho-social interventions have been developed which specifically attempt to target decisional conflict and distress related to dementia disclosure decisions for PLwD and their supporters. Although a direct transfer of the HOP programme is not possible given its length, content and individualist focus, an adaptation has the potential to address this gap in services, enabling both members of the dyad to make informed disclosure decisions that may have a positive impact on help-seeking behaviours and reduce distress in the dyad.
Aims and objectives

The aim of the study was to provide a dyadic psychological intervention which could support disclosure decision-making in people with dementia and their supporters who were fearful of sharing the diagnosis with others. This study had three objectives:

- Adapt the HOP programme (Corrigan, Kosyluk & Rüsch, 2013) for PLwD and their supporters.
- Qualitatively explore the lived experience of attendees who had been invited to attend, “Who to tell, how and when?” (the adapted HOP programme).
- Provide recommendations for the next stage of intervention development.

The research question for the qualitative interviews was framed as: What were the attitudes and experiences of participants who had been invited to the “Who to tell, how and when?” intervention towards dementia, dementia disclosure and the group?

Method

Intervention adaptation

The HOP programme (Corrigan, Kosyluk & Rüsch, 2013) was adapted in line with the Medical Research Council (MRC) guidelines for the development of complex interventions (Craig et al., 2008). MRC guidelines (Craig et al., 2008) state that you should conduct a systematic review to identify the evidence base and relevant theories and models and consult stakeholders when developing such interventions.

Reviewing the evidence base

In line with MRC guidelines (Craig et al., 2008) the results of the systematic review from chapter one of this thesis, a systematic review which looked specifically at decision-making in dementia disclosure (Bhatt, Walton, Stoner, Scior, &
Charlesworth, 2018), a review of the evidence base which informed the introduction to this chapter, along with models of disclosure decision making (Chaudoir & Fisher, 2010; Greene et al., 2009) was used to inform the adaptation.

**Consulting stakeholders: the online public consultation**

Additionally, an online public consultation was conducted by Jemini Bhatt (Bhatt, Scior, Higgs & Charlesworth, 2018). The public consultation aimed to identify the barriers to disclosing a diagnosis of dementia and determine design preferences for a psychological intervention for PLwD and their supporters. Data was collected from 226 respondents; PLwD (n=18), family supporters (n=85), health and social care workers (n=43), members of the public (n=64), researchers (n=13) and other (n=3). ‘Worry that others will view them differently (e.g. less able)’ was identified as the top barrier to disclosing a diagnosis of dementia. In addition, being scared of what might be ahead, worry that others may avoid or exclude them, not wanting to burden or upset others, shame, being unsure of what to say or what language to use, not wanting to use the word dementia, not knowing who to tell and not accepting or denying the diagnosis were identified. The face-to-face delivery of the intervention to a small group of dyads of PLwD and their supporters combined with intervention materials attendees could navigate in their own time was preferred by respondents. Respondents unanimously preferred one session a week for a three-week period with sessions lasting 60 to 90 minutes delivered outside of clinical settings.

**Expert consultation**

Expert consultation was conducted with researchers who had recently developed the Promoting Independence in Dementia intervention (PRIDE), a psycho-social intervention which aims to support the engagement of PLwD in cognitive, social, and
physical activities (Yates, et al., 2019). Informal feedback on the HOP adaptation and creation of the “Who to tell, how and when?” manual prototype was sought and amendments or additions made where necessary and a manual prototype was created by Jemini Bhatt.

Public and Patient Involvement

The manual prototype was then taken to a small group of stakeholders (n=4 carers of PLwD) by two members of the research team; Jemini Bhatt and Dr Georgina Charlesworth. At this meeting the group was asked what they liked and disliked, what they would like removed, what they would like to keep and what they would change about the manual. No formal method of data collection was used during this meeting but minutes of this meeting were taken and a list of recommended changes to the manual was fed back to me in an informal meeting between myself, Jemini Bhatt and Dr Georgina Charlesworth. All recommended alterations were implemented (see appendix b for a copy of the minutes of this meeting, items in bold were recommended alterations that were carried out).

The research team then reviewed subsequent drafts via informal meetings and over email and further alterations were made by the author. This process was repeated until all members of the team were happy for further intervention developments to be informed by the qualitative exploration of attendees’ experiences of a pilot of the intervention (see appendix c for a copy of the prototype participant booklet, appendix d for a copy of the facilitators workbook used). A list of all changes made to the HOP manual is available from the author upon request.
A summary of the HOP manual adaptations

**Intervention target population and location**

A dyadic adaptation to HOP was felt to be appropriate given the well documented effect of dementia on PLwD and their supporters (Braun et al., 2009; Menne, Judge, & Whitlatch, 2009; Moon & Adams, 2012). A group format for the intervention made up of dyads, of PLwD and their supporter and delivery outside of clinical settings was planned in line with the results of the public consultation (Bhatt, Scior, Higgs & Charlesworth, 2018).

**Intervention content**

References to ‘mental illness’ were replaced with dementia relevant information gathered from national guidelines, peer reviewed papers, advice from experts in the field of dementia research and clinicians experienced in working with PLwD and their supporters. Psychoeducation and vignettes were included which aimed to speak to the dyad’s respective dementia disclosure experiences and discursive exercises were designed to facilitate communication between the dyad and within the group around the issue of dementia disclosure. An overview of the content of the “Who to tell, how and when?” programme is provided in table one.

*Table 1: An overview of “Who to tell, how and when?”*

<table>
<thead>
<tr>
<th>Topic</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1: Talking about dementia</strong></td>
<td></td>
</tr>
<tr>
<td>Introduction / overview</td>
<td>Aims of the group and structure of the sessions</td>
</tr>
<tr>
<td>Group guidelines</td>
<td>Group rules</td>
</tr>
<tr>
<td>Talking about dementia; what’s in a name?</td>
<td>Dementia definition, facilitators normalise the difficulties around talking about dementia and the impact of the diagnosis on the dyad. Vignettes from PLwD and their supporters speaking to the varied reactions that can be experienced when receiving the diagnosis.</td>
</tr>
</tbody>
</table>
Discursive exercises:
- What words have you noticed being used instead of dementia?
- What might the diagnosis mean for a person’s sense of “who they are” and their outlook on life?

Why tell others? Information and illustrative vignettes from PLwD and their supporters on pros and cons of disclosing a diagnosis of dementia.
Discursive exercise:
- What advantages or disadvantages to disclosing informed your disclosure decision?

Session summary
Next time

Summary of the session and attendee feedback.
Overview of the content of session two.

2: Who to tell, how and when?

Introduction and session one
summary
Reminders of group aims, rules and structure.
Thoughts or questions from session 1.
Overview of session two content.

Who to tell Range of disclosure positions available to the dyad illustrated by vignettes from PLwD and their supporters.
Discursive exercise:
- What might the consequences be of telling no one to telling everyone?
Network circles exercise – participants identify individuals who might sit in the following categories: want to tell, may want to tell, unsure about telling, must not be told.

How and when to tell Potential disclosure approaches via illustrative vignettes from PLwD’s and their supporters.
Discursive exercise:
- What do you think about the ways in which these people chose to disclose their diagnosis?

How others might react Normalising worries about others’ reactions; variations in reactions.
Exercise:
- Example of a disclosure provided and attendees are asked what might be going on in the mind of the person receiving the disclosure and how this might affect the person doing the disclosing.

Session summary Session summary and attendee feedback.
Between now and next time, an invitation
Attendees invited to think about;
- Who they would tell.
- How and when they would tell them.

Next time Overview of the content of session three.

3: Support for me, for you, for us

Who to tell, how and when; a review Summary of session one and two.

Whose diagnosis is it? Considering multiple others who know the diagnosis. Discursive exercise:
- What reasons do you think others may have for sharing information on diagnosis?

When others do the telling Illustrative vignettes of information sharing. Discursive exercises:
- Who is “allowed” to share the diagnosis?
- How would you deal with differences of opinion with the people that you tell?

Sources of support Signposting to sources of support. Discursive exercise:
- What groups, activities or sources of support would you consider approaching?

Summary Session and programme summary and attendee feedback.

At the end of each section and session, facilitators provided summaries of what had been discussed and gave participants’ an opportunity to ask questions. To accommodate the cognitive capacities of PLwD and the needs of potentially visually impaired older adults all participant materials were formatted in line with DEEP, the UK network of dementia voices, guidelines which aim to support the involvement of people living with dementia (DEEP, 2013). Amendments were made to the size of font in the booklet, the length of the participant booklet and the length of sessions was reduced from two hours to 90 minutes, with a 20-minute refreshment break.
**Intervention delivery**

Unlike HOP, which is peer-led, the dementia adapted sessions were designed to be delivered by facilitators skilled in working with PLwD and their supporters, such as, Admiral nurses, Age UK employees and trained Alzheimer’s Society volunteers. As a result, the research team decided that a facilitator manual was needed which provided guidance regarding how to facilitate the session and included additional prompts and information facilitators could draw on informed by the current evidence base. This was developed by the author and drafts of the facilitator manual were reviewed by the research team. All subsequent amendments were carried out by the author until the research team approved its use with this population. As this was the first time the manual prototype was being delivered to PLwD and their supporters it was decided that the groups would be facilitated by members of the research team with support from a trainee clinical psychologist and an Age UK employee.

**Field observations and facilitators reflections**

During the delivery of these groups I conducted field observations following guidelines provided by Kawulich (2005). I operated out of the observer as participant stance and made it clear to the group that my role would be to collect data on attendees’ experiences of the group and the facilitation of the group. Using this method I aimed to develop a holistic understanding of the experience of the intervention that was as objective and accurate as possible given the limitations of this method. During the session I applied a descriptive un-structured observation process which aimed to capture anything that could inform further intervention development. However, in line with MRC guidelines (Craig et al., 2008) around acceptability and feasibility I also made sure to note down times of arrival, attendance, attendees’ reactions to the topics covered in the manual and the session
tasks, the timing of each task, when conversations went “off topic” and when attendees became highly engaged in the discussion or task.

Additionally, after each session I asked for facilitators reflections regarding how they felt the session went, what went well, what they felt did not go so well and for any suggested changes to the participant workbook or the facilitator manual.

Between the first and the second group I met with Dr Georgina Charlesworth and we discussed these observations and the reflections of the facilitators and came to a consensus regarding the amendments that would be made:

- Dyads found it hard to arrive at the session start time. Participants were therefore invited to attend the sessions 30 minutes before they started to allow for difficulties in getting to the session.

- Dyads found it hard to hold on to the aim of the session; to support PLwD and their supporters in dementia diagnosis disclosure decisions. Often the focussed disclosure related discussions would evolve into discussions about the experience of diagnosis and practical support needs. This had the knock-on effect of preventing the delivery of all session materials due to time constraints. Facilitators were therefore asked to ensure the programme’s aims were clear, summaries of each exercise provided, and advised to sensitively ensure discussions remained focussed on the programme material.

- Observations of the group noted that there was a lack of energy and at times felt like a didactic teaching session. In order to make the sessions more interactive the vignettes relating to the pros and cons of disclosing were printed out and attendees were invited to physically get up and choose ones which fit best with their experience. During the subsequent discursive exercise attendees were asked to talk about any personal pros and cons that
had not been illustrated by the vignettes provided. In session two, during the “how others might react” section, dyads were invited to split up and form two small groups and answer from either the position of the discloser or the position of the person receiving the information.

**Intervention recruitment**

I recruited attendees for the intervention through the Alzheimer’s Society’s Join Dementia Research (JDR) platform (https://www.joindementiaresearch.nihr.ac.uk/). The JDR provides a database which matches volunteers with ethically approved studies. Volunteers enter and update their research profile with relevant personal details and contact preferences and researchers enter in search parameters that fit with the population they are looking to recruit. These parameters are then used to search the database and find potential matches. Researchers are required to complete training on the use of the platform before contacting volunteers.

**Inclusion and exclusion criteria**

The author completed the mandatory training for the JDR platform. In consultation with a member of the JDR team and in line with the inclusion and exclusion criteria for the subsequent qualitative study, the following search parameters were entered onto the JDR platform;

- participants must have a primary diagnosis of dementia
- symptoms must be mild
- they must have a listed carer
- they must live within a five-mile radius of UCL.

Participants were excluded if they did not have capacity to give informed consent, had significant physical or mental health comorbidities requiring care from others,
e.g. suicidal intent or delirium, or experienced sensory impairments which would 
prevent participation and were referred on for support where necessary.

Based on these parameters, 30 JDR volunteers with carers were identified as 
potential participants for the first group. Volunteers were contacted according to the 
preferred method listed on their profile, either via telephone, email or letter. A 
maximum of two attempts were made to contact matched volunteers. Eighteen 
volunteers were contacted directly and 12 through their carer. They were asked 
whether they were worried about disclosing a diagnosis of dementia and, if so, 
whether they would like to attend a three-session group exploring dementia 
disclosure. If volunteers expressed interest, they were sent details of the group via 
email or letter (see appendix e) and given a week before being contacted again to 
determine whether they would like to attend. Of the 30 volunteers contacted, 14 did 
not respond. Of the 16 who responded, four were ineligible due to the dementia 
progression, two did not want to explore the disclosure topic and were not worried 
about disclosing, five cited logistical issues, and two were only interested in taking 
part in drug trials and were not worried about disclosure. As a result, three volunteers 
were eligible and were invited to attend the group with their chosen supporter. All 
those invited took up this invitation and attended at least one session within group 
one.

As the initial list of matched volunteers had been exhausted for group one, the 
geographical parameters were extended to those living within a ten-mile radius of 
UCL for group two. Based on these extended parameters, 37 additional JDR 
volunteers were identified. Of these, 19 were contacted directly and 18 through their 
carer and asked whether they were worried about disclosing a diagnosis of dementia 
and, if so, would they like to attend a three-session group exploring dementia
disclosure. Twenty-three volunteers did not respond. Of the 13 volunteers that responded, two were ineligible due to dementia progression, three did not want to explore dementia disclosure and were not worried about disclosing, two cited psychological issues (one did not feel motivated to attend any groups and the other said they did not have a dementia diagnosis), and one cited physical health problems. As a result, five volunteers were eligible and agreed to attend group two, four with their respective supporters and one on their own.

**Intervention delivery**

Both groups were delivered to seven dyads (n=14) in central London locations by facilitators with experience of working with PLwD and their supporters as part of voluntary sector provision.

**Ethics and governance**

Ethical approval for this study was granted by the University College London (UCL) research ethics committee, reference number 14001/001 (see appendix f for ethics approval).

**Capacity and informed consent**

As dementia affects an individual’s cognitive capacities it was essential that capacity issues were considered during the consent process. In line with the Mental Capacity Act (2005) and following guidance from the British Psychological Society’s code of human ethics (2010), potential participants had to demonstrate that they had the ability to understand the participant information sheet and consent form, remember and use the information to make a decision whether or not to consent and have the ability to communicate their decision. This was established by asking potential participants to communicate in their own words their understanding of the
study, its purpose, the benefits and burdens involved and their decision regarding participation.

**Stress and burden**

Mindful of the potential burden on participants, interviews never exceeded an hour. Participants were informed that they could take a break at any point. Participants were additionally reminded of avenues of support available to them should they wish to discuss difficulties emerging from their participation in the study.

**Data Protection and Confidentiality**

All data were stored in line with the General Data Protection Regulation (2018). Anonymity was maintained by using unique identifiers for participant data. Transcripts, field observations and facilitators’ reflections were anonymised and limited demographics were reported.

**Bias**

Holding in mind the multiple roles the author played in this study and the ways in which this could bias both the conduct and analysis of the qualitative interviews, supervision was used to decide on ways to acknowledge and attenuate this bias. The author did not facilitate either of the groups. However, due to resource limitations, it was not possible for other members of the research team to recruit for or observe the intervention sessions. The author was transparent with research participants about her multiple roles at the beginning of all qualitative interviews and questions related to both positive and negative aspects of the groups formed part of the interview schedule. The author held in mind that this was the context that both participants and the author were operating out of and kept a reflective research diary to reflect on the challenges posed by holding these differing positions.
Qualitative Interviews

Sampling approach used for the qualitative interviews

This study applied a universal sampling approach to capture all individuals who had been invited and were eligible to attend the “Who to tell, how and when?” groups. The broad sampling approach applied here intended to capture the views of both attendees and non-attendees to explore whether willingness to attend the group led to differing perspectives.

Sampling procedure

After attending the third session of “Who to tell, how and when?” the author contacted all those who had been invited to the groups and asked them whether they would like to take part in a semi-structured interview about their experiences of living with dementia and invitation to/experience of the intervention. Two attempts were made to contact potential participants. If they expressed an interest, they were provided with a participant information sheet and consent form (see appendix g and h) and were given a week to read the information before being contacted via their preferred contact method. After a week had passed, they were contacted to establish their interest and eligibility. The author observed both groups and recorded observations electronically. Facilitators provided reflections orally and via email to the author after delivery of each session. All oral information was then stored electronically.

Interview procedure

Once eligibility had been established (see appendix i for eligibility questionnaire), participants were asked to identify a convenient date and time the interview could take place. They were offered the option of conducting the interview either at their home or at a local Age UK office. All participants who took up the
offer chose to complete the interview at their home. The interview was conducted with both members of the dyad present so that supporters could scaffold the recall of the PLwD. Before beginning the interview, the information sheet and consent form were reviewed and participants were given the opportunity to ask further questions about the study before consenting to take part. After giving consent, participants were asked to provide demographic information before beginning the interview (see appendix j).

**Development of the semi-structured interview**

The development of the semi-structured interview followed published guidelines and frameworks (Barker, Pistrang & Elliott, 2015; Kallio, Pietilä, Johnson, & Kangasniemi, 2016). I began by evaluating the appropriateness of the semi-structured interview as a rigorous data collection method. I came to the conclusion after discussion with the experts on the research team that a qualitative approach using a semi-structured interview was the most suitable given the research question and the stage of intervention development. I then used current evidence from the field of dementia disclosure decision making and decision making of hidden stigmatised conditions (Batsch & Mittleman, 2012; Swaffer, 214; Milne, 2010; Reed & Bleuthmann, 2008) to inform and formulate the open-ended questions which aimed to explore participants’ thoughts, feelings and behaviours around dementia, disclosure and their experience of the group. Prompts were provided which could be used to clarify or expand on participants’ experiences and meanings. Due to time constraints it was not possible to pilot the interview guide prior to its use with this population (see appendix k for interview guide).

The interview was conversational in style to create an environment that would enable participants to discuss the full range of their experiences, including critical
reflections of the group. In order to ensure that the voice of both members of the dyad was heard, each question was addressed to each member of the dyad separately; however, the other participant could prompt/explore the question with their partner if required.

**Philosophical stance**

This study adopted a critical realist and social constructionist position where reality and truth arise out of interactions between individuals situated within specific socio-economic and cultural contexts (Ritchie, Lewis, Nicholls, & Ormston, 2013). This position holds central the mutually influential ways in which language, experience, meaning, power, rules, regulations and society operate (Pistrang & Barker, 2010; Willig, 1999). In contrast to positivism, multiple realities and interpretations exist (Ritchie, Lewis, Nicholls, & Ormston, 2013). The socio-economic and cultural context that informs the meanings and experiences of participants, group facilitators and the author is central to the analysis and interpretation of qualitative data.

The author, in this case, is a white British, middle class, generation X woman who has pre-clinical lived experience of caring for a PLwD and of living with a stigmatised invisible condition. The author has worked clinically and conducted research in the NHS with PLwD and people with other stigmatised conditions as part of doctoral training. This was the author’s first use of a qualitative approach to research.

**The process of thematic analysis**

A thematic analysis, based on Braun and Clarke’s guidelines (2006), enabled an in-depth exploration and identification of important themes and sub-themes related to dementia, dementia disclosure and participants’ experiences of the intervention. The
transparent six stage process detailed by Braun and Clarke (2006) also provides a helpful framework to follow when beginning research using a qualitative approach, which was the case for this author.

All interview audio-recordings were transcribed verbatim. Four recordings were transcribed manually and the transcription checked by the author and then checked again by a second researcher on the team. Three recordings were transcribed electronically using Trint software (2019) and the transcriptions were carefully checked by the author to ensure their accuracy.

After all interviews, facilitators’ reflections and field observations had been transcribed the dataset was downloaded to NVivo (QSR International Pty Ltd. Version 12, 2018) for qualitative analysis. A data driven inductive iterative analytical approach was applied. Figure one provides a diagrammatic representation of the process of analysis. After the author familiarised and immersed herself in the data, the data set was annotated with key points and observations (see appendix 1 for an annotated transcript). Annotations and observations from the data set formed the basis from which tentative codes were identified and recorded These codes were linked with direct quotations, in line with Yardley’s (2000) guidelines on credibility checks. Codes were then tentatively arranged into clusters to reflect any shared meanings and experiences and from these codes, themes and sub-themes were identified. This iterative process meant that at each point the author repeatedly reviewed the original transcripts to ensure themes and sub-themes were a good fit. Themes were then organised into two domains: living with dementia and the experience of the intervention. A final set of themes and sub-themes was arrived at which aimed to capture participants’ experiences of living with dementia, dementia disclosure and the experience and impact of the group (see appendix m for a mind
map of the final themes and sub-themes). Primacy was given to the themes and sub-themes arising out of the transcripts which were then triangulated with the field observations and facilitator reflections.
Figure 1. A diagrammatic representation of Braun and Clarke’s six stages of thematic analysis (2006)
Results

Overview

Seven dyads (n=14) attended “Who to tell, how and when?” and chose to take part in the qualitative study. Of the 14 participants, 12 were white British and two were Israeli. Four participants were self-employed (P3,5,6,8), one was employed (P4), and the remainder were retired. Aside from one participant diagnosed with vascular dementia, all other PLwD had been diagnosed with Alzheimer’s (see table two).

Table 2: Participant characteristics

<table>
<thead>
<tr>
<th>Participant no.</th>
<th>Dyad no.</th>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1*</td>
<td>D1</td>
<td>M</td>
<td>Mid 80s</td>
<td>Postgraduate</td>
<td>G1 AS</td>
</tr>
<tr>
<td>P2.</td>
<td>D1</td>
<td>F</td>
<td>Late 70s</td>
<td>Postgraduate</td>
<td>G1 AS</td>
</tr>
<tr>
<td>P3*</td>
<td>D2</td>
<td>F</td>
<td>Early 80s</td>
<td>Graduate</td>
<td>G1 AS</td>
</tr>
<tr>
<td>P4.</td>
<td>D2</td>
<td>F</td>
<td>Early 60s</td>
<td>2ndary school</td>
<td>G1 S2</td>
</tr>
<tr>
<td>P5*</td>
<td>D3</td>
<td>F</td>
<td>Mid 60s</td>
<td>1mary school</td>
<td>G1 S2 &amp; 3</td>
</tr>
<tr>
<td>P6.</td>
<td>D3</td>
<td>M</td>
<td>Early 70s</td>
<td>2ndary school</td>
<td>G1 S2</td>
</tr>
<tr>
<td>P7*</td>
<td>D4</td>
<td>M</td>
<td>Late 70s</td>
<td>Postgraduate</td>
<td>G2 AS</td>
</tr>
<tr>
<td>P8.</td>
<td>D4</td>
<td>F</td>
<td>Early 70s</td>
<td>Postgraduate</td>
<td>G2 AS</td>
</tr>
<tr>
<td>P9*</td>
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<td>M</td>
<td>Early 70s</td>
<td>Graduate</td>
<td>G2 AS</td>
</tr>
<tr>
<td>P10.</td>
<td>D5</td>
<td>F</td>
<td>Late 60s</td>
<td>Graduate</td>
<td>G2 AS</td>
</tr>
<tr>
<td>P11*</td>
<td>D6</td>
<td>F</td>
<td>Mid 60s</td>
<td>Graduate</td>
<td>G2 AS</td>
</tr>
<tr>
<td>P12.</td>
<td>D6</td>
<td>M</td>
<td>Early 70s</td>
<td>Graduate</td>
<td>G2 AS</td>
</tr>
<tr>
<td>P13*</td>
<td>D7</td>
<td>F</td>
<td>Early 70s</td>
<td>2ndary school</td>
<td>G2 S1</td>
</tr>
<tr>
<td>P14.</td>
<td>D7</td>
<td>M</td>
<td>Mid 70s</td>
<td>2ndary school</td>
<td>G2 S1 &amp; 2</td>
</tr>
</tbody>
</table>

Note. Abbreviations: *participant living with dementia; . = supporter; D = dyad; M = male; F = female; 2ndary = secondary; 1mary = primary; G = group; AS = all 3 sessions; S1 = session one; S2 = session two.

The thematic analysis, as noted above, explored the attitudes and experiences of participants who attended “Who to tell, how and when?” towards dementia, dementia disclosure and the intervention itself. Domains, themes and sub-themes
were identified which describe the ways in which participants made meaning out of living with dementia and their experience of the intervention.

Within the domain of “living with dementia” two themes were generated; “a cross on my back” and “denial and acceptance”. Within the domain of “group experience” two further themes were generated; “a safe space”; and “wanting more”. Each theme contained a number of sub-themes (see table three). Themes, sub-themes and endorsement counts are presented in appendix n to provide evidence of face and content validity.

A summary of the themes and sub-themes are illustrated with direct quotations from the interviews. “D” refers to the dyad number, “P” to the participant number, with “*” connoting a PLwD and “.” connoting a supporter. Clarifications by the author are signified by a square bracket and three dots signify words omitted from the quotation.
<table>
<thead>
<tr>
<th>Domains</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with dementia</td>
<td>A cross on your back</td>
<td>The diagnostic experience - stigma vs. relief</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What does dementia look like?</td>
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<td></td>
<td></td>
<td>A constant fight</td>
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<tr>
<td></td>
<td></td>
<td>You get the label carer, new roles and responsibilities</td>
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<td></td>
<td></td>
<td>An uncertain future</td>
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<tr>
<td>Keeping control and</td>
<td>Denial and minimisation</td>
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<tr>
<td>maintaining identity</td>
<td>Keeping it congenial</td>
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<tr>
<td></td>
<td>Playing the glad game</td>
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<tr>
<td></td>
<td>Caution over disclosure</td>
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<tr>
<td>The group experience</td>
<td>Following the rules of disclosure</td>
<td></td>
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<tr>
<td>A safe space</td>
<td>A chance to open up</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Opportunities to hear multiple perspectives</td>
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</tr>
<tr>
<td></td>
<td>A safe and positive disclosure experience</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Space for the dyad to talk</td>
<td></td>
</tr>
<tr>
<td>Wanting more</td>
<td>Too much repetition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A mismatch between the intervention’s aims and participants’ expectations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The challenge of meeting multiple needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wanting time apart from each other</td>
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</tr>
</tbody>
</table>
Theme 1: “A cross on your back”

For the majority of participants, the journey into diagnosis was experienced as shocking and stigmatising. A number of participants reported a loss of self-esteem, confidence and independence. This was not only due to the symptoms of dementia before and after diagnosis but also as a result of the diagnostic experience itself. Beliefs regarding the public’s perception of dementia were also at the forefront of participants’ minds. Even for participants who experienced the diagnostic experience as a relief, there remained a fear for the future.

1:1 The diagnostic experience - stigma vs. relief

Participants across groups provided detailed and unprompted accounts of their diagnostic experience. For some, how the diagnosis was delivered was felt to be very undermining and in poor practice.

“He [the GP] spent the whole time talking to my husband… I was sat at the side of the room and X (husband) was nearer to him than I was. And he turned the computer around to show X my brain scan, I couldn't see it. And then he talked to X about my diagnosis.” D6P11*

For others, the diagnosis was a “relief” (D5P10), providing an explanation for symptoms and acting as a means of getting help and support. For some participants, the diagnosis helped heal a rupture in the relationship between the PLwD and their supporter caused by the symptoms of dementia.

“...A huge relief when we got the diagnosis because he was driving me away with the accusations and saying I’d said this and I’d said that. I found it really difficult, you know, and I would happily have left him because he just, because I wasn't telling the children. Keep protecting them. But it was horrendous that spell. And then we got the diagnosis and I thought thank God for that.” D5P10.
**1:2 What does dementia look like?**

Some participants were vocal about their perceptions of societal stigma associated with dementia. This was notable in the terms participants used when talking about others’ perceptions; “losing your marbles” (D2P4.), “standing in the corner, dribbling at the mouth” (D2P4.), “a cross on your back” (D2P3*), “going mental” (D2P3*), “everyone thinks of dementia as its end stage” (D6P11*). A palpable sense of distress experienced as a result of the contrast between these felt perceptions and participants’ experiences of living well with dementia was noted in the group sessions. From field observations it appeared that participants had internalised these negative perceptions. This was poignantly illustrated by the surprise participants experienced at the first meeting when they were unable to determine who was a PLwD and who was a supporter.

“It was going that first day and sitting in the waiting area waiting for the whole thing [the group] to start. Knowing that there's a group of people sitting there. Some of whom received a diagnosis. Some of whom are carers, be they spouses. And thinking to myself there is no way you can tell looking at people whose you know go[...] the diagnosis. That's sort of instructive in itself.” D5P9*

**1:3 “A constant fight”**

The majority of participants living with dementia noted the negative impact the diagnosis and symptoms had had on their sense of self, likening it to an “attack” which needed to be repelled. Some specifically noted a difficulty in reconciling others’ and their own perceptions of themselves and their abilities.

“I’m in a constant fight because I myself don’t feel I’ve lost all my ability. I can think, I can plan, I can do all sorts of things...My memory is weaker than it was, that is how I feel but I am still myself and the stamp given by the doctor is undermining
that confidence, that feeling. And I have to fight constantly against that undermining.” D2P3*

The disabling and distressing nature of symptoms for some participants reduced their self-confidence and led to a negative shift in their view of self. The painful adjustment from viewing themselves as independent and capable to dependent and “flawed” (D6P11*) is illustrated in the following quote.

“It raises my anxiety level when you suddenly think can I do this?... I can see that that [independence and ability] is becoming flawed and that's difficult to accept... because I'm a very independent person.” D6P11*

1:4 “You get the label carer” - new roles and responsibilities

For supporters, the diagnosis necessitated an adjustment to their identity, from wife, husband or friend to that of carer. This adjustment required harnessing new skills and taking on new responsibilities, notably the protection of the PLwD’s pre-morbid identity in the context of a felt sense of uncertainty and a perceived lack of support from services. Observed across sessions, supporters acted as guardians of the memory of the PLwD and scaffolded recall in the interviews. For some, this shift in the relationship and the new roles they were required to adopt was felt to add another layer of distress to an already distressing situation, as illustrated by D5P10.’s account.

“You know I have to double check everything...I’m all the time feeling I'm watching him, checking in... It must be a pain for him. Knowing that I'm looking over his shoulder to remind him what else to do...You get the label carer on the day and then you get pieces of paper.” D5P10.
1:5 An uncertain future

An ever-present fear of the future was reported by a number of participants. For some, managing the inevitable disease progression brought up questions regarding their future capabilities and what this would mean in terms of their reliance on others for this awareness.

“I'm still wrestling with the idea of how is it going to progress? How do I react to changes? What do I do about those changes, and am I going to be able to detect them? Am I going to have to rely on other people to tell me that you know I am repeating myself much more?” D5P9*

Theme 2: Keeping control and maintaining identity

This theme speaks to the coping strategies employed by dyads as a way of keeping control in the face of dementia. Observed across both groups and reported by participants across interviews, keeping control and maintaining the pre-morbid identity of the PLwD were cited as coping strategies by the majority of participants. Supporters noted the ways in which they managed dementia disclosure was determined predominantly by the PLwD rather than the result of a consensus between both members of the dyad. Such strategies were felt to protect the identity, interests and relationships of the PLwD.

2:1 Denial and minimisation

Participants predominantly minimised the impact of their symptoms. For some, this involved attributing symptoms to normal ageing, for others avoiding using the diagnostic label altogether. Aside from two participants, all others stated that they would use words other than ‘dementia’ when talking about their lived experience of the disease. Across both groups, it was observed that the use of this coping strategy
informed a minimal disclosure approach (close family only). For some, this strategy appeared to complicate the acceptance process.

“In some ways I can’t accept that I have dementia because I have a poor memory for short term things” D2P3*

2:2 Keeping it “congenial”

Across both groups, it was observed that supporters provided the PLwD with a containing environment. This was seen, for example, in the ways in which supporters mirrored the language of the PLwD (“memory problems” D1P2.) or in the way they communicated a sense of containment regarding the challenges posed by the disease.

“Well like all things you grow old, you gotta manage stuff...you don’t go into hair tearing lunacy, you just sort of get on and adapt things round so life is as congenial as possible.” D1P2.

2:3 Playing “the glad game”

A number of participants focussed predominantly on positives and tried to be grateful for what they had in the present moment as well as reflecting positively on past experiences. For some this involved focussing and making the most of the present moment, their strengths and areas of enjoyment. For others it involved comparing dementia to other illnesses that can have a terminal trajectory to hold on to a sense of perspective.

“I play the glad game, it's not cancer, I'm not getting something chopped, something cut out of my body. You know I think of all the things it could be.” D6P11*

2:4 Caution over disclosure

For participants the ways in which they chose to disclose or not disclose the diagnosis enabled them to protect the identity, interests and relationships of the
participant living with dementia. They often chose not to disclose the diagnosis to others because this was felt to protect them from unwanted interference and exploitation by others.

“Coz we got the business going on and things like that, if my brother-in-law knew what was going on he probably wouldn’t sell the property thinking that they’re gonna get out of it you know coz she can’t do it anymore so we can have the shop.” D3P5*

For some participants living with dementia, not disclosing allowed them to hold on to valued aspects of their pre-morbid identity and relationships. This position served to protect them from feared and potentially painful shifts in how others view and interact with them and prevented abandonment and isolation.

“I don't want to start telling everybody I've got this wrong and I’ve got that wrong. I don't want people to say oh that’s alright I’ll help you because I don't want that. I just rather, with most of our friends just be, well, just be as we would.” D7P13*

2:5 Following the rules of disclosure

The disclosure position held by the dyad often served to give participants living with dementia an empowered sense of information control regarding the diagnosis. Aside from one supporter, all other supporters were eager to state that they “abide by the rules” (D6P12.) set by the PLwD, regardless of their own views around disclosure.

“Yeah I abide by the rules so to speak and I think everyone’s got to deal with it in their own way. X [D6P11*] definitely doesn’t want to [tell others], she wants to be seen as she was, and at the moment she can get away with it.” D6P12.
However, it was observed in group sessions that supporters often had a more nuanced and flexible approach to disclosure, with some choosing to disclose outside of the group sessions against the explicit wishes of the PLwD as a way of explaining symptoms. Although this went against the views of the PLwD, a tacit acceptance of such incidents by the PLwD was observed by the author.

**Theme 3: A safe space**

All participants noted the safety of the group environment. This was variously attributed to positive facilitator - participant interactions, the session structure, the materials, the use of discursive and experiential exercises, skilled facilitation, and the non-judgemental, accepting and validating environment established by the group as a whole. Field observations and facilitators’ reflections support this theme of safety, additionally noting the value of a co-created set of ground rules and the skill of the facilitators in providing a containing, supportive and at times fun environment. From this position of safety, participants felt able to experience a safe and positive disclosure experience, hear multiple perspectives, including narratives from their supporter, which informed subtle changes to their disclosure position. Such was the experience of safety and connection, that participants established a new support network that extended beyond the intervention.

**3:1 A chance to open up**

Participants noted the ways in which the non-judgemental, accepting and containing environment allowed them to be themselves and not mask their symptoms in the way that some participants felt they needed to when in the community. Participants reported how this facilitated the exploration of dementia disclosure, a topic often felt to be difficult and sensitive. Having this opportunity to open up was found to be “instructive” and to provide some with a sense of comfort.
“There was a lot of useful discussion. It felt comforting to be part of a group where you could be open about many of the things that you don't discuss with anyone else...It was...fine to actually be...happy about somebody seeing that you had a problem in that environment. So, you had that kind of safety aspect to it.” D6P11*

3:2 Opportunities to hear multiple perspectives

Participants noted the normalising and validating experience of hearing multiple perspectives. Observations from both groups highlighted that participants often had well thought out reasons for not disclosing but had not considered why they might want to disclose; the group provided space to explore these issues. For some, the group sessions subtly changed how they approached disclosure, either with regards to words used, the manner of delivery or around a consideration of what need the disclosure act intended to serve.

“Well you've obviously made me consider it [disclosing]...some people I've started sharing it with that I hadn't in the past, to feel safer and more supported but they were always still people I knew. But they were perhaps people that I didn't see very often.” D6P11*

3:3 A safe and positive disclosure experience

It was observed across groups that participants voluntarily disclosed the diagnosis during the introductions, regardless of their normal disclosure position, without prompting from facilitators and described the experience to be both safe and positive.

“It was something to open up in that group, it felt safe there, it helped.” D7P13*

3:4 Space for the dyad to talk

Participants additionally noted the ways in which the group facilitated communication within the dyad, giving them an opportunity to discuss sensitive
differences in their disclosure positions, as illustrated in this exchange between a participant living with dementia and their supporter below.

“[We] have different views about this [disclosing the dementia diagnosis] and we don’t talk about it, to hear how he feels, we don’t talk about this at home and I got a chance to hear that.” D7P13*

“You wanted to brush it under the carpet whereas I feel you tell people on a need to know basis.” D7P14.

Participants valued the increased transparency the group experience facilitated regarding their respective disclosure positions.

“It did actually make us have a conversation. We don't have many conversations about Alzheimer’s…it did enable us to talk about, did we handle that the right way, should we keep doing it in this way?...This [group] gave [us] an opening.” D5P10.

3:5 A new support network

Participants noted the ways in which the group context enabled them to talk about their feelings of isolation triggered by their experience of living with dementia. Observations and facilitators’ reflections of both groups noted that participants offered comfort and support to each other both within and outside of sessions. In group two, participants voluntarily exchanged personal information at the end of the last session and established a support network that extended beyond the intervention. This participant notes the value of the opportunity the group gave to connect with others.

“It’s quite nice to know that there are a lot more people there suffering from this problem...than you actually think because you do tend to think that you're the only one out there.” D2P4.
Theme 4: Wanting more

The aim of the groups was to provide a reflective space for the dyad to explore dementia disclosure and all participants reported finding the sessions helpful and instructive. However, some noted a discrepancy between the aims of the intervention and their expectations and hopes. A sense of wanting more from the intervention was observed across both groups through the ways in which discussions often moved beyond dementia disclosure despite facilitator efforts. Discussions about the stigma of the diagnostic experience, the methods of diagnosis, treatments, symptom management, and requests for advice regarding wider sources of support were noted. The challenge of meeting the differing needs of each member of the dyad within the sessions was also noted in the ways in which participants evaluated the makeup of the groups, the materials used, content of the sessions, and the ways in which they were facilitated.

4:1 Too much repetition

In line with current guidance (DEEP, 2013), which aims to enable the involvement of people living with dementia, facilitators provided numerous summaries of both the content of the manual and the discursive exercises. Further repetitions were provided to enable the full inclusion of participants who missed sessions. For some participants, the group experience felt repetitive, particularly the discursive exercises and observations across groups and facilitators’ reflections supported this.

“We felt it did rather go in circles quite honestly.” D1P2.

4:2 A mismatch between the intervention’s aims and participants’ expectations

Some participants articulated a hope that the groups would tackle all aspects of
the dementia experience rather than focus on the specific issue of dementia disclosure. Participants variously reported a desire for the group to provide a space where they could discuss and process painful diagnostic experiences, support the dyad’s adjustment to the diagnosis, and provide them with additional skills and practical support to help manage living with dementia. Often discussing disclosure was not high on participants’ list of priorities. The disappointment experienced by some participants at the mismatch between the intervention’s aims and their own hopes is palpably illustrated in this quote.

“It did not really give me any new angle or ammunition about how to make my way in society and circumstances...I was somewhat disappointed because I thought it would give me something new, something that would be more comforting about you know, to take the fact that I have poorer memory not as the hack of dementia but as ok, but you know I can live with it” D2P3*

General support, advice and guidance from facilitators was felt to be of greater value than disclosure discussions. Solutions were paramount in the minds of participants, with many expressing a need for concrete solutions to the problems they faced living with dementia.

“I was thinking more in everyday experiences you know what you struggled with. What solution did you find. Has anyone else got an answer... maybe something...that actually got around a problem.” D6P11*

Some participants suggested that the intervention’s aims and participants’ needs might have been more in line if the group was delivered at the time of diagnosis, when considering disclosure of the diagnosis might be more of a priority and when the approach to disclosure might be more flexible.
“I think the limitation of this is, it would be helpful to be primarily directed at time of diagnosis. I got the impression sitting there that there were people that had the diagnosis probably for longer than I had and had a fixed way of telling others.”

D5P9*

4:3 The challenge of meeting multiple needs

Observations from the groups and participants’ responses noted the challenge of providing a group intervention for dyads of people living with dementia and their supporters. The quote below illustrates the difficulty of pitching the intervention at the right level.

“Precisely because the people present would have different degrees of dementia and different comprehension of what it was all about, that it’s almost impossible…to know exactly how one can pitch the talk in order that everyone is going to come out of it in a sort of comforted way or an understanding way. It’s very difficult because it’s quite a wide range [mild dementia].” D4P7*

For some, the size of the group seemed right but others expressed a desire for a larger group. Across both groups, participants found the content of the intervention understandable and validating. However, views differed in relation to the workbook, the formatting of which some viewed as accessible but others as simplistic and childlike.

“I thought that the participant booklet was a bit, you know big lettering and so on as if it’s tailored for people with visual impairment or something like that…it was a bit childlike, I thought.” D4P8.

4:4 Wanting time apart from each other

Participants across both groups appreciated the inclusion of the dyad in the intervention. However, some felt there would be an added value gained from
incorporating some time apart from each other during the intervention. Participants noted that this could have afforded them an opportunity to talk freely about their respective experiences without hurting the other member of the dyad.

“I thought it would have been beneficial for the carers or husbands to be able to talk amongst themselves independently for a while. For half an hour or have a separate session where they just come alone.” D6P12.

Discussion

This is the first qualitative analysis of the experiences of participants who had been invited to attend the “Who to tell, how and when?” intervention. Results from this study highlight the ways in which participants’ context informed how they managed factors implicated in their dementia disclosure behaviours. Participants in this study were poignantly aware of public stigma that surrounds this diagnosis and were motivated by a desire to maintain their pre-morbid identity in the eyes of others, avoid societal stigma and social exclusion. This desire informed the minimising language both members of the dyad used in the disclosure act, in line with aspects of current disclosure models (Chaudoir & Fisher, 2010; Greene et al., 2009). For participants in this study, the “Who to tell, how and when?” intervention afforded them a safe space to discuss dementia disclosure and to communicate within the dyad regarding views of dementia disclosure. Findings furthermore highlighted participants’ unmet needs regarding the wider issue of diagnostic adjustment and the support afforded to the dyad post diagnosis.

The theme, “a cross on your back”, and the sub-themes, the diagnostic experience - stigma versus relief, and, what does dementia look like, support findings from previous research on dementia stigma regarding the external and internal stigma that PLwD and their supporters experience (Milne, 2010). In line with models of
disclosure (Chaudoir & Fisher, 2010; Greene et al., 2009), the theme of keeping control and maintaining identity appears to speak to the avoidance motivations at work in non-disclosure. Further illustrated by the sub-theme caution over disclosure participants feared being treated or thought of differently by others as a result of their diagnosis. Many responses suggested that they feared being pitied, ignored, avoided or invalidated. Participants did not explicitly state that they had internalised societal stigma and all participants felt that their identity had not been affected by the diagnosis. However, observations of the groups appeared to suggest that stigma had been internalised and acted as a barrier to disclosure.

The safe space afforded by the group appeared to overcome the fears participants held regarding disclosing the diagnosis. All PLwD chose to voluntarily disclose the diagnosis during the introductions. The space furthermore appeared to address the psychological needs of PLwDs identified by Kitwood (1997) of comfort, attachment, inclusion, occupation and identity, and maps onto Yalom’s (1985) research on group processes in the ways in which it served to provide participants with a sense of universality, imparted information, altruism and led to the development of socialising techniques. The experience of the group as a space where individuals felt that they were with like-minded others and where they could share their own perspective without being judged mirrors other group processes identified by the qualitative systematic review of psycho-social interventions for dementia conducted by Dugmore, Orrell and Spector (2015).

The study highlights that disclosure is negotiated within the dyad but primarily determined by the PLwD in the early stages of the diagnosis, as evidenced in the theme “following the rules” of disclosure. For the majority of participants in this study, a fixed approach to disclosure had been explicitly agreed but beneath this was
an implicit acceptance by the PLwD that supporters might well not abide by their agreement. The themes, “denial” and minimisation and keeping it “congenial”, highlight the activities supporters engage in to empower the PLwD around dementia disclosure. Supporters acted not only as guardians of the memory but also of the PLwD’s pre-morbid identity. A desire to talk about and explore the interpersonal aspects of the disclosure of a dementia diagnosis was particularly evident in the themes ‘a chance to open up’, and ‘wanting time apart from each other’. The sub-theme ‘you get the label carer’ emphasised the impact the diagnosis can have on interpersonal dynamics within the dyad, which for some participants involved a repositioning of power within the relationship. This theme served to highlight the psychological tasks the supporter takes on to hold and protect the PLwD pre-morbid identity.

**Strengths and limitations of the study**

**Development of the intervention**

This study was conducted in line with MRC guidelines (Craig et al., 2008) and the development of “Who to tell, how and when?” benefitted from feedback from PLwD, their supporters, experts in the field of dementia research, healthcare professionals, the facilitators of the groups and observations by the author. However, it would have been beneficial to get further feedback from a focus group of PLwD, supporters, experts, healthcare professionals, and volunteers working in this field on the prototype manual and the semi-structured interview guide before it was delivered and used in this study. The results of which could have informed further helpful amendments to the manual and the study materials.
The study design

Given the stage of the development of the intervention field observations, facilitators reflections and a qualitative exploration of participants experiences using a semi-structured interview was the most suitable approach as it enabled me to collect a large amount of in-depth subjective information. The use of a reflective diary throughout this process was beneficial in raising my awareness to any biases I had in the collection of this information.

However, there are limitations and inherent biases in the use of an unstructured approach to field observations and in the collection of facilitators reflections. In the case of the field observations of the groups, the ways in which information was gathered was limited to that which I could practically collect given the pace of the sessions and my focus of attention. For example, my physical position in the room meant that I was not able to observe the facial expressions of all attendees at all times. Furthermore, I may have missed critical information when I was making notes. The decision was made not to audio record the sessions due to the desire to maximise the recruitment of participants to the intervention which required attendees to discuss a potentially highly sensitive topic. However, it may have been beneficial to test this assumption by comparing recruitment rates for an audio-recorded group to one that was not recorded. Furthermore, the limitations and biases of the unstructured observational approach may have been overcome to an extent by the use of idiosyncratic structured forms of observation, as discussed by Morley (2017) in his book on single case methods in clinical psychology, such as counting the number of times attendees mentioned words such as “stigma”, “fear” or distress”, and using an idiosyncratic adherence to the manual measure. Facilitators reflections were often limited to brief notes or emails written down after the session. It may have been
helpful to use a more rigorous form of data collection, such as a semi-structured interview with facilitators to allow for more reflection on the process which may have yielded more information pertinent to intervention development.

The development of the semi-structured interview was strengthened by following the robust framework provided by Kallio, Pietilä, Johnson, and Kangasniemi (2016). Furthermore the dyadic nature of the interview privileged both the voice of PLwD as well as their supporters, and thereby attempts to bring balance to the field of dementia research where historically the views of supporters have been given primacy. The scaffolding provided by supporters at times supported PLwD recall of intervention sessions, this further enabling the voice of the PLwD to be heard. This approach also allowed me the flexibility to follow interesting lines of enquiry and gather large amounts of data on participants’ experiences of the group. However, due to time constraints it was not possible to pilot the semi-structured interview prior to its use with study participants which may have biased findings.

There were limitations to the use of a purely qualitative approach to exploring participants experiences of the group and how this informed future intervention development. This method is not a reliable method when it comes to the identification of the specific effects of the intervention or the ways in which the intervention was achieving these effects. Although quantitative measures of stigma have not been developed or psychometrically tested with this population on reflection I feel the study may have benefitted from the use of interpersonal measures highlighted in chapter one of this thesis. Such measures could have been used before delivery of the intervention, just after delivery of the intervention and one month later to assess any changes in the dyadic relationship. For example, it may have been helpful to supplement the interview with the use of the Dyadic Relationship Strain
Scale (Bass, Tausig & Noelker, 1989) which has been used with this population and found to be reliable and valid (Judge, Yarry, Looman & Bass, 2012) or the Quality of Caregiver Patient Relationship scale (Struyette, Van Audenhove, Lammertvn & Storms, 2002) which has also been used with both carers and PLwD (Woods et al., 2012).

**Recruitment**

A lack of uptake meant that it was only possible to conduct interviews with those who attended the sessions. As a result, it remains to be seen whether eligible non-attendees held different views regarding dementia disclosure and interventions that addresses these issues. Recruiting through JDR also led to a sample whose average educational attainment was high and not representative of the general population. Thus, these results may not generalise to other PLwD and their supporters.

**Analysis**

As the group was only trialled twice it is impossible to determine whether I achieved data saturation. Additionally, participants were interviewed on average two weeks after the group took place and recall of group content was limited. Direct questions regarding the specific aspects of the group experience were often answered with generalised responses. Participants appeared to have recall of the felt sense of the group rather than specifics about the contents. Due to time constraints, it was also not possible to conduct validity checks by asking participants whether the results were reflective of their experiences and views.

**Clinical implications and directions for future research**

Current models of disclosure (Chaudoir & Fisher, 2010; Greene et al., 2009) are designed with individuals in mind and assume that they have autonomy and control
over disclosure of a concealable, stigmatising diagnosis. These models do not address the issues at work when a diagnosis, such as dementia, is held by multiple individuals, or over time may become less concealable. They do not speak to the process issues at work in the dementia dyad where supporters may have to weigh up risks and benefits of disclosing or not disclosing the diagnosis for their loved one despite their loved ones’ disclosure position. Future research should consider the development a dyadic model of disclosure of stigmatised conditions. Furthermore psychometrically tested stigma measured need to be developed for use with this population to determine whether interventions are successful in reducing stigma, a key barrier to disclosure and helpseeking in this population.

The present results also have important implications for the further development and future implementation of the “Who to tell, how and when?” intervention. Intervention developments would benefit from further piloting and feasibility testing using a mixed methods approach and evaluation in a randomised controlled trial where the intervention is delivered around the time of diagnosis when the dyad’s attitude to disclosure may be more flexible. The intervention may benefit from being trialled within the NHS to recruit a more representative sample. Future developments of the programme could also include PLwD and supporters as peer facilitators, in line with the HOP programme (Corrigan, Kosyluk & Rüsch, 2013).

Using a mixed methods approach with semi-structured interviews delivered both to the dyad and the individual in combination with pre, post and follow up idiosyncratic and interpersonal and stigma outcome measures psychometrically tested for reliability and validity with this population may better identify the impact and effect of attendance with a more representative sample in line with MRC guidelines (Craig et al., 2008). Qualitative interviews within such a mixed methods
approach could benefit from exploring further the interpersonal processes at work in
the dyad and the effects of the multiple roles the supporter is required to hold in both
the group but also within the interview process itself.

In conclusion, the results provide evidence that the diagnosis and disclosure of
dementia are more nuanced topics than is reflected in the current NICE guidelines
(NICE, N.G. 97, 2018). PLwD and their supporters may benefit from access to an
intervention such as the one presented here, around the time of diagnosis within a
broader intervention focussed on helping the dyad adjust to the diagnosis, paying
particular attention to the interpersonal needs of these dyads.
References


Dementia UK. (2016). Higher Education Dementia Network and Curriculum for Dementia Education. Retrieved from
https://www.dementiauk.org/for-professionals/hedn-and-curriculum-for-dementia-education


Part 3: Critical Appraisal

Reflections on the experience of developing the “Who to tell, how and when?” intervention and using a qualitative approach
Introduction

This critical appraisal will reflect on the challenges of adapting an intervention for dementia dyads. It will consider the impact holding multiple roles had on both myself and the participants in this study. The study design, recruitment methods used, and administration of study materials will be reviewed, along with an evaluation of the thematic analysis applied. Future implications for research and practice will then be considered.

Adapting “Honest, Open, Proud” (Corrigan, Kosyluk & Rüsch, 2013)

From the outset both I and the research group held in mind the ways in which “Honest, Open, Proud”, HOP, (Corrigan, Kosyluk & Rüsch, 2013) needed to be adapted for a dementia population in terms of its format, content and length. We utilised experts in the field of dementia research, current peer reviewed papers, national dementia guidelines (NICE, N.G. 97, 2018) and the Medical Research Council’s guidelines for the development of complex interventions (Craig et al., 2008). I was not able to attend the York patient and public consultation meeting due to childcare commitments and the information garnered from this meeting was limited to that taken down in the minutes of the meeting. On reflection I feel that intervention development would have benefitted from a more formal method of data collection; for example, by audio-recording this meeting, transcribing the results and using a thematic analysis to identify pertinent changes to be made where bias in interpretation could be more transparently assessed. By trying to make materials accessible to all I wondered whether the materials simplistic format had inadvertently served to feed into stigmatising views of older adulthood and had been received as ageist. Due to time constraints it was not possible to take the final version of the participant booklet or semi-structured interview back to the patient and public
consultation group or pilot the semi-structured interview. Such steps could have picked up on the experience of the intervention materials as patronising and lacking in depth and could have highlighted the need for a more interpersonal focus in the interview prior to their use in this study which could have informed further adaptations and amendments. Observations and reflections by the authors and the facilitators noted that the majority of vignettes included in session one only spoke to the views of PLwD rather than their supporters. I wondered whether I had subconsciously given primacy to the voices of PLwD in the manual as a response to the historical context where the views and experiences of supporters outweigh those of PLwD. On reflection, I wondered whether this aspect of the programme, specifically the section which considers the pros and cons of disclosure, had fallen into the trap of being tokenistically dyadic without truly addressing the interpersonal dynamics at work or the position of the supporter when considering this aspect of dementia disclosure. Furthermore, facilitators reflections were received informally after each session. Future intervention developments may benefit from a more formal evaluation by facilitators, potentially through an appropriately designed brief semi-structured interview delivered after each session.

**Holding multiple roles**

Throughout the major research project I was aware of and used supervision and the research diary to reflect on and manage the challenges posed by holding multiple roles through the research process. I noted that being involved in the adaptation of the intervention meant that I became invested in its outcome and supervision was helpful in designing a semi-structured interview that asked questions that welcomed both positive and negative responses from participants towards the programme. However, due to capacity issues it was not possible to get another member of the
research team to conduct field observations of the group and my presence may have biased participants responses to the interviews. Directly addressing this issue at the start of the interview was one method I used to overcome this issue. From the responses participants gave to questions in the semi-structured interview it appeared to achieve this aim. However, this was not addressed directly in the interview and may be an incorrect assumption.

Although I was aware of the multiple roles that I held in the study I failed to account for the multiple roles played by the supporters. In the intervention supporters were not only there to explore their own dementia disclosure needs but also as informal co-facilitators within the group, facilitating the recall of the PLwD and holding onto the pre-morbid identity of the PLwD throughout the intervention and the interview. PLwD in the study never directly stated that their identity had been affected by the diagnosis in the interview. Supporters supported this position that the PLwD identity had not been affected by the diagnosis despite appearances to the contrary. The effects of these efforts by supporters was not explored in the interview given the distress that this may have caused the PLwD. When reflecting on this I noted how I could have overcome this issue by conducting sections of the interview with each member of the dyad individually as well as together. For the majority of participants in this study a fixed approach to disclosure had been explicitly agreed by the dyad. However, it was also observed that PLwD tacitly accepted that supporters may not abide by these rules. On reflection I noted that the semi-structured interview did not fully explore these multiple roles and future qualitative studies could consider exploring this further.
The study design

A purely qualitative approach was used given the stage of intervention development and the lack of psychometrically tested dyadic dementia disclosure outcome measures. However, on reflection I feel that the study would have benefitted from a mixed-methods approach. Future intervention developments could use valid and reliable interpersonal measures at pre, post and follow-up and design structured idiosyncratic observation methods of the groups to enhance the exploration of group outcomes and lived experiences to address the practical limitations imposed by a sole researcher using an unstructured field observation method which has the potential to miss valuable information.

A universal sampling approach was used as there is no existing framework that considers the various dimensions that influence dementia dyads’ perspectives on diagnosis and dementia disclosure thus ruling out a purposive sampling approach. However, a universal sample was not achieved in this study and no individuals who were eligible and had been invited to attend the group but who chose not to attend took up the invitation to be interviewed. It remains to be seen whether these individuals had differing views not represented by participants who took part in the study. Furthermore, the group only ran twice and therefore the sample available was small. Future evaluations of the next iterations of this intervention could consider using a randomised controlled design within the NHS which could apply the mixed methods approach above to overcome these challenges.

Recruitment methods

Recruitment for the groups was conducted through the Join Dementia Research platform (https://www.joindementiaresearch.nihr.ac.uk/). This platform is for individuals who would like to take part in dementia research. It requires signing up
for and completing a volunteer profile. The platform therefore requires the disclosure of a diagnosis of dementia. The difficulties experienced in recruiting sufficient numbers for the group may have been reflective of the lack of concern this population had regarding dementia disclosure given the disclosure requirements inherent in using the platform. An unexpected additional consequence of recruiting through this platform was that participants average educational attainment far exceeded that of the normal population, with a number of participants holding multiple postgraduate qualifications. It appeared from the results that educational attainment may have impacted on participants’ evaluation of the materials as overly simplistic. Future studies could consider recruiting for the groups in memory services where attendees may be more representative of the population of PLwD and their supporters. Evaluating the impact of the intervention with this population may enable the exploration of the disclosure views of dementia dyads who are unlikely to take up the services afforded by the voluntary sector due to worries regarding any form of disclosure post diagnosis.

**Administration of study materials**

Although I had completed work clinically and felt confident when working with dyads and families of people living with stigmatising conditions this was part of a systemic set-up where I was supported by a reflective team. I did not anticipate the anxiety that I went on to experience when conducting dyadic semi-structured interviews alone as part of a research process without this support system in place. This was partly exacerbated by my attempts to remain neutral when delivering the interview. On reflection, when listening, transcribing and analysing the interviews with participants I noted the ways in which this anxiety, my relative naivete as a qualitative researcher, and managing the multiple roles I held over the course of the
study had affected my abilities to fully explore all the lines of enquiry available to me in the interview. I noted that in early interviews my attempts to administer the interview in as neutral a format as possible led to a rigidity in delivery. This had the unintended consequence that I stuck too rigidly to the interview schedule and pre-planned prompts rather than fully exploring the unique responses of the dyads I was interviewing. As the interviews progressed, I noted that I was able to respond more flexibly to participants’ responses. However, after analysing all the transcripts and triangulating emergent themes with facilitator reflections and my observations I realised that I had failed to fully explore the impact of dementia on the relationship and how or whether this is discussed. Specifically, exploring the psychological tasks the supporter takes on in holding the PLwD identity. I also wondered, when I looked back on the interview process, whether the dyadic structure of the interview inadvertently inhibited the responses of supporters, particularly when responses could run counter to strategies designed to support the PLwD. Future studies examining the views of populations attending this intervention could therefore consider conducting individual and dyadic semi-structured interviews as a way of overcoming these potential barriers.

Participants were interviewed on average two weeks after the group took place and recall of group content was limited. Direct questions related to the impact of the diagnosis on identity and the experience of the group were often answered with generalised responses. Participants appeared to have recall of the felt sense of the group rather than of specific content. It was impossible from this study to conclusively determine whether this was reflective of the facilitation of the intervention or the cognitive capacities of attendees. Measuring adherence to the manual could provide useful information around how the manual is delivered by
facilitators and whether this correlates with session impact. Audio-recording future groups could also capture the generalised discussions which speak to the issues which are difficult to discuss directly in a semi-structured interview format, such as the impact on the dyad of the dementia diagnosis. Future studies could consider conducting outcome measures at multiple time points; before the sessions begin, then at the time of the last session and then again, a month later, to capture whether the intervention has an impact and whether this lasts over time.

The thematic analysis

Given the small sample size achieved in this study it was impossible to determine whether data saturation was achieved in the thematic analysis. Time constraints also meant that it was not possible for respondent validation. These are important limitations when considering the validity of the results of this study, particularly around the issues of sensitivity to context and reliability of findings (Yardley, 2000). On reflection I noted that I had not anticipated the amount of time required to fulfil each of my roles within this research process. Particularly time consuming was the complex adaptation required for this intervention’s development. Another issue was the time needed to recruit participants for the groups. Inevitably this had a knock-on effect on other aspects of the study; specifically, respondent validation.

Future implications for research and practice

The lack of models and research on dyadic dementia disclosure decision making meant that when adapting the HOP programme (Corrigan, Kosyluk & Rüscher, 2013) we were piecing together information from a number of sources focussed on either the PLwD or the carer. The results of this study highlight the need for a model of dementia disclosure designed for dyads. Future research could consider exploring
more fully the psychological tasks the supporter takes on in holding the PLwD identity which may be an important aspect feeding into carer burden. Notable in this study was the ways in which supporters used minimising language around dementia which mirrored that of the PLwD and actively supporter the PLwD’s perspective that their identity had not been affected. Future research could therefore explore the impact this takes on the supporter intrapersonally and interpersonally with the PLwD and the wider social network of which the supporter is a part over time as the condition progresses using a mixed-methods approach.
References


Appendices

Appendix A: PRISMA checklist

<table>
<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist item</th>
<th>Reported on page #</th>
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<tbody>
<tr>
<td>TITLE</td>
<td></td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td>12</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td></td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations, conclusions and implications of key findings.</td>
<td>13 and 14</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td></td>
<td>Rationale: Describe the rationale for the review in the context of what is already known.</td>
<td>15-21</td>
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<tr>
<td></td>
<td></td>
<td>Objectives: Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
<td>21</td>
</tr>
<tr>
<td>METHODS</td>
<td></td>
<td>Protocol and registration: Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eligibility criteria: Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td>22-23</td>
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<td>Information sources: Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td>23</td>
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<tr>
<td></td>
<td></td>
<td>Search: Present full electronic search strategy for at least one database, including any limits used, such that it could be replicated.</td>
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<td>Study selection: State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
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<td>Data collection process: Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>23</td>
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<td>Data items: List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.</td>
<td>23-24</td>
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<td>Risk of bias in individual studies: Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</td>
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<td>Summary measures: State the principal summary measures (e.g., risk ratio, difference in means).</td>
<td>25-26</td>
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<td>Synthesis of results: Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I²) for each meta-analysis.</td>
<td>24-26</td>
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<th>Section/topic</th>
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<th>Checklist item</th>
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<tbody>
<tr>
<td>Risk of bias across studies</td>
<td></td>
<td>Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).</td>
<td>24-26</td>
</tr>
<tr>
<td>Additional analyses</td>
<td></td>
<td>Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.</td>
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</table>

| RESULTS       |   | Study selection: Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | 25-26             |
|               |   | Study characteristics: For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations. | 31-34             |
|               |   | Risk of bias within studies: Present data on risk of bias of each study and, if available, any outcome level assessment. (see Item 12). | 28, 30            |
|               |   | Results of individual studies: For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot. | a) 26-43         |
|               |   | Synthesis of results: Present results of each meta-analysis done, including confidence intervals and measures of consistency. | 36-43             |
|               |   | Risk of bias across studies: Present results of any assessment of risk of bias across studies (see Item 15). | 30                |
|               |   | Additional analyses: Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression) (see Item 16). | -                |

| DISCUSSION    |   | Summary of evidence: Summarize the main findings including the strength of evidence for each main outcome, consider their relevance to key groups (e.g., healthcare providers, users, and policymakers). | 43-45             |
|               |   | Limitations: Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias). | 45-46             |
|               |   | Conclusions: Provide a general interpretation of the results in the context of other evidence, and implications for future research. | 47-48             |

| FUNDING       |   | Funding: Describe sources of funding for the systematic review and other support (e.g., supply of data), role of funders for the systematic review. | -                |


For more information, visit: www.prisma-statement.org
Appendix B: Public and Patient Consultation Meeting Notes: York

Wednesday 30th May 2018

NB: All items in bold were amendments suggested by the group that were made to the manual.

MO: Care homes? Why not recruit from there? Communities and care homes.

Interim time, where clinical disclosure has changed, patients are now told directly about their diagnosis and therefore this has introduced a different type of challenge where a different kind of support is required = this intervention

RC: part of that stigma is that it is a disease but it is managed within the mental health umbrella, I think the disease is disadvantaged by the association with mental health, this is in terms of blame where a person is easily blamed for having a mental health problem. It has transferred to dementia where someone is also to “blame” but in actual fact dementia is more organic

We’ve created a challenge that we now have to find a solution to due to the public attention dementia is getting. As more people talk about it and awareness is raised people now need support to disclose due to this surge in public discourse. Whereas some years ago, secrecy was the thing everything did. And an intervention such as this would have been redundant – ish.

Picture on the front: shows dialogue, communication, consensus = good. Katrina flagged up about the jokey cartoon nature of it but actually the research advisors disagreed that the first place one goes to is not a negative connotation.

Do people want to be named by name when it comes to acknowledgements – Georgina said to email the advisors later so that no one has to decide on the spot. The question would be whether we write individual names of the people that contributed to the development of this manual OR just say research advisory group

Title needs a question mark after - who to tell, how and when.

Include a contents Page

Reduce the number of personal pronouns and try and avoid phrases that would not be relevant to both plwd and supporters.

One of the research advisors asked “What if both members of dyad have dementia?” which can sometimes be the case. This is something to address in the facilitator notes rather than something we need to include in the design of things or when recruiting.

Refer to intervention as a programme and materials as a booklet not workbook.

Participants should be handed relevant sections of the booklet on a session by session basis and it can build from session to session. Rather than the original idea of having one big workbook that people take away and bring back.
If they are a carer they have that “baggage” that would be helpful to take to a programme like this with the person they care for. The idea being that it gives people the space to voice that inner voice. But this is something that the facilitator notes should accommodate.

BIG ISSUE NEEDS TO BE ADDRESSED: there is a lack of consistency (partly my fault) in language throughout the manual. So essentially this is because parts of it have been changed and revised in line with GC and KS comments but I haven’t updated the entire manual based on this. An example being that the contents page doesn’t reflect the actual language used in the session.

Session 1

RC: Dr called it organic memory loss when husband was diagnosed not even dementia

Add another quote to accompany the harsher one (“I couldn’t even say the word”).

Facilitator Notes: Dealing with responses here will be very important and must be done well with whomever is running the group and many people will have lots to say on both ends of the spectrum.

Great that other “names and phrases” for dementia is a discussion point, it is a good idea to get a sense of what other people use

Good to have a pause and think about identity and dementia – “it is a life changing diagnosis to have”

Identity is too abstract – use “outlook” instead and take out the word “identity”.

DO NOT use costs and benefits, “advantages and disadvantages” is better.

Need a foot note for dementia friends, explaining briefly what the initiative’s about.

Vignettes = got a good reaction from the research advisors, capture the situation and issues nicely

Difficult to know when to step in with decision making at first, as a carer

Facilitator notes: section on vocabulary – things like avoid sufferer.

Put the two bullet points at the bottom of page 8 – who was doing the telling and being told within the discussion point bubble.

Take out the table for advantages and disadvantages and just replace with a notes section like previous pages (same style).

Infographic: quotes on decision making would be good here.

In the summary section of session 1, the use of “you” is actually fine because they have sat the session and so referring to them actually makes sense.

Session 2
Like the quotes on varying degrees of telling

Diagram of circles – works well, like the use of the word “unsure about telling” and like the idea that they are circle and not lists or boxes

Tobias quote – good illustration of the ways of telling

Jessica quote – good quote – friend would feel trusted

Like the idea that people are going to pick each other’s brains about how to tell, and how to give that information so the questions beneath the quotes should indeed stay

Facilitator notes – make it clear the lines for notes are optional and it is up to you – this is throughout the programme

Ambiguous reaction (page 16):

- Maybe if the examples were male and female it would be less confusing
- Work not army in that case of gender change
- Meet for coffee or lunch/ football match

GENDER CHANGED, SITUATION CHANGED, TIMING CHANGED

One of the advisors said the example is strange in the sense that you would not tell someone unless they asked you if everything is okay – I partly disagree because the idea is people do want to disclose so this is something up for discussion

We need to incorporate the idea of timing – when to tell someone, you would probably not drop it at a school reunion but more likely to someone you see regularly – I think some of the examples do capture this

The spider diagram for people’s reactions = good, keep

Mentioning “you” in session summaries is completely fine because people would have completed the session by then

Session 2 summaries good, just the general concept of having the summaries was well received particularly because they were not exhaustive

ADD at the end – requests for what to cover in the next session

Facilitator notes – have somewhere written in the notes that facilitators should do finding out for people if they ask after something one session so they can get this info the next session e.g. sign posting if they ask.

Session 3

Good that it is a discussion as points to cover so that people can share their (positive experiences) What worked well? What helped when telling others

Tables previously were taken out, possible do the same for the future advantages and disadvantages as the discussion point with note sections are enough.

Coffee and cake at the end?
Appendix C: “Who to tell, how and when?” Participant workbook

“Who to tell, how and when?”

A HOP Programme

Participant booklet
Programme development

This programme has been adapted from the original Honest, Open, Proud programme written by Pat Corrigan and Jon Larson. It has been developed by Tamatha Ruffell, Jemini Bhatt, Dr Georgina Charlesworth and Dr Katrina Scior at UCL in consultation with the PPI group and the Promoting Independence in Dementia, PRIDE, programme WP2/3.
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**Introduction**

The “Who to tell, how and when?” programme is designed to support people living with dementia\(^1\) who are worried about telling others about the diagnosis.

Throughout the programme you will find quotes from people living with dementia. These have been taken from interviews carried out as part of research studies. Quotes are used to illustrate the different views and experiences that people living with dementia may have and their lived experience. You may relate to some quote more than others. This is to be expected as there is no “one size fits all” for who to tell, how or when to share the diagnosis.

**Overview**

The programme is split into three sessions. Each session is about different aspects of sharing a dementia diagnosis:

Session 1: Talking about dementia  
Session 2: Who, how and when to tell?  
Session 3: Support for me, for you, for us

Each session will include a discussion of the issues we cover. The aim of these discussions is to give you time and space to think about whether or not to share the diagnosis, and to

---

\(^1\) A “person living with dementia” is someone who may have received a diagnosis or someone who is supporting a person with dementia.
consider, how you might do this with family, friends, neighbours or acquaintances.

In this booklet there is a notes section at the end of each session. Please feel free to use this to write down anything that you found helpful in the session.

The course is not designed to give individually tailored advice or legal guidance. For support on how to tell employers, and the issues that may surround this, please contact the organisations listed on the last page.

Guidelines for each session

Please be aware that during sessions attendees may wish to talk about their own personal experiences.

We ask that you:

- Talk about your thoughts and reactions to sessions with others outside the programme if you wish but do not repeat the things you hear from other people. Keep others’ information confidential.

- Be mindful that everyone’s opinion counts

- Respect each other
Session 1: Talking about dementia

Dementia can be difficult to talk about.

For many years, doctors have received training on how to tell a person they have dementia, but this is not the case for people living with dementia. People living with dementia sometimes feel fearful of telling others, not knowing what to say, or how to say it.

This session looks at:

- How dementia is talked about and the effect of receiving the diagnosis
- The advantages and disadvantages of telling or not telling others
Talking about dementia; what’s in a name?

The word ‘dementia’ describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

Many people find it difficult to talk about a diagnosis of dementia.

Part of the difficulty can be around not wishing to use the word, dementia. It is not unusual for people to use other terms rather than dementia.

“I couldn’t even say the word. Since I got my diagnosis I feel as though I don’t know where to turn or who to talk to about it.”

Jim
The effect of a diagnosis

Most forms of dementia do not directly affect a person’s personality\(^2\). However, being given a diagnosis of dementia can affect a person's sense of ‘who they are’ and their ‘outlook’ on life.

“I used to be a confident person but since the diagnosis my confidence has been shaken. Now I find it difficult to talk to people and start discussions. I just don’t feel like the person I used to be”

**Leila**

“I was shocked. Then I thought about all the plans I’d made for my retirement with my wife. I realised it would no longer be possible. Now, much later, I’m enjoying life with my wife but it’s different and sometimes I feel bitter about it.”

**George**

A person’s thoughts and feelings about dementia and the diagnosis may also affect whether they feel able to talk to others.

For some it might feel easier to accept the diagnosis and reach out, like Anisha below.

“I finally had a name for what was happening. It was a bit of a relief. It meant I could finally talk to others and get help with the things I was struggling with”

**Anisha**

\(^2\) If certain frontal areas of the brain, or connections to them, are damaged, this can cause personality change such as disinhibition, or, at the other end of the scale, extreme apathy.
DISCUSSION:

- What words have you noticed being used instead of the word “dementia”?
- What might the diagnosis mean for a person’s sense of “who they are” and their outlook on life?

Why tell others?

There can be advantages and disadvantages to telling or not telling others. Below Samira, Raj and Philip talk about the advantages they have experienced as a result of sharing the diagnosis.

“When I get muddled with change at my local shop, the shopkeeper reaches over to help me. He usually says, “yes that one and that one”, and I say, “thank you very much”. It relaxes me that he knows.”

Samira

“I play golf with the lads regularly. I have told them about my dementia in case I forget something, just to remind them I am not doing it on purpose and I won’t be offended if they remind me. They understand. It means I can carry on doing something I love.”

Raj
"I've told very close friends I have a memory problem so they make allowances and understand."

Philip

Some people do not find it helpful to tell others. Here Sarah and William talk about their experiences of losing friends and not feeling listened to.

"I have lost a couple of friends who do not want to see me anymore. I think that is very hurtful. I am not sure why this is the case. One of them in particular used to be a close friend who I used to see almost every week. It just means that I don’t want to tell other people about it."

Sarah

"After telling my family, I have been feeling that people have put me down. They don’t listen to my opinion. I don’t want other people to think I don’t have anything to say because of the dementia."

William

For some, like Jane and Nicki, it might feel like there are advantages to not sharing a diagnosis.

"I’m not telling anyone because it’s nice just to be part of a group, as a person and not as someone with dementia."

Jane

"I am worried that other people will look at me differently. I don’t want people to exclude me or think that I am a burden to them."

Nicki
However, not telling others might not be so helpful. For Inge it meant that she did not feel able to continue doing the things that she loved.

“I used to have lots of different hobbies that I loved, like knitting and sewing, but now I find it difficult to understand and remember instructions and keep making mistakes. No one offers to help so I’ve just stopped doing these hobbies. I feel really disheartened.”

**Inge**

**DISCUSSION:**

- Having heard about the experiences of others are there any advantages or disadvantages that you identify with?

- Are there any advantages or disadvantages anyone has not considered before?
In this session we talked about:

- The words that are sometimes used instead of the word dementia
- The effect of receiving the diagnosis on sense of self and outlook
- The advantages and disadvantages of sharing and not sharing the diagnosis

Next time

We are going to consider who to tell, how and when, and think about how others might react.
Session 2: Who to tell, how and when?

This session looks at:

- Who to tell?
- How and when to tell?
- How others might react
Who to tell?

There are a range of options available to you from ....

Telling no one       to       Telling everyone

Here is what Malika, Sarah, Atul and Jeremy say about the approach they took.

“I haven’t told anyone... I don’t want anyone else to know right now.”

Malika

“I was having coffee with an old work colleague, a really good friend of mine. We’ve been friends for years and all of a sudden I just came out and said it. I didn’t want to keep it from her.”

Sarah

“If it doesn’t concern them they don’t need to know, that is the policy my wife and I use when deciding who to tell about my dementia. We decided that we would just tell the children and that’s it.”

Atul

“I wanted to show people that you can live with dementia and there’s support out there. So I arranged to go on the local radio to talk about my dementia.”

Jeremy

DISCUSSION: What might the consequences be of telling no one, to telling everyone?
For some telling others may give you access to sources of support. Feeling supported can make a difference for a person’s well-being and help you to live well with dementia. It may be that others already know about the diagnosis.

Take a moment now to note down the people that you have already told or may already know about the diagnosis.

Who have I already told? Who do I think already knows?

Now we are going to spend some time thinking about the people you may want to tell about a diagnosis. We are not going to share this with the group but we will refer to it later on when considering who you want to tell.
Using the circles on the next page start in the middle and work outwards:

- Put the people who you want to tell the most in the centre.
- In the second circle put those people you may want to tell.
- The third circle is for those people in your life you are unsure about.
- The outer area is for those who you may feel must not be told.
Must not be told

Unsure about telling...

May want to tell...

Want to tell...
How and when to tell?

There are different ways that people tell others about a diagnosis of dementia. Here Tobias talks about how he went about it.

“My neighbour is one of the first people I told. My wife passed a few years back and I have grown closer to him recently. We were talking about our health generally and I just said that I am having some memory problems. I didn’t really think about it.”

**Tobias**

**DISCUSSION:** What do you think about how Tobias told his neighbour?

Maria took a different approach. Below she talks about her experience.

“My husband and I decided to tell my friend Jessica together. All three of us have known one another a long time. We told her that we had something important to tell her and invited her over for dinner. Before she came over we talked about what we would say and told her over coffee at the end of the night. I said, Jess, I’ve been forgetting things recently so I went to the Doctor because I was worried. I had some tests and they’ve told me I have Alzheimer’s. I just want you to know just in case I do things I wouldn’t normally do”

**Maria**

**DISCUSSION:** What do you think about how Maria told her friend?
How others might react

Often people living with dementia worry that others might guess. Choosing to tell others can help people feel more in control of the situation than living with the uncertainty of whether others can guess.

Not everyone reacts well to hearing that a friend or relative has dementia but there are many ‘dementia friends’ in all parts of the country. Everyone will react in their own unique way.

Here is an example where Claire tells her friend Geoff about the diagnosis.

Claire and Geoff have known each other for years, they had worked together for many years and saw each other regularly for coffee. One afternoon over coffee Claire decides to tell Geoff about her diagnosis.

---

1 Increasing numbers of people are signing up to be a “Dementia Friend”; https://www.dementiafriends.org.uk/. Being a “Dementia Friend” means finding out more about how dementia affects a person – and then, armed with this understanding, doing small everyday things that help. For example, being patient in a shop queue, or spending time with someone you know who’s living with dementia.
“Geoff, I don’t know whether you’ve noticed anything different about me recently but I went to the doctor and they told me I have dementia”

There was a pause...

**DISCUSSION:** What do you think is going through Geoff’s mind? What do you think is going through Claire’s mind?
Session summary

In this session we have covered:

- Who to tell
- How and when to tell
- How others might react

Something to try

Between now and the next session we invite you to think about:

- Who you would tell; no one, someone, everyone?
- How and when you would tell them; plan it or be spontaneous, face to face, over the phone or in a letter?
- The words that you would use; would you talk about memory problems or dementia?

We will come back to this at the beginning of next week’s session.
Next time

- We will discuss our thoughts from last week’s session on who to tell, how and when.

- Support for me, for you, for us; we will consider the issues that arise when others do the telling and think about how to access the sources of support that are out there.
Session 3: Support for me, for you, for us

A summary so far

- In session one we discussed the language used around dementia and the advantages and disadvantages of telling others.

- In session two we discussed who to tell, how and when. We also thought about the reactions of others.

This session looks at;

- Who to tell, how and when – a discussion of your thoughts from last week’s session

- When others do the telling

- Sources of support
Who to tell, how and when: a review

At the end of the last session we invited you to think about;

- Who you would tell
- How and when you would tell them
- The words that you would use

**DISCUSSION:** Has anyone taken the step of telling someone about the diagnosis? If so, how did this go?
Whose diagnosis is it?

For some of you in this room today the diagnosis may have been delivered to you and your supporter at the same time. Deciding how this information is shared can be challenging.

**DISCUSSION:** What reasons do you think others may have for sharing this information?

When others do the telling

Sometimes people may tell others about the diagnosis. There may be times when you agree with this but other times when you may not.

Below Jacinda talks about her experience.

“I had told a friend who attends the same Church. I thought he would keep the information to himself as I hadn’t wanted anyone else to know. Anyway, when I was at Church one day another parishioner came up to me and said they were so sorry to hear about my diagnosis. I felt really taken aback and I didn’t know what to say.”

_Jacinda_

**DISCUSSION:** Who do you think is “allowed” to share the diagnosis?
Thinking about this issue when telling others can be helpful. There are no right or wrong approaches to this.

Here is just one example of how Anoushka went about it.

“We sat down as a family and talked about who else should know. We all agreed that my family can share the information about the diagnosis with their close friends and our wider family as long as they make sure the people they tell do not tell anyone else. I was happy for this to happen as telling others was really difficult for me.”

Anoushka

**DISCUSSION:** How would you deal with differences of opinion with the people that you tell?
Sources of support

There is wide ranging support available that values and respects people living with dementia and supports them to live well.

**DISCUSSION:** What groups, activities or sources of support have you heard of in your area and who would you consider approaching?

Session summary

**In this session we have considered:**

- Our current thoughts about who to tell, how and when
- When others are doing the telling
- Sources of support
Programme Summary

Over the course of the programme’s 3 sessions we have talked about:

• the diagnosis and the way it can affect lives

• the advantages and disadvantages of telling or not telling others

• who, how and when you might tell others and how they might react

• when others do the telling

• sources of support
What happens now?

This workbook is yours to keep. You can refer to it whenever you wish to.

The next page has important details of organisations who can provide support for those living with dementia and their supporters.

For more information about this research please contact Tamatha Ruffell or Jemini Bhatt at;

Address: 1-19 Torrington Place, University College London, WC1E 7HB

Telephone: 020 7679 8275

Email: tamatha.ruffell.16@ucl.ac.uk or jemini.bhatt@ucl.ac.uk or tamatha.ruffell.16@ucl.ac.uk
Acknowledgements

We are indebted to the original authors, Pat Corrigan and Jon Larson, and other members of the HOP "community" for their support in developing this workbook.
## Where to find support?

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Email/Contact Details</th>
</tr>
</thead>
</table>
| Alzheimer’s Society (local services and information provision) | Email: enquiries@alzheimers.org.uk  
          Telephone: 0300 222 11 22  
          Website: www.alzheimers.org.uk |
| Pathways Through Dementia (legal support and information provision) | Email: swilcox@pathwaysthroughdementia.org  
          Telephone: 0203 405 5940  
          Website: www.pathwaysthroughdementia.org |
| AgeUK (local services and information provision) | Email: contact@ageuk.org.uk.  
          Telephone: 0800 055 6112  
          Website: www.ageuk.org.uk |
| CarePlace (care and community services, information and guidance) | Telephone (The Silver Line): 0800 4 70 80 90  
          Website: www.careplace.org.uk |
Appendix D: Facilitators booklet

“Who to tell, how and when?”

A HOP Programme

Facilitator booklet

Programme development

This programme has been adapted from the original Honest, Open, Proud programme written by Pat Corrigan and Jon Larson. It has been developed by Tamatha Nuttall, Jenni Bhatt, Dr Georgina Charlesworth and Dr Katrina Solar at UCL in consultation with the PPI group and the Promoting Independence in Dementia PRIDE, programme WP23.
Facilitator Booklet

General guidelines for facilitators

Before starting each session ensure you have;

- 2 A3 boards with stands
  - Board 1 = a reality orientation board with the day, date, season, year,
    programme name (“Who to tell, how and when?”) start and end time of
    session, session number and time of breaks.
  - Board 2 = a board with lots of blank A3 paper the facilitators can use to
    write down the outcomes of the discussion.

- lots of A3 paper to put on the boards
- markers
- a large clock
- stickers for name tags
- pens for attendees to use
- chairs for all attendees, have these placed in a circle in the room
- bluetac to display the outcomes of the discussions around the room during the
  session
- refreshments for the break and cups/mugs for the refreshments
- reminder cards for attendees of the next day, date, time, location of the next
  session.

Facilitator notes throughout this booklet are in black. At the end of each
discussion point is a list of possible answers that may arise in the discussion.
These are for your general information to aid facilitation and are not designed
as a check list to follow.

A list of local groups, activities and sources of support available in the area that
you can share with attendees throughout the course but specifically in session 3.

Ensure you keep a register recording attendance and attrition.

Facilitator Booklet

Begin the session by...

- introducing yourself and thank everyone for coming
- provide information relating to toilets, fire exits and break times. Draw
  attendees’ attention to the reality orientation board in the room
- inform all attendees that they can take a break or leave the session at any
  point if needed/as necessary
- invite attendees to write their names on the stickers provided and wear
  these

Now read out the introduction, programme development, overview and
guidelines out loud.
Facilitator Booklet

Introduction

The “Who to tell, how and when?” programme is designed to support people living with dementia who are worried about telling others about the diagnosis.

Throughout the programme you will find quotes from people living with dementia. These have been taken from interviews carried out as part of research studies and are used to illustrate the different views and experiences of people living with dementia may have and their lived experience. You may relate to some quotes more than others. This is to be expected as there is no “no size fits all” for who to tell, how or when to share the diagnosis.

Overview

The programme is split into three sessions. Each session is about different aspects of sharing a dementia diagnosis:

Session 1: Talking about dementia
Session 2: Who, how and when to tell?
Session 3: Support for me, for you, for us

Each session will include a discussion of the issues. The aim of these discussions is to give you time and space to think about whether or not to share the diagnosis, and to consider, how you might do this with family, friends, neighbours or acquaintances.

In this booklet there is a notes section at the end of each session. Please feel free to use this to write down anything that you found helpful in the session.

The course is not designed to give individually tailored advice or legal guidance. For support on how to tell employers, and the issues that may surround this, please contact the organisations listed on the last page.

Guidelines for each session

Please be aware that during sessions attendees may wish to talk about their own personal experiences.

We ask that you:

- Talk about your thoughts and reactions to sessions with others outside the programme if you wish but do not repeat the things you hear from other people. Keep others’ information confidential.

Facilitator Booklet

- Be mindful that everyone’s opinion counts
- Respect each other

FACILITATOR: “Now could each person introduce themselves and say “one thing” they would like to get out of the sessions” Note down these points and return to them at the end of the programme.

“Does anyone have any questions at this point?”. Answer them to the best of your ability. If you are unable to answer an attendee’s question, note it down and let them know that you will look into this and that you will do your best to answer the question at the beginning of the next session.

Now read aloud from the text underneath the title “Session 1: Talking about dementia” through to the discussion after Anisha’s vignette.

Session 1: Talking about dementia

Dementia can be difficult to talk about. For many years, doctors have received training on how to tell a person they have dementia, but this is not the case for people living with dementia. People living with dementia sometimes feel fearful of telling others, not knowing what to say, or how to say it.

This session looks at:

- How dementia is talked about and the effect of receiving the diagnosis
- The advantages and disadvantages of telling or not telling others

Talking about dementia; what’s in a name?

The word ‘dementia’ describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Many people find it difficult to talk about a diagnosis of dementia. Part of the difficulty can be around not wishing to use the word, dementia. It is not unusual for people to use other terms rather than dementia.

“I couldn’t even say the word. Since I got my diagnosis I feel as though I don’t know where to turn or who to talk to about it.”

Jim

1 A “person living with dementia” is someone who may have received a diagnosis or someone who is supporting a person with dementia.
The effect of a diagnosis

Most forms of dementia do not directly affect a person’s personality. However, being given a diagnosis of dementia can affect a person’s sense of who they are and their ‘outlook’ on life.

“I used to be a confident person but since the diagnosis my confidence has been shaken. Now it is difficult to talk to people and start discussions. I just don’t feel like the person I used to be.”

Leila

“I was shocked. Then I thought about all the plans I’d made for my retirement with my wife. I realised it would no longer be possible. Now, much later, I’m enjoying life with my wife but it’s different and sometimes I feel bitter about it.”

George

A person’s thoughts and feelings about dementia and the diagnosis may also affect whether they are able to talk about it. For some it might feel easier to accept the diagnosis and reach out, like Anisha below.

“I finally had a name for what was happening. It was a bit of a relief. It meant I could finally talk to others and get help with the things I was struggling with.”

Anisha

DISCUSSION: Dementia and language, dementia and outlook

FACILITATOR: Throughout the discussion note down attendees’ thoughts.

Q: “What words have you noticed being used instead of the word, dementia?”

A1: many different words are used. Acknowledge the confusion ‘out there’ as to whether dementia is the same or different to specific illnesses such as Alzheimer’s

2 If certain frontal areas of the brain, or connections to them, are damaged, this can cause personality change such as disinhibition, or, at the other end of the scale, extreme apathy.

Facilitator Booklet

Disease, Vascular disease etc. and the euphemisms used, such as, ‘memory problems’ and ‘having senior moments’.

Q: What might the diagnosis mean for a person’s sense of “who they are” and their outlook on life?

A1: there will be a range of emotional responses that may come up: denial, anger, anxiety, shame, fear, depression, despair, suicidal ideation, relief, acceptance.

A2: receiving the diagnosis might mean
- a loss of personal identity/sense of self
- grief and fear for the future loss of the self
- struggle to accept the new identity as a person living with dementia

At the end of this discussion summarise the points raised and read out the key takeaway points below. Bluetac these somewhere where attendees can see them.

KEY TAKEAWAY POINTS:
- lots of different words are used when describing dementia
- people sometimes find it hard to use these words
- a diagnosis can impact a person’s sense of “who they are” and their outlook on life
- everyone will react differently, it is normal to spend time adjusting

Offer 10 minute refreshment break here.

Why tell others?

Facilitator: Now read out the advantages and disadvantages of telling or not telling others.

There can be advantages and disadvantages to telling or not telling others. Below Samira, Raj and Philip talk about the advantages they have experienced as a result of sharing the diagnosis.

“When I get muddled with change at my local shop, the shop keeper reaches over to help me. He usually says, “yes that one and that one”, and I say, “thank you very much”. It relaxes me that he knows.”

Samira
DISCUSSION: Your own advantages and disadvantages, other advantages and disadvantages not considered before

Facilitator: throughout the discussion note down attendees' thoughts.

Q2: Are there any advantages or disadvantages anyone hasn't considered before?

A1: Potential advantages to telling others: “living well with dementia” - accessing support, being able to make informed decisions about your future, emotional processing, taking on valued goals (being a spokes-person).

A2: Potential disadvantages to telling others: loss of friends, stigma, shame, “being seen differently”.

A3: Potential advantages to not telling others, “keeping” your identity, avoid discrimination, loss of friends.

A4: Potential disadvantages to not telling others: social isolation stigma/shame, fear of being “found out”, lots of effort spent on “covering up” the symptoms which could be spent elsewhere.

A5: Potential barriers to telling others (this might come up in the discussion so below are some potential answers):

- thoughts: individual - perception that help is not needed, family discourses (“never washing our linen in public”), socio-cultural discourses (stigma/shame), anxiety based thoughts “my friends will reject me”
- feelings: ambivalence – what help will it do, fears upsetting others, being rejected/treated differently
- behaviours: avoidance of feared outcomes

At the end of this discussion summarise the points raised and read out the key takeaway points below. Bluetac the key takeaway points onto the wall for attendees to see.

KEY TAKEAWAY POINTS:

- there are advantages and disadvantages to telling/not telling others about the diagnosis
- the advantages and disadvantages will be personal
- it is important to spend time thinking them through and deciding what is most helpful for you

It may help to consider barriers to telling others the diagnosis.

Now read session 1 summary.
Session summary

In this session we talked about:

- The words that are sometimes used instead of the word dementia
- The effect of receiving the diagnosis on sense of self and outlook
- The advantages and disadvantages of sharing and not sharing the diagnosis

FACILITATOR: "Does anyone have any questions or comments about today’s session?"

Answer these as best you can. Any questions you are unable to answer note down and tell the attendee you will find out the answer and get back to them in the next session.

End of session feedback:

1. "How has everyone found today’s session in terms of its
   - what we talked about
   - length

2. What have you found most helpful about the session?

3. What would you have liked to have changed?"

Now read out what will happen in next week’s session.

Next time

We are going to consider who to tell, how and when, and think about how others might react.

FACILITATOR: Thank everyone for coming and say goodbye.

Session 2: Who to tell, how and when?

FACILITATOR: Before the session ensure last week’s session summary is visible on a sheet.

Begin the session by...

- introducing yourself and thank everyone for coming again
- provide information relating to toilets, fire exits and break times. Draw attendees’ attention to the reality orientation board in the room
- inform all attendees that they can take a break or leave the session at any point if needed/as necessary
- invite attendees to write their names on the stickers provided and wear these
- “As always we ask that you talk about your thoughts and reactions to sessions with others outside the programme but keep confidential the things you hear from other people. Be mindful that everyone’s opinion counts and respect each other.”

Once attendees have written their names down on the stickers say,

“Last week we talked about the language used around dementia and the advantages and disadvantages of telling others. Has anyone had any thoughts or questions about last week’s session?”

Now read out what this session will look at, who to tell up to the discussion at the end of this section.

This session looks at:

- Who to tell?
- How and when to tell?
- How others might react
Facilitator Booklet

Who to tell?

There are a range of options available to you from ...

Telling no one  to  Telling everyone

Here is what Malika, Sarah, Atul and Jeremy say about the approach they took.

“I haven’t told anyone... I don’t want anyone else to know right now.”

Malika

“I was having coffee with an old work colleague, a really good friend of mine. We’ve been friends for years and all of a sudden I just came out and said it. I didn’t want to keep it from her.”

Sarah

“If it doesn’t concern them they don’t need to know, that is the policy my wife and I use when deciding who to tell about my dementia. We decided we would just tell the children and that’s it.”

Atul

“I wanted to show people that you can live with dementia and there’s support out there. So I arranged to go on the local radio to talk about my dementia.”

Jeremy

DISCUSSION: The consequences of telling no one, to telling everyone

Facilitator: throughout the discussion note down attendees’ thoughts.

Q: “What might the consequences be of telling no one to telling everyone?”

Keep in mind the link between attendees’ points and what they know, what’s important to them and who supports them. Encourage attendees to explore what changes to life the person may have to make depending on where they sit on the disclosure range e.g. avoidance of activities/people.

Facilitator Booklet

A1: telling no one may mean that the person feels they are protecting their identity but it may mean the person has to make extensive changes to their lives avoiding situations or persons.

A2: a lot of energy might be spent on “hiding” the symptoms. It may also be hard to access support and “live well with dementia”.

A3: telling some TRUSTED people may mean you get access to support and can continue to “live well with dementia”.

A4: telling everyone may mean that you become a spokesperson and develop a new valued empowered identity where you “live well with dementia” and provide others with hope and support.

At the end of this discussion summarise the points raised. Now read out the key takeaway points below. Bluetac the key takeaway points where attendees can see them.

KEY TAKEAWAY POINTS

- Consequences are personal
- Telling no one may seem “safe” but it may also be exhausting, there may be “hidden” consequences.

Now read about support systems and instructions for the network circles exercise. Give attendees approximately 10 minutes to complete the exercise.

For some telling others may give you access to sources of support. Feeling supported can make a difference for a person’s well-being and help you to live well with dementia. It may be that others already know about the diagnosis. Take a moment now to note down the people that you have already told or who may already know about your dementia:

Who have I already told? Who do I think already knows?

Now we would like you to spend time thinking about the people you may want to tell about a diagnosis. We are not going to share this with the group but we will refer to it later on when considering who you want to tell.

Using the circles on the next page start in the middle and work outwards:

- Put the people who you want to tell the most in the centre.
- In the second circle put those people you may want to tell.
- The third circle is for those people in your life you are unsure about.
- The outer area is for those who you may feel must not be told.
FACILITATOR: “How did you find completing that exercise? Please feel free to edit the circles as we progress through these sessions and beyond if this is helpful.”

Offer 10 minute refreshment break here.

Now read out the “How and when to tell?” section with Tobias’ vignette.

How and when to tell?

There are different ways that people tell others about a diagnosis of dementia. Here Tobias talks about how he went about it.

“My neighbour is one of the first people I told. My wife passed a few years back and I have grown closer to him recently. We were talking about our health generally and I just said that I am having some memory problems. I didn’t really think about it.”

Tobias

DISCUSSION: How Tobias told his neighbour

FACILITATOR: throughout the discussion note down attendees’ thoughts.

Q: “What do you think about how Tobias told his neighbour?”

A1: It was unplanned but in the context of a chat about health in general so this could be seen as an appropriate time to bring it up, “spotting opportunities to tell”.

A2: It was to a neighbour Tobias was close to so potentially someone trustworthy and who could be of some support in the future.

Now read out Maria’s vignette.

Maria took a different approach. Below she talks about her experience.

“My husband and I decided to tell my friend Jessica together. All three of us have known each other a long time. We told her that we had something important to tell her and invited her over for dinner. Before she came over we talked about what we would say and told her over coffee at the end of the night. I said, ‘Jess, I’ve been forgetting things recently so I went to the Doctor because I was worried. I had some tests and they’ve told me I have Alzheimer’s’. I just want you to know just in case I do things I wouldn’t normally do”

Maria
DISCUSSION: How Maria told her friend

Q: What do you think about how Maria told her friend?
A1: A “safer” approach? Thought about and planned. Maria told a trusted friend so reduced the risks and used it as a way of giving her friend an explanation for her symptoms. May address her need to “live well WITH dementia”.

At the end of this discussion summarise the points raised and read out the key takeaway points. Bhutan the key takeaway points where attendees can see them.

KEY TAKEAWAY POINTS:
- Who and how people tell others about their diagnosis will depend on their knowledge, values, needs and support system which are constantly changing.
- The method and timing that people do this will be based on what they feel most comfortable with. There is no right or wrong. You can do this spontaneously or plan it. You could write a letter, or an email, talk on the telephone or face to face.

Now read the section below, including “how others might react” and stop at the discussion points related to Claire and Geoff’s vignette.

How others might react

Often people living with dementia worry that others might guess. Choosing to tell others can help people feel more in control of the situation than living with the uncertainty of whether others can guess.

Not everyone reacts well to hearing that a friend or relative has dementia but there are also many “dementia friends” in all parts of the country. Everyone will react in their own unique way. Below is an example where Claire is telling her friend Geoff.

1 Increasing numbers of people are signing up to be a “Dementia Friend”; https://www.dementiaphriends.org.uk/. Being a “Dementia Friend” means finding out more about how dementia affects a person – and then, armed with this understanding, doing small everyday things that help. For example, being patient in a shop queue, or spending time with someone you know who’s living with dementia.

DISCUSSION: The reactions of others, the Claire and Geoff vignette

FACILITATOR: throughout the discussion note down attendees’ thoughts.
Q1: “What do you think is going through Geoff’s mind”
A1: How awful for Claire, I want to be supportive, let me think about the best way to express my concern, sympathy and support. Maybe I can offer her help if it feels appropriate.
A2: That’s taken me by surprise, I’m not sure quite how to respond. I’m going to need to think for a moment.
A3: I thought something was up. It’s reminded me of my other friend’s experience of living with dementia. Now let me think what they found helpful, maybe Claire might want to know.
A4: Oh no, I feel really awkward. I don’t know what to say.
Q2: “What do you think is going through Claire’s mind”
A1: Worries related to negative reactions: “he’s not going to want to be my friend anymore”, “he’s only going to see they dementia”, “he’s going to treat me differently now”, “oh no I’ve upset him.”
A2: Thoughts that the pause might indicate a positive and supportive reaction from Geoff, "maybe he's taking some time to process what I've just told him and is thinking about what to say, that's really sensitive and supportive".

At the end of this discussion summarise the points raised and read out the key takeaway points. Bluetac the key takeaway points where attendees can see them.

**KEY TAKEAWAY POINTS:**
- There is no way we can know somebody else's thoughts or opinions unless we ask.
- Often the fear of what might happen is much worse than what actually happens.
- There are many ways that people can react and a lot of them are supportive.

Now read the session summary.

**Session summary**

In this session we have covered:
- Who to tell
- How and when to tell
- How others might react

FACILITATOR: “Does anyone have any questions or comments about today's session?”

Answer these as best you can. Any questions you are unable to answer note down and tell the attendee you will find out the answer and get back to them in the next session. **Now read out “something to try”**

**Something to try**

Between now and the next session we invite you to think about:
- Who you would tell; no one, someone, everyone?
- How and when you would tell them; plan it or be spontaneous, face to face, over the phone or in a letter?
- The words that you would use; would you talk about memory problems or dementia?

We will come back to this at the beginning of next week's session.

FACILITATOR: Now ask attendees for their end of session feedback.

1. How has everyone found today's session in terms of its
   - what we talked about
   - length
2. What have you found most helpful about the session?
3. What would you have liked to have changed?

Now read out what will happen in next week's session.

**Next time**

- We will discuss our thoughts from last week's session on who to tell, how and when.
- Support for me, for you, for us; we will consider the issues that arise when others do the telling and think about how to access the sources of support that are out there.

FACILITATOR: Thank everyone for coming and say goodbye.
Session 3: Support for me, for you, for us

Before the session ensure the session summaries for the last 2 weeks are visible in the room and can be seen by all attendees.

Begin the session by...
- Introducing yourself and thank everyone for coming again.
- Providing information relating to toilets, fire exits and break times. Draw attendees’ attention to the reality orientation board in the room.
- Informing attendees that they can take a break or leave the session at any point if needed as necessary.
- Inviting attendees to write their names on the stickers provided and wear these.
- “As always we ask that you talk about your thoughts and reactions to sessions with others outside the programme but keep confidential the things you hear from other people. Be mindful that everyone’s opinion counts and respect each other.”

Once attendees have written their names down on the stickers provided go around the room read out “A summary so far”.

A summary so far
- In session one we discussed the language used around dementia and the advantages and disadvantages of telling others.
- In session two we discussed who to tell, how and when. We also thought about the reactions of others.

FACILITATOR: “Has anyone had any thoughts or questions from the last 2 sessions?”
- Note down these points on board 2 and address the questions as best you can. If they are going to be covered in this session tell the attendee that.
- Some attendees might talk about the between session exercise. Thank them and tell them that you are going to cover this in more detail in a moment.

Now read out “who to tell, how and when: a review”

Who to tell, how and when: a review

At the end of the last session we invited you to think about:
- Who you would tell
- How and when you would tell them
- The words that you would use

DISCUSSION: Exploring disclosure: Has anyone taken the step of telling someone about the diagnosis? If so, how did this go?

FACILITATOR: throughout the discussion note down attendees’ thoughts. This exercise is an invitation for group members to share their experiences. For those that have told others the diagnosis invite them to share how they went about it and ask them how they felt it went, what they found helpful or not so helpful about it, and what the consequences have been.

Read out key takeaway point.

KEY TAKEAWAY POINT:
- thinking or doing this may change your thoughts about telling others the diagnosis and how you live your life.

Now read “whose diagnosis is it?”

Whose diagnosis is it?

For some of you in this room today the diagnosis may have been delivered to you and your supporter at the same time. Deciding how this information is shared can be challenging.
DISCUSSION: Whose diagnosis is it? Reasons others may share the diagnosis

FACILITATOR: Throughout the discussion note attendees' thoughts.
Q: “What reasons do you think others may have for sharing this information?”
A1: To get access to support and services for themselves if they are also affected by the diagnosis.
A2: To share their experience and knowledge with others who are “living with dementia” as a way of supporting others and to help them feel less alone.

At the end of this discussion summarise the points raised and read out key take-away points. Bluetac these somewhere where attendees can see them.

KEY TAKEAWAY POINTS
- It is important to be aware that anyone you share the diagnosis with may share this information with others.
- This might be something to consider before sharing.

FACILITATOR: Offer 10 minute refreshment break here.

Now read “When others do the telling” and Jacinda’s vignette.

When others do the telling

Sometimes people may tell others about the diagnosis. There may be times when you agree with this but other times when you may not. Below Jacinda talks about her experience.

“I had told a friend who attends the same church. I thought he would keep the information to himself as I hadn’t wanted anyone else to know. Anyway, when I was at church one day another parishioner came up to me and said they were so sorry to hear about my diagnosis. I felt really taken aback and I didn’t know what to say.”

Jacinda

DISCUSSION: Who is “allowed to share the diagnosis?”

FACILITATOR: Throughout the discussion note attendees’ thoughts.
Q: “Who do you think is “allowed” to share the diagnosis?”
A1: Only me
A2: Only me and my friends/family with trusted others
A3: Anyone I tell

At the end of this discussion summarise the points raised and read out key take-away points. Bluetac the key take-away points where all attendees can see them.

KEY TAKEAWAY POINTS:
- Once you have told someone the diagnosis it may be hard to “control” who they then go on to tell.
- Thinking and talking about this issue before telling others the diagnosis can be helpful.
- There are no right or wrong approaches to this.

Now read Anoushka’s vignette.

Here is just one example of how Anoushka went about it.

“We sat down as a family and talked about who else should know. We all agreed that my family can share the information about the diagnosis with their close friends and our wider family as long as they make sure the people they tell do not tell anyone else. I was happy for this to happen as telling others was really difficult for me.”

Anoushka

DISCUSSION: Navigating differences of opinion with the people you tell

FACILITATOR: Throughout the discussion note attendees’ thoughts.
Q: “How would you deal with differences of opinion with the people that you tell?”
A1: Put the boundaries in place before sharing the information.
A2: Discussing each other’s points of view and trying to see it from the other person’s position.
A3: Both parties coming from a position where they are open to being flexible in their position and willing to potentially compromise.

At the end of this discussion summarise the points raised and read the key takeaway points. Blueteach these somewhere where attendees can see them.

KEY TAKEAWAY POINTS
- It may be helpful to be clear about your boundaries about information sharing when telling others the diagnosis.
- It may be helpful to have a discussion with others when differences of opinion arise.
- Being flexible in the opinions you hold about information sharing may be helpful when considering how you and those closest to you can "live well with dementia".

Now read sources of support

Sources of support

There is wide ranging support available that values and respects people living with dementia and supports them to live well.

DISCUSSION: What groups, activities or sources of support have you heard of in your area and who would you consider approaching?

FACILITATOR: Have to hand a list of local groups, activities and sources of support available in the area that you can share with attendees. This exercise is aimed at getting group members to share information with each other and highlight the resources available to them.

At the end of this discussion summarise the points raised. Give each attendee a copy of the list of local groups/activities and sources of support available in your area.

Now read the session and programme summary.

Session summary

In this session we have considered:
- Our current thoughts about who to tell, how and when
- When others are doing the telling
- Sources of support

Programme Summary

Over the course of the programme’s 3 sessions we have talked about:
- the diagnosis and the way it can affect lives
- the advantages and disadvantages of telling or not telling others
- who, how and when you might tell others and how they might react
- when others do the telling
- sources of support

FACILITATOR: “In session 1 we hoped that we would (read out attendees hopes from session 1).”

Go through each point and evaluate how well these have been addressed by the group.

“Does anyone have any questions from today’s session or any of the previous sessions?”

Answer them to the best of your ability. If you are unable to answer a attendee’s question, note it down and let them know that you will look into this and that you will get their details so that you can send them the answer in the next day.

End of session feedback:

1. How has everyone found today’s session in terms of
   - what we talked about
   - its length

2. What have you found most helpful about the session?

3. What would you have liked to have changed?

Now read out “what happens now?”
Facilitator Booklet

What happens now?

This workbook is yours to keep. You can refer to it whenever you wish to. The next page has important details of organisations who can provide support for those living with dementia and their supporters.

FACILITATOR: "As this is a new group UCL is undertaking an evaluation. You are all invited to take part in an audio recorded interview that will ask you about your experience of the group and help with the group’s further development. The interview will take place either here or in your home and will last around an hour. If you are interested in taking part please speak to Tamatha Ruffell, trainee Clinical Psychologist from UCL, before leaving today. Thank you very much for attending these groups. We hope they have been helpful and informative. It has been a pleasure delivering them. Thank you and goodbye."

For more information about this research please contact Tamatha Ruffell or Jemini Bhatt at:

Address: 1-19 Torrington Place, University College London, WC1E 7HB
Telephone: 020 7679 8275
Email: tamatha.ruffell.16@ucl.ac.uk or jemini.bhatt@ucl.ac.uk or tamatha.ruffell.16@ucl.ac.uk

Acknowledgements

We are indebted to the original authors, Pat Corrigan and Jon Larson, and other members of the HDP "community" for their support in developing this workbook.

Facilitator Booklet

Where to find support?

<table>
<thead>
<tr>
<th>Organization</th>
<th>Email</th>
<th>Telephone</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Society (local services and information provision)</td>
<td><a href="mailto:enquiries@alzheimers.org.uk">enquiries@alzheimers.org.uk</a></td>
<td>0300 222 11 22</td>
<td><a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a></td>
</tr>
<tr>
<td>Pathways Through Dementia (legal support and information provision)</td>
<td><a href="mailto:swlicox@pathwaysdementia.org">swlicox@pathwaysdementia.org</a></td>
<td>0203 405 9840</td>
<td><a href="http://www.pathwaysdementia.org">www.pathwaysdementia.org</a></td>
</tr>
<tr>
<td>AgeUK (local services and information provision)</td>
<td><a href="mailto:contact@ageuk.org.uk">contact@ageuk.org.uk</a></td>
<td>0800 000 0000</td>
<td><a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a></td>
</tr>
<tr>
<td>CarePlace (care and community services, information and guidance)</td>
<td></td>
<td>0800 4 70 80 90</td>
<td><a href="http://www.careplace.org.uk">www.careplace.org.uk</a></td>
</tr>
</tbody>
</table>
Appendix E: Email sent to matched JDR volunteers

Dear [Redacted],

My name is Tamatha Ruffell, I am a trainee Clinical Psychologist at University College London. I am conducting research into dementia.

I am writing to you because you and your supporter have been matched on the Join Dementia Research Network to the study that I am currently conducting.

This study aims to explore the experience of attending a group for people living with dementia who may be worried about talking about the diagnosis with others. The groups are currently being run as part of voluntary sector provision.

**When and where the group will take place**

The group will take place on the 3rd, 10th and 17th December at 130-13:30pm over 3 weeks at University College London (UCL) or in a central London Age Concern or Alzheimer’s Society location. There will be 8 attendees in total and I, along with my supervisor, Dr Georgina Charlesworth, will run the group. Each session will last approximately 90 minutes and will cover the following topics:

- Session 1: Talking about dementia.
- Session 2: Who, how and when to tell.
- Session 3: Support for me, for you, for us.

Refreshments will be provided.

After you have attended the 3 sessions I will invite you both to take part in an interview, either at home or in UCL, where we will talk about your experiences of the group.

You can still attend the group if you do not want to take part in the interview.

If you feel that attending such a group might interest you and your supporter or if you have any further questions please call me on 020 76 79 82 75 or email me at tamatha.ruffell.16@ucl.ac.uk.

Kind regards,

Tamatha Ruffell
Trainee Clinical Psychologist

Department of Clinical, Educational and Health Psychology,
University College London
1-19 Torrington Place, London, WC1E 7HA
Appendix F: Ethics approval email and letter

From: VPRO.Ethics  
Sent: 04 October 2018 10:47  
To: Ruffell, Tamatha  
Subject: RE: 14001_001 UCL Ethics Application

Thank you Tamatha.

This revised sheet is good to go. You may proceed.

Best,

Ed

From: Ruffell, Tamatha  
Sent: 02 October 2018 15:51  
To: VPRO.Ethics <ethics@ucl.ac.uk>  
Cc: Charlesworth, Georgina <g.charlesworth@ucl.ac.uk>  
Subject: Re: 14001_001 UCL Ethics Application

Dear Ed,

Please find attached the updated Participant Information Sheet which I hope sufficiently addresses the provisos laid out in the letter i.e. a clear explanation of the aims of the study and the intervention. This can be found on page 3. I have also updated the privacy notice as advised in your email. This can be found on pages 7 and 8.

Please let me know if you need any further information or if I need to make any further amendments.

Best wishes,

Tamatha

Tamatha Ruffell  
Trainee Clinical Psychologist  
UCL

From: VPRO.Ethics  
Sent: 28 August 2018 10:43:46  
To: Ruffell, Tamatha  
Cc: Charlesworth, Georgina  
Subject: RE: 14001_001 UCL Ethics Application
Dear Tamatha,

I am pleased to confirm that the REC Chair has approved your application subject to the provisos outlined in the attached approval letter.

**IMPORTANT: For projects collecting personal data only**

Change to legal basis for the processing of data: If you are processing (i.e. collecting, storing, using, disclosing or destroying) identifiable personal information about living individuals as part of your research then you should ensure that you comply with the requirements of the GDPR and the Common Law Duty of Confidentiality. An appropriate legal basis for the processing of your data must be identified, and you must be explicit about this and document it as part of your ethics application, and in the information you provide to your research participants. UCL’s view is that, for the vast majority of research undertaken at UCL, the appropriate legal basis will be ‘a task in the Public interest’: the processing is necessary for UCL to perform a task in the public interest - rather than ‘consent’.

However, even though the legal basis for the processing of a person’s data is most likely to be ‘a task in the public interest’ rather than ‘consent’, from an ethical perspective, obtaining a person’s informed consent for their involvement in the research is still likely to be required in order to abide by the fairness and transparency elements of principle GDPR Article 5(1)(a) or to meet confidentiality obligations.

We have recently changed the data privacy section of our template participant information sheet (PIS) to reflect this change to the legal basis for data processing – see attached. You will need to update your PIS accordingly.

With best wishes for the research,

Ed

Edward Whitfield MA, MLitt
UCL Research Ethics Administrator
2 Taviton Street,
London WC1H 0BT
E-mail: ethics@ucl.ac.uk
Tel: +44 (0)20 7679 8878 (Int: 55427)
https://ethics.grad.ucl.ac.uk/
28th August 2018

Dr Georgina Charlesworth
Research Department of Clinical Education and Health Psychology
UCL

Dear Dr Charlesworth

Notification of Ethics Approval with Provisos
Project ID/Title: 14001/001: The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study.
Further to your satisfactory responses to my comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that I have ethically approved your study until 1st September 2019.

Ethical approval is subject to the following provisos:

- The information sheet: please rephrase in such a way that you clearly spell out the aims of this study, not what people have to do formally. What is your intervention?

Notification of Amendments to the Research
You must seek Chair’s approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an ‘Amendment Approval Request Form’
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research
i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL’s Code of Conduct for Research: http://www.ucl.ac.uk/ers/governance-and-committees/resgov/code-of-conduct-research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Cc: Tamatha Ruffell
Appendix G: Participant information sheet

PARTICIPANT INFORMATION SHEET for

The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

UCL Research Ethics Committee Approval ID number: 14001_001

We are the research team

Tamatha Ruffell; Researcher
Jem Bhatt; Researcher
Dr Georgina Charlesworth; Principal Researcher and Project Supervisor
Dr Katrina Scior; Project Supervisor

from the Research Department of Clinical, Educational and Health Psychology
University College London (UCL)

We would like to invite you to take part in our study
Title of Study: The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

Department: Research Department of Clinical, Educational and Health Psychology University College London (UCL)

Name and Contact Details of the Researchers: Tamatha Ruffell (tamatha.ruffell.16@ucl.ac.uk), Jem Bhatt (jemini.bhatt.15@ucl.ac.uk), Dr Georgina Charlesworth (g.charlesworth@ucl.ac.uk), and Dr Katrina Scior (k.scior@ucl.ac.uk), Research Department of Clinical Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB. Telephone: 020 7679 1897

Name and Contact Details of the Principal Researcher: Dr Georgina Charlesworth (g.charlesworth@ucl.ac.uk) Research Department of Clinical Education and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB. Telephone: 020 7679 1897

Invitation to participate in a research study
You are being invited to take part in a “one off” interview as part of an evaluation of the “Who to tell, how and when?” groups for people living with dementia. Before you decide to take part, it is important you understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is
anything that is not clear or if you would like more information. Thank you for reading this information sheet.

What is the aim of the study

The aim of this study is to explore and understand the views and experiences of participants who have been invited to attend a “Who to tell, how and when?” group for people living with dementia. This will be done through a “one-off” audio-recorded interview with a University researcher where participants will be asked questions that explore how acceptable they found the group and whether it was felt to have had an impact on their lives.

Why have I been invited?

We are inviting everybody who was invited to take part in the “Who to tell, how and when?” groups. We hope to interview 20 people.

You will not be eligible to take part if you do not have the capacity to provide informed consent for the study, have any significant mental or physical health problems that require care from others or experience sensory impairments to the extent that you would not be able to participate or engage in the interview.

Do I have to take part?

You do not have to take part. Participation is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to take part, but then change your mind, you will be asked what you wish to happen to any information that you have already provided up to that point. Up to 31st March 2019 you can choose to have all your information withdrawn from the study.
What does taking part involve?

- Reading this information sheet.

- Signing a consent form. A signed copy will be given to you to keep for your records. You will also be given a participant identification number so that your participation in the study is anonymous.

- Answering some questions about you; name, address, age, gender, type of dementia and length of time since diagnosis, if applicable, ethnicity, marital status, living situation, education level, employment status and first language.

- Taking part in an audio-recorded interview with a University researcher. This can take place either in your home or at your local Alzheimer’s Society, Age Concern or Tapestry office where the groups have been held, dependent on your choice. During this interview you will be asked questions about your experience of the group, or your reasons for not wanting to take part. You will also be asked about your views of telling others about your diagnosis. The interview will take approximately 30 to 60 minutes. If you start to feel tired, you can choose to stop and continue on another day.

Those who attend the interview will be reimbursed with a £7.50 shopping voucher for their time.

How will the recording be used?

The audio recording of the interview made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of it without your written permission, and no one outside the project will be allowed access to the original recordings.
**What are the possible disadvantages of taking part?**

We do not think that taking part will involve any disadvantages. Some questions are about your dementia experience, and you might feel upset about this. The research team will make every effort to be supportive and signpost you to sources of support where needed. It is also important to remember that participation is voluntary and you can change your mind at any time.

**What are the possible benefits of taking part?**

We hope that you will find taking part in the study interesting and enjoy talking to the researcher during the interview. Participating in this research will deliver wider benefits to others living with dementia. It is hoped that this work will determine the helpfulness of the “Who to tell, how and when?” groups for people living with dementia.

**What if something goes wrong?**

If you are unhappy or dissatisfied with any aspect of your participation or if you wish to make a complaint you should contact either Tamatha Ruffell (researcher), or Dr Georgina Charlesworth, (project supervisor) and we will do our best to address your concerns and find a solution. If you feel your complaint has not been handled to your satisfaction then you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk.

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the study will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Any personal details will be kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records.
**Limits to confidentiality**

The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your health, safety or wellbeing. This could include possible risk to yourself, risk to others, criminal behaviour or professional misconduct. If this happens the researchers have a duty of care to report to the relevant authorities possible harm or danger to participants or others. We would make every effort to explain to you why we need to share this information before doing so.

**What will happen to the results of this study?**

Personal data will be stored at UCL in a locked cupboard in a locked room. The audio recording from the interview will be stored on an encrypted memory stick for transport back to UCL and transferred to the UCL network after which time the recording will be deleted from the memory stick. After transcription the anonymised recording will be destroyed. You can ask for your information to be withdrawn and destroyed at any time up to 31st March 2019.

The findings from this study will be presented within a doctoral thesis and used to inform the further development of the “Who to tell, how and when?” groups. Information about the development of “Who to tell, how and when?” will be presented at conferences and published in peer reviewed journals. Findings will also be summarised in an article for an Alzheimer’s Society newsletter, within a blog on the UCLUS website and distributed to the Alzheimer’s Society staff / branches and / or other voluntary sector organisations, where the ‘Who to tell, how and when?’ groups took place.

**Data Protection Privacy Notice**

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the
processing of personal data and can be contacted at data-protection@ucl.ac.uk. UCL’S Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Further information on how UCL uses participant information can be found here: www.ucl.ac.uk/lega-services/privacy/participants-health-and-care-research-privacy-notice

Your personal data will be used for the purposes outlined in this notice. The category of personal data used will be as follows: name, address, age, gender, type of dementia and length of time since diagnosis, if applicable, ethnicity, marital status, living situation, education level, employment status and first language.

The legal basis that would be used to process your personal data will be performance of a task in the public interest. The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent.

Your personal data will be processed and the anonymised recordings will be stored electronically in data archives provided by University College London for 10 years. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

You have certain rights under data protection legislation in relation to the personal information that we hold about you. These rights apply only in particular circumstances and are subject to certain exemptions such as public interest (for example the prevention of crime). They include:

- The right to access your personal information
- The right to rectification of your personal information
• The right to erasure of your personal data
• The right to restrict or object to the processing of your personal data
• The right to object to the use of your data for direct marketing purposes
• The right to data portability
• Where the justification for processing is based on your consent, the right to withdraw such consent at anytime and
• The right to complain to the Information Commissioner’s Office (ICO) about the use of your personal data.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact Spencer Crouch at UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the ICO. Contact details and further details of data subject rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who is organising the research?

The study is being organised by Tamatha Ruffell, a trainee Clinical Psychologist, Jem Bhatt, a PhD student, Dr Georgina Charlesworth and Dr Katrina Scior, Senior Lecturers, from University College London (UCL). UCL is sponsoring this study. It is funded by Economic Social Research Council and Alzheimer’s Society.

Who can I contact for further information or if I have any concerns or complaints about this study?

Tamatha Ruffell
Research Department of Clinical Educational and Health Psychology, University College London
1-19 Torrington Place
London
WC1E 7HB
Email: tamatha.ruffell.16@ucl.ac.uk

Who can I contact if I have any concerns or complaints about this study?

Dr Georgina Charlesworth, Research Department of Clinical Educational and Health Psychology, University College London, University College London

1-19 Torrington Place

London

WC1E 7HB

Email: g.charlesworth@ucl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research study.
Appendix H: Consent form

Research Department of Clinical, Educational and Health Psychology
UNIVERSITY COLLEGE LONDON

CONSENT FORM for

The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

UCL Research Ethics Committee Approval ID number: 14001_001

Title of Study: The experience of attending a “talking about diagnosis” group for people with mild dementia: a qualitative interview study

Study summary: This study is evaluating the “Who to tell, how and when?” groups for people living with dementia. You are being invited to take part in a one-off interview because you were invited to take part in these groups. The interview will take approximately 30 to 60 minutes and can take place either in your home or at your local Alzheimer’s Society, Age Concern or Tapestry office where the groups have been held, dependent on your choice. During this interview you will be asked questions about your experience of the group, or your reasons for not wanting to take part. You will also be asked about your views of telling others about your diagnosis. It is important to note that participation is voluntary and you are free to withdraw from the study at any time without this causing any negative consequences for you.

Department: Research Department of Clinical, Educational and Health Psychology
University College London (UCL)

Name and Contact Details of the Researchers: Tamatha Ruffell (tamatha.ruffell.16@ucl.ac.uk), Jem Bhatt (jemini.bhatt.15@ucl.ac.uk), Dr Georgina Charlesworth (g.charlesworth@ucl.ac.uk), and Dr Katrina Scior (k.ctor@ucl.ac.uk), Research Department of Clinical Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB. Telephone: 020 7679 1897
**Name and Contact Details of the Principal Researcher:** Dr Georgina Charlesworth (g.charlesworth@ucl.ac.uk) Research Department of Clinical Education and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7H8. Telephone: 020 7679 1897

**This study has been approved by the UCL Research Ethics Committee: Project ID number:**

Thank you for considering taking part in this research. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. **You will be given a copy of this Consent Form to keep and refer to at any time.**

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that un-initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Please initial box

1. I confirm that I have read the information sheet dated ___ / ____ / ____ for the above study. I have had the opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions and have had these answered satisfactorily and would like to take part in:

- an audio-recorded interview that will take place after being invited to or attending a "talking about diagnosis" group

2. I understand that I will be able to withdraw my data up to the 31st March 2019

3. I consent to the processing of my personal information (name, address, gender, age, type of dementia and length of time since diagnosis if applicable, ethnicity, marital status, living situation, education level, employment status and first language) for the purposes explained to me. I understand that such
information will be handled in accordance with all applicable data protection legislation.

4. Use of the information for this project
   
a. I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that confidentiality may be limited and conditional given that you have a duty of care to report to the relevant authorities possible harm/danger to participants or others.
   
b. I understand that the interview recording will be stored anonymously and securely. It will not be possible to identify me in any publications.
   
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason without the care I receive or my legal rights being affected. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.
   
6. I understand that the interview will include discussion of my dementia diagnosis, and that discussing issues about dementia might be upsetting.
   
7. I understand the direct and indirect benefits of participating.
   
8. I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.
   
9. I understand that I will not benefit financially from any possible outcome of this study that may result in the future.
   
10. I understand that I will be compensated for the portion of time spent in the study if I choose to withdraw.
   
11. I understand that the anonymised information I have submitted will be presented within a doctoral thesis and used to inform further "Who to tell, how and when?" groups. Information about the development of "Who to tell, how and when?" will be presented at conferences and published in peer reviewed journals. Findings will also be summarised in an article for an Alzheimer's Society newsletter, within a blog on the UCLUS website and distributed to the Alzheimer's Society staff and branches, and/or other voluntary sector organisations, where the "Who to tell, how and when?" groups took place.
12. I consent to my interview being audio recorded and understand that the recordings will be destroyed immediately following transcription.

13. I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher i.e. an invitation to the “Who to tell, how and when?” groups.

14. I hereby confirm that
   a. I understand the exclusion criteria as detailed in the Information Sheet under “Why I have been invited to take part?” where it talks about why you would not be eligible to take part in the study and explained to me by the researcher
   b. I do not fall under the exclusion criteria

15. I am aware of who I should contact if I wish to lodge a complaint

16. Use of information for this project and beyond
   a. I would be happy for the data I provide to be archived at UCL for 10 years
   b. I understand that other authenticated researchers (Jen Bhatt, Dr Georgina Charlesworth and Dr Katrina Scoon) will have access to my anonymised data

17. I voluntarily agree to take part in this study

TO BE COMPLETED BY THE PARTICIPANT:

Name of participant: ____________________________

Signature: ____________________________ Date: ____________________________

TO BE COMPLETED BY THE RESEARCHER:

Researcher’s Name: ____________________________

Signature: ____________________________ Date: ____________________________
Appendix I: Eligibility criteria

Research Department of Clinical, Educational and Health Psychology
UNIVERSITY COLLEGE LONDON

Participant Identification Number: _____________

The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

Eligibility criteria

INSTRUCTIONS: Please complete the below questions to establish eligibility for participation, the questions should be completed through a free-flowing discourse with the participant.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is an adult over the age of 18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Has a diagnosis of a primary progressive dementia (e.g. Alzheimer’s disease, vascular dementia) or is the family supporter/carer of a person living with dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Can understand, communicate, read and write in the English language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Was invited to attend the “Who to tell, how and when?” groups.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In order to be eligible participants must have “yes” answers for ALL the inclusion criteria.

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does not have capacity to provide informed consent for the study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Has chronic, terminal medical conditions in which they are in the later stages</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Has a sensory impairment to the extent that the participant is unable to participate or engage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Is expressing suicidal ideation or intent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In order to be eligible, participants must have “no” answers for ALL the exclusion criteria.
Appendix J: Demographic questionnaire

The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

UCL Research Ethics Committee Approval ID number: 14001_001

Demographics Questionnaire

The purpose of the short questionnaire is to get baseline information about you. The answers you give are completely confidential and will not be shared with anyone outside the research team. All data will be kept anonymously.

Please try and answer all questions to the best of your ability. You do not have to answer anything you wish not to.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Categories (please circle, unless text is necessary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 What is your gender?</td>
<td>Male</td>
</tr>
<tr>
<td>2 How old are you? (age)</td>
<td>_ _</td>
</tr>
<tr>
<td>3 Do you have a formal diagnosis of dementia?</td>
<td>Yes</td>
</tr>
<tr>
<td>If ‘yes’ skip to question 5</td>
<td></td>
</tr>
<tr>
<td>4 Are you a carer of someone living with dementia?</td>
<td>Yes</td>
</tr>
<tr>
<td>If ‘yes’ skip to question 7</td>
<td></td>
</tr>
<tr>
<td>5 How long have you had a diagnosis of dementia?</td>
<td>_____ Days _____ Months _____ Years</td>
</tr>
<tr>
<td>6 Please specify what type of dementia you have been diagnosed with?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix K: Semi-structured interview guide

Research Department of Clinical, Educational and Health Psychology

UNIVERSITY COLLEGE LONDON

The experience of attending a “talking about diagnosis” group for people living with mild dementia: a qualitative interview study

UCL Research Ethics Committee Approval ID number: 14001_001

Interview Guide

Below is the interview guide that outlines the domains to be covered.

<table>
<thead>
<tr>
<th>Subject</th>
<th>Question(s) for participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>How are you? Complete demographics questionnaire</td>
</tr>
<tr>
<td>Decision Making</td>
<td>What was it like making decisions about who to tell about your diagnosis (before/after this programme)? How do you feel about making decisions to disclose your diagnosis? How conflicted are you about disclosing your diagnosis?</td>
</tr>
<tr>
<td>Stigma/Fear/Distress</td>
<td>How have the sessions made a difference to your thoughts, feelings and behaviours? How do you feel about telling others about your diagnosis? [fear/distress] What is your attitude towards your dementia diagnosis? Have your attitudes towards your diagnosis changed? [stigma]</td>
</tr>
<tr>
<td>Self-identification</td>
<td>What does being diagnosed with dementia mean to you? Do you identify with your diagnosis?</td>
</tr>
<tr>
<td>Programme</td>
<td>Overall how did you find the programme? What aspects did you like/dislike? What sticks in your mind about them? Do you have any suggestions for how the sessions could be changed (materials, session content)? Would you recommend this programme to someone else living with dementia/friends and family?</td>
</tr>
</tbody>
</table>
Appendix L: An example of an annotated transcript

“Who to tell, how and when?” Qualitative Interview Transcript Annotated

Date: 4.3.19
Time: 10am

Interviewer: So S I’ll start with you, overall how did you find the who to tell, how and when programme?

P11: Um, well I was. We had doubts about coming to it. But in the end I thought it would be good to actually be in a collection of people who perhaps were looking at the same issues. I think I made it fairly clear at some of the meetings that my one of my big concerns was meeting people who were further down the line to me because I wanted to be slightly blindfolded by choice because I tend to live in the now I've said that a lot of times. And basically it was fine to a certain extent and I did manage it and you know it was it was interesting and perhaps that's something that's necessary for you to see. Yeh I think probably I was a bit more vocal than most people in the group which maybe wasn't helpful to others. But I think it was it was good to take part because perhaps knowledge is more important. I think it would have been perhaps better if we had more people with more diverse backgrounds and and experiences and age group perhaps and not as many people of my age who've been affected by this that were willing to come or knew about it because that would have been interesting to have had a younger age group there as well. Maybe at the level I was at but you know this is a voluntary thing to you. You have diverse groups. And the the lady you choose not to come in the end. I could particularly see her reasoning and I have to say I left on the last day and there were some things perhaps I didn't really need to know about or take part in and I didn't feel it left me feeling quite emotional. Just managing it. I think that this diagnosis does give you moments of depression. I don't think there's much support for that. You know I still haven't actually had the courage to go to my doctor and say I get depressed at times because you know the thought of anti-depressants and people I've known who've been on them for the most of their lives is not something I want to do. But you know maybe that kind of counselling or how to handle what you're dealing with not by my husband because he needs his own space but something that I can say that is maybe a private setting I would find quite useful and in many ways I actually realized why that lady to a certain extent had made her choices. So I also believe that the more you remove yourself from society the more you, what's the right word for it? The progression of this condition increases, you need to keep an active profile. I was going to be an active mind but perhaps a certain phrase (laughs)

P12: You try to normalize it. You try to keep it, rather than give in to it which you can do.

P11: I do sometimes there are some things I have given into as you know so mainly because I don't want to put anybody or anything in danger you know or actually it raises my anxiety level when you suddenly think can I do this? you know Am I going to upset someone or particularly upset my husband who's you know and sometimes he'll pick up things I'm doing and he's really good about it and I'm just, but I know because I've always been a very independent woman and you know I've had quite a sort of proactive career and I had to do a lot of analysis and you know to go to meetings and child protection and stuff like that. You have a belief in your independence and
ability because you've had to and decision making and I can see that that is becoming flawed and that's difficult to accept. But then that's just personal thing for me. You know other people come from different backgrounds and different careers. So.

R: Overall how did you find the program?

P12: I, like S, thought it was good to see and make sure other people were in a similar situation and took interest in the different ways they were dealing with it because everybody had a different, before everybody had a slightly different way of dealing with their problems and that made me realize that everybody's going to be doing it in a different way and we've got to do it in a way that's right for us and they've got to do it in a way that's right for them. I think it was an interesting event in that none of us were obviously aware, and initially it was hard for me with one particular couple when we first met I wasn't sure who had the problem, but in other cases it was obvious. So it does make you realize that sometimes, we're all at diff, everybody's suffering at a different stage and it's interesting to hear the comments from other spouses. Which, you know, I can identify with. And it's good to realize that they too have the same situations but are dealing with it in different ways. So I found it really interesting I found that the people honest which is nice and. You know it was a good. It was a good experience for me personally.

S: what sticks in your mind about the sessions?

P11: What sticks in my mind about the sessions? Well just just being part of the group was was good. Being able to share with R things that we, well we wouldn't normally discuss at home. We just get on with our lives you know. Listening to other people's experiences and perhaps how they're dealing with it. Yeah I'm just, I think knowledge is always important and that was really about learning as much as you could from what you might consider. I do have, I always have had quite strong views about most things. I mean because I've had to in the career I had. And it was interesting to perhaps vocalize some of those and listen to other people and maybe change some of the ways I thought or you know. It made me feel stronger about some things.

R: same question for you, what really sticks in your mind about the sessions. What stands out?

P12: Well as I said earlier the honesty that people spoke, it was definitely good to hear other people open up about their situation and how it works for them. I think the actual event was it was pleasant to go to. It wasn't something you need worry about but the thing that stood out most for me is that you know is the fact that other people had the same problem. We think we feel we're quite isolated. Of course everybody we know doesn't know. And it was good to hear S. admit to her situation which she normally wouldn't do, only to me but never to anybody else (laughs). So that was that was interesting cause I think that did her some good and in some ways she did benefit from it but it was good for her overall it was good for her to do that.
I: S you mentioned that it was a good learning space, a good place where you found you gained knowledge. What, I mean if anything what particular bits of knowledge or learning do you think you learnt from the session. What did you take from them?

P11: Well about what R said about how other people have dealt with situations. Oh you know sort of. Yeah very much that about you sort of families and how they've managed their issues within family groups. I mean obviously the other couples there were still in a very different situation in many cases they were all retired whereas basically you know sort of I'm now retired but I worked right up and even when the diagnosis was that it had come to be. And I still as I said volunteer so I'm still out there in the world and and so yeah there was a there was a lot of useful discussion. It felt comforting to be part of a group where you could be open about many of the things that you don't discuss with anyone else. You know that I have a choice of when I'm out in the environment with people. It's something I don't actually mention unless I suddenly think people are going to think there's something wrong with me so it was it was fine to actually be you know be happy about somebody seeing that you had a problem in that environment. So you had that kind of safety aspect to it.

I: And S what aspects of the sessions either individually or as a whole. Did you really really like or even not like?

P11: OK. Well I mean the people they were they were lovely. I mean obviously that's not by choice. It's just who accepts it, to come. I think perhaps there was a camaraderie in the fact that everyone really was facing many of the same issues albeit maybe in different ways. But all of a sudden we are in the same boat. So you know there was it broke down barriers about wherever anyone came from or what their background was because if you are just there for one purpose. It was useful being with people who were professionals who could give you information because it is difficult to source information in the right areas. I think it was good for R to have support because obviously again it's difficult for him to have support because where do you go and what do you do you know and yeah I think as an individual is probably more difficult. Also you have a group of carers all turning up without their spouses or something because I think that would, that would concentrate a discussion in the wrong way. So I thought that was that was good as well. It was an outing. We did other things as well didn't we? (Laughs)

P12: Yes.

P11: Always had tea and cakes or went to (says place name) or as went and visited a somewhere.

P12: We made a day of it

P11: Yes, we made a day of it. I mean I've lived in (says place name) for years and R a (says place name). But you know it was just places I hadn't been to for a while we are. It was sunny day but the last day it poured. But if it was a sunny day it was like why don't we you know take a walk up there. You know I ate far too many sweet things. So yes
P11: That’s a really difficult question for somebody who’s got Alzheimer’s. You’re asking me to remember so I might actually ask R if he can give me a prompt about things. And there was the definitely for me the issue has always been who you tell and how you tell it. And there were other things that perhaps we already had some knowledge of, that in fact I think we shared which was good and other people had some knowledge that we were able to help with. I think which was good. So that was a sharing aspect. And perhaps we maybe thought or certainly I maybe thought there would be more information. I mean our biggest issue is in any kind of funding you know. We’re now in a situation, that retirement came about. I wasn’t intending on retiring when I reached 65 I was going to work part time. It’s now, I now probably wouldn’t be able to do that although I’ve never really plumbed the depths of that. I think I had that discussion then about you know even if when I’m volunteering should I tell them. But I think health and safety in schools would suggest that that might not be a possibility although I’m sure there is other reasons why they would have to review that differently from the point of view of you know sort of employment law and stuff. I bet you would put you at a disadvantage and when you’re taking children on trips or doing (says an exercise) with them or you go to (says place name) as we did you would start to doubt your safety and that you couldn’t put children into that situation. So when it came to a point where it basically my retirement was forced not because of anything to do with me but cutbacks in financing. And that sort of meant that my income dropped by an enormous amount of money. I never even considered what you get for your pension because it’s never been part of something I was interested in I was going to work until I dropped. Well I’ve dropped a little bit sooner than I expected. And so, and I do have this big issue of I have paid into a system that was supossed to be there for me when I wasn’t well and I haven’t had any awful illnesses or thank God luckily or had anything that meant the National Health had to spend tons of money on me. And you know I knew it it’s support for everyone but it just feels that in times of need a little bit would be helpful.

P12: I think getting back to her point, well the things that made her unhappy or depressed linked to the meeting. Yeah I think um. The fact that there is a future ahead that we don’t know enough about and what we do know scares, is frightening and in the course of the meeting, everybody there was a fairly similar state except (says other attendees name) who was obviously further down the line and didn’t want to come. I think it’s, that upset her, upset S, it’s because she doesn’t want to go there. And she knows she’s going to have to obviously at some stage. And I think that hit her hard. And she got very down. So when you go to these groups among other things she’s adamant that she doesn’t want to go to a group where the disease has progressed so far. She wants to be able to be with people who are in a similar state. And obviously you can’t pick and choose the level that you choose who are in the groups because it’d be unfair. And if you want to have a mix so that people who are further down the line maybe it can be brought back into more of a conversation with type of existence if they are with other people, that did upset her. She’s frightened of what’s coming. And you know it’s as we all would be I guess you know there’s no doubt about that but I think at times that came home because we don’t spend time. The people we spend time with are normal people with no illness and they wouldn’t do, 99 percent of the time. I mean, understand that there’s a problem with S.
P11: I mean by definition you say people with no illnesses but you have one. Saw a lot of your friends have diagnosed illnesses but the problem with this diagnosis is that and I said it round the table is that because everyone thinks of dementia as its end stage. That's how they typify anybody who's got it and that's. That was one of the things that I think so needs to be changed. Yeah I think I said round the table you know the PR has to be changed. They have to show people who've had an early diagnosis and encourage people to have an early diagnosis.28 I was saying this to one of my school friends. And we meet we do Ladies Who Lunch. I've mentioned this many times, about you know sort of in the same way that we're encouraged to go and have smear tests and biah biah biah. Can we not have something that national health puts in place to monitor how people are managing in terms of you know because this disease is becoming more common. Is that the right word? Well, or people are finding it more in people as they age whether it's the environment or what we're eating or just I don't know what it is we're living longer. Perhaps if it's caught quicker people wouldn't be deteriorating as fast as they are. And that was that's one of my big bugbears about this. You know then for early testing

P12: We're living longer as well

P11: Yeah. Yeah and actually and the PR showing not people struggling like that poor lady that was sitting next to me who is much further down the line. But PR showing people if you like like myself even like some of the other people around the table who are actually living a full life you know who are managing well and actually you know being encouraged to do that because that's a plus. Whereas the other thing is a minus. And that's one of my reasons for not wanting to be part of something. I don't want to see the end result I want to see what I can do while I've got it, yeah.29

I: R, looking back at the sessions for you and from your position as S's husband, her supporter, her carer, however you define yourself, what aspects of the sessions did you like or dislike?

P12: I didn't dislike any of it to be honest I thought it was, it would hold down in the fact that everybody was encouraged to be involved and what I found interesting is, this was obviously listening to people who are suffering but listening to the people in my position as well I found that interesting because you tend to as I said earlier we tend to think you know you're the only one and you're not.30 And it was nice to you know, exchange views and just a general conversation with people who know what the situation is. I found that encouraging and as S said earlier that if the people in the group were you know easy to get on with, I wouldn't mind meeting them again. I've got their numbers I've got theirs and I'm sure if the phone call came we'd meet no problem at all but I think I found it very beneficial and I found it informative. A lot of it is. Because you're dealing with people in different levels I suppose a lot of it I found easy to deal with, and, you know, too simple sometimes. But that's just my view. But you know the other people have a different, have a different view and it would have been much more difficult if it had been more complicated you know. So but in general terms I did, I wasn't disappointed with it. It was what I expected. To be honest and you know. Apart from the fact that I didn't have any diabetic biscuits (laughs with P11)

P11: You did offer to bring some.
I: You just mentioned that you felt that parts of it were too simple. Do you have any more, can you tell me a little bit more about that? And if you can specific bits but don’t worry if you can’t.

P12: Well I just it’s just it’s some of the things, the question you know. Yeah I think. For me personally if it didn’t go deep enough into some of the situations that arise and it was, and it’s got to be fairly bland and widespread

P11: It touched on them but there was no solutions.

P12: So. Yeah I can’t really get any specific. I can’t remember the specifics but you know there were some things I think. But of course I’m not suffering.

P11: Perhaps being more solution focused might have helped you know because we talked a lot about what we were struggling with. Which was viewing things and obviously there was lots of people struggling with exactly the same things but there were no solutions offered. So perhaps maybe more professional people there who could offer that kind of information or other things.

P12: Also I think the solution thing is that everybody just to find out their own way for a solution

P11: Or even know where to look for it. (laughs)

P12: But it is as you say guidance. There was not much guidance.

I: You talked about it didn’t go deep enough into the situations that arise. What sort of situations do you think we should go into a bit more detail, into a bit more depth?

P12: Well things that. It’s about the help and the solutions as S said but also you know when you’ve got two options and neither of those options are falling into what you are or what your situation is and you get it it’s okay to pass a comment. You’re really passing a comment on somebody else’s solution. You’re not passing comment on your own situation and how you can sort of find a solution for your own problem. But that means that each one’s got to be individually. So there was no other way than what you’re doing.

P11: Individual tailored.

P12: You’ve got to keep it broad broad spectrum. It’s not too focused on the individual or you’d have a book or sheet about that thick (puts hands far apart) but I just sort of sometimes you know, it asked questions that.
P11: were quite general

P12: yeah, there was no answer that fitted you or that they were the sort of questions a bit too simple you know. I don’t want to criticize you know coz I thought it was a success.

P11: At the end of the session we were actually, some of the people around the table we’re talking about solutions they’d found to certain things. I think perhaps having spent more time on that would have been quite useful. You know sort of when I go back to being told I was adapting and I’ve had to find solutions to problems that I’ve never had in my life before. I’m not an anal person either and I’ve had to become incredibly anal about stuff which goes against my grain completely. And I think that if we’d actually had a little session where we discussed about where a problem arose and how we’ve dealt with it might have been a really binding way of dealing with something as well. Because I’m sure we’ve all had problems whether even if it’s a financial side or if it’s just in general around the house thing or you know I was a bit horrified to find out you could get the tracker on your phone so my husband knew where I was when I visiting the sales (laughs) spending our money. He’s like what (laughs). But you know that’s on the lighter side. But how good would that be. I don’t even know if the Alzheimer Society has got some solutions. Keep going on about this woman because my daughter as soon as she heard what was what my diagnosis was. She’s got a very investigative mind. She discovered this lady called Wendy Mitchell who has written a book. I’m somebody I used to know she got. She made me buy it. And this woman has found solutions to every single problem her Alzheimer has brought about for her. She goes and talks in hospitals about it and she’s been a mine of information for me.

P12: She’s been good.

P11: Yeah absolutely amazing she’s got a blog on and you can go on a blog on the phone, I’ve got it. She writes every single day and when I first had the diagnosis and it’s a difficult one to take although I play the glad game it’s not cancer I’m not getting something chopped, something cut out of my body. You know I think of all the things it could be. She reading that book gave me a way of thinking I can beat this I can put this into my life and adapt which is the word I never thought of. And I think perhaps that they could be quite uplifting sessions for people because everyone’s obviously struggling with different problems but solutions can be either major or minor and actually make a big difference can’t they. And that’s just everyday living.

P11: I think the sessions were just the right length. I think that was good for all of us. Yeah yeah I think it really goes too long especially people with the diagnosis that it goes it’s not not very good. I think perhaps to be inclusive it might have been maybe quite good to maybe have us around the table. What sort of help people would like to have you know whether they know. I know you did to certain extent, a lot of people came out with the age concern and stuff like that. But I was thinking more in everyday experiences you know what you struggled with. What solution
did you find. Has anyone else got an answer to that. You know that with that and that could have been quite a binding way of of of people joining in couldn't it. 40 Obviously you got a partner who's you know not in the same situation as myself as as in all cases who can actually probably put their tuppence worthy in or talk about maybe something they've seen me do or their partner do that actually got around a problem and some of that came out on that last day in session didn't it and I think that's that was a more lighthearted thing as well because I think things have to be uplifting as well as depressing. 41 Yeah and maybe sessions could be, based on the fact that you deal with some pretty shitty things quite honestly 41 and then you have a kind of uplifting part to go out on which you know I've done social skills groups and with children and that's a lot the way I used to do it with them. But you have to you can't do that straight away you have to gauge who you've got and and and maybe anticipate what how you can handle that. But I also think the length of sessions was fine. But I think perhaps more weeks would have been quite good as well. 42 So more a few more weeks yeah.

I: How did you find the booklet?

P11: It was fine for me. I'm used to stuff like that all the time. So yeah.

I: And how did you experience the way it was facilitated?

P11: Yeah. No that was that was good. It was all absolutely lovely and very approachable and you know sort of listened very carefully and kept order 43 (laughs) and I've been to some interesting meetings in my time when it comes to a staff meeting in a school (laughs).

P12: Yes the atmosphere in the meetings was, you was welcoming from yourselves. And you couldn't fault the way it was handled. 44

I: How did you find the length and the number of sessions?

P12: The length was fine. I wouldn't have minded seeing those people more often. But obviously I would imagine money comes into play and that's where the problem is. I mean it was good. It would have been good to have more sessions, maybe run for say six weeks rather than three because I think then you can become more open with each other because you've become more familiar with each other.

P11: I think we were just starting to bond by the time it finished. 45

P12: Yeah.
P11: Yeah. Like school term, half term you know it would have been good to have had that kind of length you know.

P12: I mean we don't go to anything like that. We had a bad experience with Age UK where we'd been. You've had this story before but. So we don't tend to, well S doesn't want to go for her reasons and you know it is good to be around people in the same boat you don't feel so isolated. I don't know we don't have any friends with a similar illness. Well they may have it and we don't know of course. I mean there was there was an incident where we found out someone had the problem who really is very close to us and we didn't know and we found out by accident. Same hospital on the same day.

P11: My next door neighbor, we knew that there was something strange. Obviously it affects people in different ways doesn't it. And also she's Asian, is that the right phrase? And so you know when people come from different cultures the obviously, they quite often have different views and friendships and stuff, perfectly friendly you know neighbors. That's it. But yeah I think people have their own ways and their own privacy. But yeah we literally bumped into them in the (says hospital name) thinking Oh my God. (laughs)

P12: I think it did me good anyway to be in conversation with similar minded and similar suffering people.

I: And speaking to that kind of individually tailored approach. Do you think that a group format, you've spoken that you really valued the group format

P12: I think I think the group format is good. From S's point of view and obviously to mine as well to some extent. I think she needs some time to chat one to one with somebody, she talks openly to me sometimes but not always. She tries to hide things. I think. In a more confined space where it's more intimate she would open up more than she would do in that group.

P11: Well it depends on the person I'm talking to because I have been in situations like the person we had to and (says name) who I disliked on my first meeting. Yeah. He was in fact he spent the whole time talking to my husband. He was at his computer and I was sat, he was at his desk and the computer and I was sat at the side of the room and R was nearer to him than I was. And he turned the computer around to show R my brain scan, I couldn't see it. And then he talked to R about my diagnosis. He didn't look at me once and I'm I'm (says place of birth) and sometimes I can get very annoyed. And it was all I could do not to be incredibly rude. And the only best thing he ever did for me was he said to me we think it might be quite good to refer you to the (says hospital name). I couldn't take that quick enough I tell you I would have done it anyway. I'm thinking I can't stand you I don't like you. Because this is very personal you've got to be able to relate to somebody haven't you in the same way that I would do it with parents and children and the job I used to do. Even if you don't particularly like then you find a way to relate to them. And and you know he was that was an impossible situation as it turned out. We went to the (says hospital name) and he was the nicest very handsome young man that I met there to start with (says name) and everybody there has been absolutely delightful you know. So you know one bad experience makes
you appreciate the good. That's what I say. So there's me playing the glad game again but it was interesting because actually I felt that was really useful to be able to see the bad side and the good side and really appreciate the professional people that you're meeting who are really good at what they're doing.

I: We're going to speak more about the experience of dementia now. What would you say being diagnosed with dementia means to you?

P11: Loss of independence. That was my big thing because I'm a very independent person. It took me a long time to accept how much of my independence I was going to lose. R's great, he just watches me until I fall and then picks me up. I've never I don't put myself in a position where I could be in danger in that sense of I you know I I was the most confident person. I mean I've lived in London for years I go out go anywhere I find my way around unless I've got a satnav or something with me now I'm not confident about going places and quite often what I say to R, even if I'm going to meet girlfriend. Can we just. Or you know I take part in the reading thing I do the reading recovery is attached to an organization called (says name). Okay because they train us. They didn't need to train me but they trained us anyway. And they have conventions and stuff like that and they are all in swanky places and even in different settings in different scenarios if I'd got to go somewhere like that R and I do a trial trip so that I know where I'm going. And and if he worries that I'm not going to get there he'll accompany me there, come and collect me if that's necessary but usually once I've worked out where I'm going I'm okay with it. So I, and that's something I've never had to do in the past. So it's. For my own safety I've had to accept that there are some things I can't be independent with.

P12: And I think a lot of it is not to do with the fact that you can't do it, it's that you don't have the confidence.

P11: No no no, yeah.

I: Would you say that you identify with the diagnosis? What impact would you say it's had on your identity, how you see yourself?

P12: I kind of ignore it most of the time. I think that you must be aware you must be aware of that from where I talk and my attitude. There are times when I have to accept it because I notice I'm not managing to do something. Or I'm not. I don't really know how to describe it properly. It's an intuition that hang on a minute you're finding this more difficult than you would have done before. I have a real problem with facial recognition so yeah. So sometimes people, it's not with somebody I've known for like three or four visits. But you know if I've only seen somebody twice I might actually not recognize who they are, you know. I might well I've got you firmly in my head now but I might well look at your face and not remember your name is so you know there are things like having to to accept in that sense. I still put it down to lack of independence because the whole effect of that means that I am not an independent person anymore because in order to be safe, safeguarding's always been a big thing in my life for others I have to accept that I'm not safe if I don't have that ability. So. So perhaps that's something I have to be careful with but also doesn't
I: What has S's diagnosis meant in terms of how you seen her. Do you see her differently in any way?

P12: No I don't see her. She's still S to me. And when, she does have bad days and good days and when she has a bad day I just think we'll know that's not her. That's just to the illness you know. I don't see her any differently really. She still does 90 percent of what she's always done. There's not much that she's still not capable of doing and we know that will change but you know. Life is like that. And you know it. If you just stay with it. You know we could, I said, I tell her everyday, I've said, we got what we got we've got to make the best of it. You know and that's my philosophy on life you know. It's no good expecting miracles. But we have got a good life. We've got a nice home. You know I'm always going to be here for her. We'll get by whatever, no matter what. She says no we won't and I say yes we will (laughs).

P11: We still do things independently though. Don't we?

P12: Oh yeah, well I think as (says name) said at the (says hospital name) one of the nurses. She said to me do you do things on your own? And I said Yeah. You know that's important that you do. You know you must. You must have a life as well. And you know football and drink with the lads and things like that.

P11: Friday night out.

P12: Yeah. So. But you know she knows it. I think S knows I'm here and I'll always be here for her. And. We'll cross every bridge when we get to it.

I: S, how did you feel about sharing the diagnosis before you came to the groups?

P11: Within the group obviously I knew I was gonna share it so that wasn't a problem. I haven't actually really changed my opinion about who how who and how I want to share my diagnosis with from how I felt before the group. I still feel exactly the same about that. I'm on a need to know basis and not only a need to know basis but also if I am sharing it with somebody I'd like them to know who I am. Before they know you know. So I'm not going to go away and you know go into a shop or an environment you know where I'm there for the day or something and say Hi I'm S, I've got Alzheimers you know I just, I don't think it's necessary. There might come a time when it will be I think there will come a time when it's obvious unfortunately. A gentleman who worked for R a couple, well about a year ago now and was struggling hard with that particular project. He was doing for R and already I'd been diagnosed at that point. And I said to R are you sure he hasn't
got, you know, cause you start to recognize it in people don't you. And he's just had his diagnosis recently, hasn't he?

P12: Yeah

P12: He's much further down the line. Yeah. Yeah yeah. So it will be recognizable in me at some point.

I: And before you came to the groups were there any any people with whom you felt conflicted about sharing the diagnosis with?

P11: Oh lots of people. Lots of people. Yeah I have a real strong view of that, real strong

I: That kind of not sure to tell but want tell but weighing it up, that kind of conflict?

P11: Yeah, I think I'm more black and white. I think I'm more black and white yeah there's some people I would tell and some people I won't. I thing that's, I'm very black and white about that.

I: So you would you say then that you weren't conflicted about sharing it then?

P11: yeah if you want to put it in that way yes. Yeah probably. Yeah.

P12: You share it with who you want to share it. Yeah. I mean it's true. It was interesting. One of the interesting things from the meeting was the way that (says attendees name) seem to want to tell everybody you know that he had a problem and that's interesting in the fact that the two views diametrically opposite you.

P11: Can I just ask you a really difficult question with (says name) the gentleman who's come from a Jewish background.

P12: No no, that was (says name).

P11: Okay because I've been brought up in a Jewish family. And we have lots of celebrations and lots of festivals. The talk around the dinner table is about everyone's diagnosis. That is the joining point of everybody once they discovered which bracket of wealth you're in or whatever. All they talk about is who's got what illness and that's. And I was brought up in that and I always swore as a child that I would never ever ever have that conversation unless it was so obvious like there's
blood pouring out my eyes or something. And I guess that's my is I've carried it all through my life.  

P12: I can only surmise that he does that as a safeguard he's laid down really early is safeguarding his self and his actions.

P11: Yeah yeah. I know and I understand that he is a bit further down the line than me.

P12: Well I don't think he was actually I don't think he was I think he was in a similar situation but you know you're different people different personalities you know you deal with it differently.

I: R how did you feel about sharing the diagnosis before you came to the group? I know you said it in the group but please feel free to say it again.

P12: Well, S made it pretty clear that she didn't want anybody to know. Obviously our immediate family knew, the children and whatever. To be honest there are a couple of friends that I did, have shared it with but they know S and they know that she is, she can have a normal conversation. The word is Alzheimer's or dementia or whatever word you use. As S just said, you go directly to the end result. And there's a large gap before you get to that end result. But they don't see, they don't, when they hear that someone's got Alzheimer's they think she's in a sorry state and doesn't, don't know who I am. So especially that, they needn't know. It is good for me to have a couple of friends and they, all they say now is, how's S, still the same, you know or I would say an improvement in your cognitive ability (laughs). So yeah I I. So in the main I don't tell people. Our neighbours know. Because I've told one of them across the road. And I think you must have told (says name)

P11: Here mum's got Alzheimer's. It was her dad wasn't it and she knows me so.

P12: But no, as far as we know only 2 of the neighbours know.

I: Would you say you experienced, before you came to sessions would you say you experienced conflict in terms of who you shared with?

P12: No. I think I've got a similar view to S's in that you know it's a need to know basis.

P11: We discussed it quite early on.

P12: There are people when it would become more obvious. And you know they will know. At the moment S doesn't want to feel that she is isolated from the rest of society by anything. And so if
people get cheap or think of you differently. She doesn’t want that to happen. So if they don’t know then she’s safe. 64

I: And S you said that. I think it was a word that you used in the group, you experienced a great deal of trepidation about coming to the group and being in that group context and obviously by extension because of what the group was about it meant telling others about the diagnosis. Do you think that coming to the group meant that you were kind of changing your opinion about who you would share the diagnosis with in any way even in a small way?

P11: I didn’t particularly mind coming to the group. My big issue which is still my big issue and it’s a very personal thing and probably very selfish of me is that, obviously I’ve got no control over who’s in the group. So you’re going in, you’re stepping into the unknown. 65 Okay. So one of the things I’ve realized now is that I know I understand it’s part and parcel of this diagnosis is that you, I have always been quite an anxious person. You get anxious and and that was my anxiety of how I was going to deal with this, opening up, telling strangers, as it happened, you know the people in the group were lovely it all went really well. You guys were great as well. 66 This is very very new for me. I’ve never been ill in any shape or form. I’ve always been a leader. I’ve always very much been on my own, my mum died when I was 13. You know I’ve been responsible for my own life. I left home when I was 17. So I’ve been an independent person all my life. And so you know to to a certain extent I’ve always had to be responsible for me. I don’t have much in the way of family. So when you find all of a sudden you’re vulnerable which I have never been vulnerable before. 67 And I’ve got a lovely husband. But you know. There is every part of me that thinks you didn’t sign up for this. And if one day you decided you saw a lovely blonde bombshell and you wanted to go off with her I completely understand. You know there is I take all that stuff on board and think about it because you’re right. I’m functioning now but I don’t know what’s going to happen in the future. None of us do. In all fairness. But you know sort of I’m having to focus more on that thought and so that anxiety will always be with me and the anxiety. But what you do is you blank your mind to it. 68 So if you actually then asked to join in the group with people and I talked about this in the group about, you know, I know it’s almost impossible but you know to actually have groups focused on people with the same concerns that was helpful. It was open it was really good and the people were lovely that were there and I think we all got on really well. And you know there was no judgments at all involved. 69 And and it’s my own problem my own psychological problem that I don’t want to look into the future because it’s just a place I don’t want to go. Obviously financially all that sort of thing we’ve dealt with that side of it but you know in my everyday life I just want to be me who I am today. Yeah. If we’ve got trips planned or something like that the safeguarding thing of me I’ve had all through my career comes into being. And I just think safeguarding issues I would do it when I was taking kids on trips, check the route see where the buses are you know memorize that and I would do that if I was taking children out you know.

I: Would you say the sessions have made any difference to how you maybe think about who you share the diagnosis with or how you share the diagnosis with them or how you feel about sharing the diagnosis or how you even act as regards sharing the diagnosis? Would you think that say the sessions have made any impact at all on that aspect?

P11: Well you’ve obviously made me consider it. I’m actually there probably some people I’ve started sharing it with that I hadn’t in the past, to feel safer and more supported, but they were
always still people I knew. But they were perhaps people but I didn't see very often. And you know but intrinsically I don't think I've changed my mind at all. I still think that this is my diagnosis. this is my private world but I'm actually quite private person.70 I've always been a private person so maybe I'm the wrong person to be asking those questions.

P12: Well ironically I think we mentioned it at the last session. We had recently had a meeting coming, her best friend from school days.

P11: Yes.

P12: She came down from Manchester. We had a meal with her at the weekend and she said what's wrong with you. Now before the session we would have brushed it off but

P11: She's my, I met her at nursery. She's my childhood friend.

P12: So anyway we told her what it was.

P11: She lives in Manchester. So I mean I see her about once a year. But I would never have not considered telling her. But I think what I might well have wanted to do and I felt the session confirmed for me was that I wanted to tell her face to face.

P11: In person

P12: Yeah, Yeah.

P11: And so that's actually what did happen wasn't it and she could see when I was talking that I was still the same S as she remembered because we were in fits of laughter.

P12: Now I don't think her view has changed at all but I think it's helped to think it through.71

I: Would you say that your view either either how you think about sharing the diagnosis or how you feel about sharing the diagnosis or even how you act around sharing the diagnosis has changed at all as a result of the sessions?

P12: I don't think it has changed that much because to be honest I try to do what S wants to do. If if her if she took the (says name) line and I want to come out with it then fine.
P11: You would be alright with that wouldn't you?

P12: Then we would let people know. But because that's not what she wants. Yeah I abide by the rules so to speak, and I think everyone got to deal with it in their own way. S definitely doesn't want to, she wants to be seen as she was. And at the moment she can get away with it so

P11: there'll be a time when I won't and that's when we'll have to tell everyone you know especially if it's a safeguarding issue. And I keep going back to the whole safeguarding issue. You know I was trained in safeguarding. I know when I've been I've been working with children and families and I've gone into child protection meetings. When when I do update, when I did the update training which we had to do every year, one thing they banged on to us every time was that information that you have on children and families does not get shared unless you're in an environment like child protection meeting where the professionals are there and you share the information. Okay. And you have to sign the documents saying that you understand that. And I know that my diagnosis makes me a vulnerable adult. Just as a child who's in child protection is a vulnerable child. So therefore. Because maybe I have this knowledge I also know that my, nobody has a right to share my information unless I gave them permission. Um and so maybe R's at a disadvantage because he hasn't had the sort of training I have. I know we're quite a private person. And yeah. Yeah. Um so I guess the sort of knowledge of that and the privacy and I've seen what happens when people have information that cannot be relied on and use it in a bad way within families. So I've seen the other side of it. I'm um so I'm just maybe more wary than most people would be. Who didn't come from that background. So maybe I'm the wrong person to ask because I have such a different view of it.

P11: Both of you in different positions. S you have the diagnosis and R you're living with the diagnosis. How well would you say that the sessions addressed your differing needs from those two perspectives?

P12: Well I found it interesting in one particular session where we've sort of shifted round seats and I sat next to (says attendee name) and talking to her it was interesting because S has, does have mood swings and she gets angry quite quickly sometimes and. She was saying exactly the same about (says attendee name) that he you know he he and she finds it difficult and I just said well that's not really them. It's just not to take it personally if they get angrier. And that was interesting talking amongst yourselves as two spouses or whatever you want to call it. So I did find that interesting to being able to talk to them at this session and in some ways it would've been nice to have a session with just them. Because I can't say things that I might find as true but will be upsetting for S. And you know there are. And just to find out how other people are it how they deal with the same situation. My my my view is I've had some really bad ups and downs in my life and my view with it is that I let it all go over my head. If I bite it it becomes a fight.

P11: I mean one of the other things that you have to bear in mind is that R and I both had careers you know. You know obviously I was in teaching so we had to go wallabies and stuff but we were busy. You know the kids were at home. We had careers. We were. We have busy lives. The amount of time we actually spent with each other was any couple you ask who's got children and they've got separate careers. You don't actually spend that much you might make a meal together
every now and again or you know and R had his own friends and I had my own friends and I'd been catapulted into a life as he has where we are pretty much in each other's company 24/7 if we choose to be. We have a big house and we do different things in different rooms and stuff. And R has his own friends and I have mine and we really work hard at making sure we've got our own spaces. But you know my career is gone. R still does a little bit here and a little bit there and and adjusting to that has been quite difficult too. And yes I am short tempered. I am quite dominant.

P12: I would add to that, she is (says place of birth).

P11: Yes. I've always had to fight to find my place. Yeah. So as you do in some careers. So I've always got opinions and I'm basically actually I don't think we do too badly now we're thrown together 24/7. And in fact you know sort of to a certain extent not long after we went on our first holiday when I wasn't working we actually found that we really cared for each other a lot. So that was quite a nice revelation as well. It was about a rekindling of our relationship. But that's necessity for, to protect yourself which I've always had to have. Because I've been on my own a long time you know really sort of from the age of 13 without a mum. And then from the age of 17 having left home I've had to be responsible for myself. And in R's not my first husband, in previous relationships I've pretty much been independent person in those relationships to have an independent career.

I: So how well do you feel that the session met your needs as a person living with the diagnosis?

P11: I'll be honest it's such a new thing for me I'm not entirely sure what my needs are. I have you know I only have my own consideration of why I feel I need to certain extent and it doesn't seem to be an awful lot out there. So it's very much you know you sort of find your own way. And yes. So I'm. It's kind of difficult because as you probably aware I'm an opinioned key person so you know perhaps I'm. Perhaps I'm not the norm not the norm in terms of you know what people whose expectations with but I would be fighting for families needs and you know you know getting in touch with other agencies and putting that in place. I mean that's one of the things I've said to R you know if I was working with a family who were very disadvantaged perhaps or facing housing problems domestic violence blah blah blah involved with mental health issues I would be connected to all those different agencies and putting in place meetings probably going with them to those meetings getting the best deals for them or whatever but you know we'd be writing papers about that. But that's on a one to one basis because obviously my job was then to work with these families and maybe somebody who hasn't come from my background would not have that kind of expectations. That was a fairly unique position. I thought it would be nice to be able to know where to go for things and maybe to now and again have somebody who can fight your corner for you because I'm. I don't have knowledge in this issue. I don't know what's out there and to be honest it's sometimes incredibly difficult to get any isn't it.

P12: Yeah we we have to struggle with getting good help to push you know in fact. To be honest we gave up to be honest. S said I'm not going through this again, so we didn't.
P11: In the field I come from again go back to families and this is ridiculous because it doesn't relate to this at all is there would be one person who represented you which was me who then went to all these agencies and then spoke to them and said they need this this this and this Okay can we have a meeting and then that person would come I'd have the parent in probably and we would talk through what we'd need to do. Now I'm finding that when I haven't got the wherewithal to do that totally I mean you've seen me at my best time, you want to see me in the afternoon I can't put sentence together. We we just get fobbed off I mean I know it's a busy world there's not much money there and there seems to be a lot of agencies who are out there who maybe don't communicate with each other or don't have connecting you know sort of ways of doing things. Bear in mind this is an epidemic it really needs to be a little bit better coordinated. 

I: And would you say that the sessions met your needs around exploring disclosure decisions with others?

P11: I think it in the sense of having a discussion it did, it didn't change my opinion but it was interesting to hear other people's opinions and what I would say was in my head it completely justified my own opinion of what I wanted to do of how I wanted it to be. I know it conflicted with some of R's and I completely understand and that's something that we have to iron out between us but you know maybe that was good it came out in the open anyway. So it was interesting to hear other people's versions of how they dealt with things. They were all considerably older than me as well you know, certainly one gentleman he told me he was in his 80s and I didn't mean to be very rude but you know by the time I'm in my 80s I doubt whether I'll have limbs that work or you know there would be a lot a lot of other things that are not working for me I won't actually care who knows what. I mean my hair will have fallen out yeah yeah probably have sticks or something but I'm in a difficult position in that if you see me in the street you would just think I was an ordinary person.

I: And R do you think the sessions met your needs around exploring disclosure decisions?

P12: Yes, but as I say my needs irrelevant in terms of who knows and who doesn't know, it's what S wants at this moment in time. So I wasn't there to, the fact of telling people or not telling people was not really my priority. My priority is to sort of try and get support and be able to talk to people in a similar situation and it was good for me. In terms of disclosure who knows and who doesn't know I stick to S's rules that's how she wants it.

I: And finally was there anything that either of you would like to feedback about any aspects of the sessions at all?

P12: As I said earlier that. It would have been. I thought it would have been beneficial for the carers or husbands to be able to talk amongst themselves independently for a while. For half an hour or have a separate session where they just come alone.

P11: I think the definition of carer means that they aren't able to.
P12: Because I have to be careful on what I say because S gets upset quite quickly if I say something that might upset her. So you know you have to sort of tread quite carefully.

P11: Well I think you need that. I think you need to be able to talk about your side of things when I’m there and in a private session and not care about what I say or hear because I don’t know what might upset you. And that’s a really important factor to be honest. I mean one of the reasons I agreed to do this was so that R might well have some support because I completely understand as I keep saying he didn’t sign up for this.

P12: There’s not a problem at all.

P11: You do need support. You know this is not something we anticipated in our lives and he needs independent support.

P12: The one thing that does hit home hard for me is I come from a big big family. And at the last moment my mom my mum’s generation died recently. She had the Alzheimer’s. she had no children. And it was left to me and two other cousins had to do everything for her.

P11: And the two other cousins didn’t live locally.

P12: No. And I did.

P11: And I’m very aware of what R has seen.

P12: And you know. I know what’s coming. And S doesn’t.

P11: And I don’t want to know.

P12: So yeah sometimes I need to talk to people and just say you know; this is happening what’s happening with you. And just to have a conversation that we both are familiar with, that are familiar with the problem. You know you talk to people. Not that I do. But you’re here, the two or three people I’ve talked to you have no experience of dementia at all.

P11: You used to come home to me and tell me how it was before I knew about the diagnosis or certainly before I was sure about it. Tell me horrendous stories about the state you found her in and everything, didn’t you.
P11. And the home wasn't exactly very successful was it either.

P12. She went in there at a relatively early stage and. She still had vocabulary and what have you. I think if you'd gone into a home that wasn't just for dementia but for a broader spectrum her brain might have been stimulated more she was just put in a chair and left. But nobody talked to coz nobody else did, no one else wanted to talk, you know. But she used to have her own she she loved it when, well how it worked was we used to go every week. My brother and I would go and my two cousins would go. So every week somebody would go. But her niece and nephews, I saw her every week sometimes but mostly every fortnight. And you could you could see it meant so much for her because she could actually talk about it. She didn't remember everything. And yet the irony is I used to take photographs from when she, childhood photographs of my mother's and she could remember, she could remember all

P11. You know you used to come back and you'd say to me you know nobody knows where false teeth are. Nobody knows where her bra is.

P12. Yeah.

P11. They don't know where her knickers are. This is a home you're paying for. You know prisoners wouldn't be treated like that

P12. The irony is we were paying

P11. A lot

P12. 107 pound a day. Yeah seven hundred seventy pounds a week and we expected more.

P11. And R was the main contact and he comes home to me and finds out I've got the beginnings of the thing that he's just seen the end of.

P12. Yeah. But you know it's it's tough but you know we will make the best of it.

P1: And would you recommend this programme to someone else who's living with it right now?

P12. Oh I thought it was good. As I say I wouldn't have minded going for another three.
P11: I think anything like this is useful because I don't think there's enough done. I truly don't. I think that well I don't, I think it's been swept under the carpet I think that people with dementia can be like me, is not the end of my world.  

P12: Sorry to interrupt. How did you find out about us? How did you get our names?

I: Join Dementia Research. So S has a profile on Join Dementia Research and that means that

P12: How did you get a profile on there?

P11: Because I joined it

P12: Oh did you.

P11: Yeah but then all of the stuff that came through and then we ended up going to (says place name) clinic didn't we. We had a whole lots of tests done. And then they told me you've actually not got the right Alzheimer's. And then they were about to do another one including a lumbar puncture and turned up on the day and the guy turned round and said oh sorry we've just read your notes and you know this is not relevant to you. So. And the same actually happened in the (says hospital name) at least they didn't actually take me on, cause I hate being fiddled with. You know I've never been ill, I've never had to have anything horrible happen to me you know. And. I was doing it obviously. You know. Not strictly totally for altruistic reasons but you know sort of in the hope that somebody might find something that worked for me that would work for other people too and to put myself through stuff I hated became ridiculous and in fact what stopped me which actually and obviously not that daft was that when we went to leave on that day when I think what had actually happened was one of my blood results come back with a funny result it's because I was taking hay fever tablets and had done something wrong. It was the right in the height of hayfever. And they said we're going to do another blood test but now you're here. And you know obviously you will be able to go further with the program if it turns out that you've still got the issue. And she said would we still do the lumbar puncture. And I said well would the lumbar puncture be relevant regardless of the blood test and they went no. And I thought Well no and you're not doing, a horrible thing to have done anyway. You're not doing it. And then I realized afterwards they probably get paid for that every time they do those tests they get paid for doing it. I mean my logic suggested that was the only reason they did it and I just thought No no I'm not doing any more of these so. So that was fine and so the only thing I do now is through the (says hospital name) because they have been absolutely amazing. But you weren't offering me anything that involved any kind of medical intervention or tablet taking. And so I just thought well I'm fine with that I don't mind doing that at all but that's, unless the (says hospital name) want me to do something I'm not doing anything else at all.

Recording ends.

Annotations
1 Yalom's group processes.

Overcoming barriers to attendance - the importance of similar stage presentations.

2 Overcoming barriers to attendance - similar stage attendees.

Coping strategies: "I wanted to be slightly blindfolded", avoidance and/or "live in the now", present focus.

3 Overcoming barriers to facilitation: mild/early stage wide range; seeing others and the impact it makes

4 add to annotation #3...the balance; seeing others at a similar stage and impact on the self.

5 session experience: a bigger, more diverse group; a desire for more perspectives.

6 the impact of knowledge; "it left me feeling quite emotional. Just managing it".

7 session experience / interview: an opportunity to reflect on unmet needs.

8 Mismatch: question vs content of the answer. A desire to talk about the impact of dementia, a sense of responsibility to resist? the progression. *Normalization*, striving to adapt to changed circumstances to keep a sense of normality.

9 impact of dementia; a loss of independence, a loss of ability.

10 group processes: being with similar others, a shared identity. Finding your own path.

11 session experience, an opportunity for a unique experience, challenging the idea of what dementia looks like.

12 session experience: challenge of creating a "same stage" group. The spousal connection. The value of honesty around a difficult topic.

The session experience - extending beyond the aim of the sessions (exploring the disclosure decision making process) to a discussion of who people coped with the experience of living with dementia. An argument for bringing this into the remit of future sessions.

13 Providing an "opening" - link with P9 and 10.

14 Session experience; an opportunity to explore ideas in a safe space with similar others and reflect on these ideas.

15 Valuing "honesty".

Experience extending beyond the aim of the session - a sharing of the experience and coping with living with dementia.
Experience "pleasant"

Experience safe "it wasn't something you need worry about", a safe space to talk about it for attendees who don't disclose widely.

Experience of connecting with others, overcoming the isolation that can come with dementia, overcoming isolation? in the dyad "it was good to hear S admit to her situation which she normally wouldn't do, only to me but never to anybody else."

16 a safe space - disclosing beyond the dyad.

17 session experience - extending beyond the aim of the session, beyond disclosure.

18 "mild symptoms" - a wide eligibility criteria - challenge of balancing multiple perspectives with similar stage, similar experiences.

19 a safe accepting space; overcoming the taboo, a space for attendees to not have to mask? their symptoms. Continuing theme of an "open" space.

20 Breaking down the barriers around dementia and yalom's group processes; "a camaraderie", "we're all in the same boat", "it broke down barriers", "you are just there for one purpose".

Identifying the difficulting of getting support and information; "useful being with people who were professionals..."

A space for support for the carer within the dyadic frame. Carer only support difficult to find and perceived as "concentrating a discussion in the wrong way". Something about the session space providing a space of openness, acceptance and transparency in the dyad.

21 extension of the "opening" theme - what happened around the session. The session itself being stimulating but also the act of getting to and from the session being valued by attendees as well. An opportunity to explore.

22 Session content as valuable.

23 participants' felt they were providing a valuable contribution; a space to foster an empowered identity.

24 a desire for the participants for the sessions to have an extended remit. Dealing with the impact of dementia..."funding".

25 see 24. a sense of unfairness. The extra stressors at work in dementia.

26 Fear of the future. avoidance as a strategy to live well with dementia.
the challenge of groups...mild symptoms presenting differently...impact on others.

Disclosure in the context of dementia, "the PR has to be changed", dementia stigma.

Challenging the stigma of dementia: living well with dementia.

good facilitation

challenging the isolating elements of dementia.

a safe, accepting space.

session experience: providing an opportunity to extend the support network.

"too simple"; session aim and remit vs desires of attendees, more support with managing the symptoms, ways of living with dementia "more solution focussed".

extends annotation 33.

coping strategy; "the glad game"

living well with dementia

a desire for a wider remit - ways of managing the symptoms of dementia.

90 minutes, "the right length".

Mismatch: sessions aims and the hopes of the participants...solutions for living with dementia.

last session - touches on session drift...aims of the session vs hopes and desires of the attendees and the way in which this impacted on the content of sessions.

attendees session hopes - offering a chance for a contrasting emotional experience when living with and talking about dementia.

more weeks: speaking to the theme of a wider remit...going beyond a discussion of disclosure.

acceptable session materials.

good facilitation, a safe space, active listening.

see annotation 43.

a desire for more sessions.

USP of the group. Challenging the isolation of dementia.

see 46...yalom's group processes.

group format acceptable...identifying unmet needs.
being ignored...the invisibility of dementia vs...

being treated with respect.

losing and maintaining independence...caregiver supporting the maintenance of a sense of personhood.

d the dyadic acceptance and adaptatio to the changes that dementia brings

dementia leading to a loss of confidence and then a loss of independence.

coping strategy - ignoring vs having to face it.

coping strategy: recognising limitations and using adaptations to maintain a sense of identity.

coping strategy: externalising dementia. "when she has a bad day i just think well you know, that's not her", seeing the person apart from the dementia.

coping strategy - acceptance, gratitude, stoicism, working with the dementia.

sessions providing an opportunity to experiment with an otherwise firm disclosure approach.

an opportunity to hear multiple perspectives.

cultural factors informing the disclosure approach...not wanting dementia to dominate the conversational space.

the group as an opportunity to witness dementia in others, a sense of that's not me.

Disclosure decisions determined by the PLwD.

Dementia "PR"; stigma preventing disclosure "you get to the end result...they think she's in a sorry state"

Informing the timing of sessions; a support for early on in diagnosis.

Non-disclosure, a way of protecting the identity "S doesn't want to feel that she is isolated from the rest of society"

experimenting with the firm disclosure position, "Stepping into the unknown"

the session as an opportunity to provide a positive disclosure experience from other attendees and facilitators. A safe space to practice disclosure. Challenging anxiety.

a shift in the identity; introducing vulnerability.

coping strategies: avoidance of thoughts related to the future.

a safe, accepting space to bring up a difficult and sensitive topic.

sessions offering an opportunity to reflect on disclosure approach. Considering the intention behind the disclosure approach "to feel safer and more supported"
session as an opportunity for reflection and a chance "to think it through", confirming the approach.

disclosure process; disclosure approach determined by the PLWD, a sense of the support respecting their position "I abide by the rules", giving them a sense of empowerment.

diagnosis = vulnerability

annotation 73 vs maintaining control. My diagnosis, my information.

disclosure decisions informed by past experience.

something memorable about the experiential exercises; separating the dyad...a chance to connect with other supporters, share strategies.

the sessions extending beyond the session aim: attendees naturally gravitated towards strategy sharing. a supporter only session...extending the remit of the sessions inline with the hopes of the attendees. An argument for a multi-component session that allows for the dyad to speak about their experiences around disclosure but also ways of living with dementia, practical and psychological strategies.

dementia diagnosis...a radical shift in one's day to day existence.

dementia; a chance to reconnect.

a sense of a lack of support for those PLWD and their families.

see 79, a lack of support.

see 79, a lack of support.

an opportunity to discuss disclosure; gaining multiple perspectives.

extending the opening theme...bringing up sensitive topics within the dyad in a transparent way.

the "difficult position" of early stage dementia; "you would just think I was an ordinary person".

the position of the supporter "my (disclosure) needs are irrelevant".

Attendees choosing to attend not for the advertised purpose of the group but to "Try and get support...".

the treatment of the dyad in the sessions; a request for a separate carer session. A chance to bring sensitive topics up transparently when both member of the dyad are present but also a chance to talk about it separately without a filter.

the disclosure approach raises the issue of support for the supporter.

a desire for more sessions.
any support is useful, a felt sense of a lack of support. "anything like this is useful because I don't think there's enough done".

89 Psycho-social tx research; for some a more acceptable alternative to other more invasive approaches.
Appendix M: Mind map of the final themes and sub-themes

The diagnostic experience – stigma vs. relief

- An uncertain future
- You get the label carer – new roles and responsibilities
- A cross on your back – a constant fight
- What does dementia look like

A chance to open up
- A safe space
- A safe and positive disclosure experience
- Opportunities to hear multiple perspectives
- A new support network

Keeping control and maintaining identity

- Denial and minimisation
- Keeping it congenial
- Playing the glad game
- Following the rules of disclosure
- Caution over disclosure

Wanting more

- Too much repetition
- A mismatch between the intervention’s aims and participants’ expectations
- Wanting time apart from each other
- The challenge of meeting multiple needs
Appendix N: Endorsement of themes and sub-themes by participant

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<th>1 A cross on your back</th>
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<td>1:1 The diagnostic experience; stigma versus relief</td>
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<th>2 Keeping control and maintaining identity</th>
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