

*This is the peer reviewed version of the following article: West, M., & Hogan, K.F. Carers' experiences of dementia support groups: A qualitative exploration. Counselling and Psychotherapy Research. 2020; 1:136-142, which has been published in final form at <https://doi.org/10.1002/capr.12253>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.*

Carers' experiences of dementia support groups: A qualitative exploration

## **Abstract**

Dementia rates are growing (WHO, 2017) and as dementia is associated with a loss of independence, carers are required. Caring for a dementia patient places great demands on the carer's resources (WHO, 2017). Previous research has indicated that whilst carers are at increased risk of poor mental and physical health (Diener & Chan, 2011; Mahoney et al., 2005; Mausbach et al., 2007) there are some effective protective measures against these increased risks (Cooper et al., 2012; Elvish et al., 2013; Kaufman et al., 2010). *Aims:* This study aimed to evaluate a dementia support group, in relation to protective measures including social and emotional support, in a real-life rural setting from a carers' perspective. *Method:* Fourteen informal carers of dementia patients were interviewed about their experiences of attending dementia support groups. The interviews were transcribed verbatim and subject to thematic analysis. *Findings:* The analysis showed that attendance to the support group was associated with subjective well-being, and that social support provided by the group was both stimulating and supportive for the carers. Participants valued the opportunity to share their experiences of being a carer with fellow group members and finding out about resources. Frequently, participants reported that that the time period surrounding their loved one receiving a diagnosis of dementia was traumatic

and they needed time to adjust to their new circumstances before attending a support group. *Conclusions:* Implications for wider employment of support groups as a format of support for carers are discussed.

**Keywords:** dementia; support groups; carers; psychological well-being

## **Introduction**

According to the World Health Organisation (WHO) dementia is a syndrome which is typically chronic or progressive, and has a negative impact on cognitive functioning, emotional control, and social behaviour (WHO, 2017). Worldwide dementia is a major cause of loss of independence in older adults, it is estimated that worldwide 47 million people have dementia, and it is believed that by 2030 this number will have increased to 75 million (WHO, 2017). The Alzheimer's Society estimates that in the UK there are currently 850,000 people with dementia (2019). The loss of independence associated with a diagnosis of dementia means that carers are required to ensure the safety and well-being of the dementia patient. It was reported that there are currently around 670,000 people in the UK who are caring for a loved one with dementia (Alzheimer's Society, 2014a). Moreover, it is believed each year carers save the UK economy approximately £11 billion (Alzheimer's Society, 2014a). Whilst the UK government report that enabling dementia patients to live in their own home for longer is now a priority (Department of Health, 2016), caring for a dementia patient places great demands on the carer's resources in terms of their physical and psychological well-being, social activities and finances (WHO, 2017).

*The effects of caring for a person with dementia*

Diener and Chan (2011) conducted a review on subjective well-being, health and longevity and reported that subjective well-being has a clear and strong relation to physical health and longevity, and that positive affect is also implicated in health and longevity. However, caring for a person with dementia can have a significant impact on the carer's physical and psychological well-being. Mausbach, Patterson, Rabinowitz, Grant and Schulz (2007) reported that carers of dementia patients may be at increased risk of cardiovascular disease (CVD), whilst Mahoney, Regan, Katona, and Livingston (2005) found that carers of dementia patients were at increased risk of experiencing anxiety and depression. Such impacts on physical and psychological well-being may in turn impact on the carers' ability to look after their loved one. Furthermore, Holst and Edberg (2011) report finding a relationship between dependency and suspected depression in the patient, and for carers satisfaction is increasingly (as the disease progresses) associated with the state of mind of the patient, and the patient's level of dependency. Taken together, this evidence highlights the importance of psychological well-being in both the carer and patient.

### *Promoting the psychological well-being of carers*

Many psychological interventions have been conducted with the aim of ensuring the well-being of carers of dementia patients with varying degrees of success. A systematic review of such interventions was carried out by Elvish, Lever, Johnstone, Cawley and Keady (2013), who identified twenty studies and categorised the interventions into four types. One type was the Psycho-educational skill-building interventions; these were described by Elvish et al. (2013) as involving increasing knowledge about dementia and providing coping strategies to help manage their caring role. Furthermore, this type of intervention also provided information on local

services and encouraging social networks. Elvish et al. (2013) report that psycho-educational, skills-building interventions may help to maintain carers' well-being over time. Moreover, a systematic review by Cooper et al. (2012) explored the effectiveness of behavioural interventions to improve quality of life of dementia patients. Cooper et al. (2012) found that interventions which focus on helping the carer to develop coping-strategies, to manage behaviour, communicate effectively and schedule pleasant events are effective at improving quality of life in the dementia patients. Cooper et al. (2012) also report that tailored activities for the dementia patients may also contribute to improved quality of life for the dementia patient. This suggestion is corroborated by the findings of Holst and Edberg (2011) which found carers satisfaction is associated with the state of mind of the patient.

#### *Social support and carers' psychological well-being*

Social support has frequently been reported as being associated with subjective well-being (Siedlecki, Salthouse, Oishi, and Jeswani, 2013; Safavi, Berry, and Wearden 2017; Strandenaes, Lund, and Rokstad, 2018). Kaufman, Kosberg, Leeper and Tang (2010) examined the relationship between social support and life satisfaction (a facet of subjective well-being (Siedlecki et al., 2013)) in carers of dementia patients who live in a rural community. The authors found a positive correlation between life satisfaction and social support. Furthermore, having others to talk to and socialise with, and receiving positive regard and self-esteem from others accounted for 32% of the variance of life satisfaction scores for the rural carers (Kaufman et al., 2010). These findings highlight the importance of socialising for those in rural communities, which the current research study investigated.

#### *Rational*

The aim of this study was to explore the individual experience of attending drop-in sessions run by experienced staff trained to work with carers and dementia patients. Drop-in sessions provide carers and dementia patients with the opportunity to make friends, socialise, and share experiences, and provide carers with information and support. Whilst previous research has reported benefits associated with interventions which utilise some of the features of the drop-in sessions e.g. social support and tailored activities, in an attempt to provide in-depth understanding of the benefits associated with information sharing (Elvish et al., 2013), tailored activities for the dementia patient (Cooper et al., 2012), and social support (Kaufman et al., 2010), it is necessary to explore real-life situations in a rural setting, best achieved through a qualitative methodology. Furthermore, as subjective well-being is reported to have a strong relation to physical health and longevity (Diener and Chan, 2011), it is important to explore whether carers perceived attending these support groups impacted on their psychological well-being.

This research attempted to go some way to fill the gap in current understanding on coping mechanisms in relatives of persons with dementia and respond to the recommendations of UK-based researchers by exploring factors which improve the patient–relative relationship and enhance psychological well-being (Safavi, Berry, and Wearden 2017).

## **Methodology**

### Design

A qualitative methodology was utilised in this study in order to generate rich interview data. Semi-structured interviews were used which were then analysed using Thematic Analysis. An experiential qualitative research stance was adopted in order

to facilitate understanding of how participants perceived, experienced, and made sense of their experiences of belonging to a dementia support groups (Braun & Clarke, 2013). This study was underpinned by a contextualist perspective which assumes 'reality' can be (partially) accessed through the language of the participants (Braun & Clarke, 2013). Thematic analysis was employed as it is flexible and suitable for use with a wide range of philosophical approaches (Braun & Clarke, 2006).

## Materials

In an attempt to enhance understanding of dementia carers' experiences of attending a drop-in support group and address the aims of this study, the interview schedule included questions about participants' experiences of attending the group and what they perceived as helpful as well as barriers to attending groups.

Demographic information was obtained from the participants including age, ethnicity, and occupation.

Interviews were audio recorded, transcribed verbatim and stored on a password protected computer. Hardcopies of participant information sheets, consent and debrief forms were stored in a locked filing cabinet.

## Participants

Participants were fourteen informal carers of dementia patients. All participants had been attending on average once a week for 2 years (ranging from 3 months to 5.5 years), in the capacity as carer, of a support group for dementia patients. The mean age of participants was 70 years (range = 51-84) and the majority were female (Male = 2). See Table 1 below for further details of the sample.

INSERT TABLE 1 HERE

## Ethics

This study was granted ethical approval from the university ethics committee. The BPS (2014) code of ethics was also adhered to. Written and verbal consent was obtained from all participants. All participants were given pseudonyms in order to maintain confidentiality. All data was stored in accordance with the Data Protection Act (1998) (this research was conducted prior to the introduction of GDPR in 2018).

## Procedure

A single investigator attended various drop-in sessions across a rural county in the West Midlands. The purpose of the research was explained to all participants and face-to-face interviews were conducted in a private room within each centre. All interviews were digitally audio recorded. The semi-structured interview schedule offered participants the opportunity to express issues of importance to them, whilst capturing the areas the researcher wished to explore (Braun & Clarke, 2013).

Interviews varied in length from fifteen minutes to 65 minutes. Each interview was transcribed verbatim. Thematic analysis was used to analyse the data, following the six-phase process set out by Braun and Clarke (2006). Themes were selected because they were deemed to capture something of importance in relation to the research question (Braun & Clarke, 2006). Each theme had a central organising concept, which captured a pattern or meaningful aspect of the data, in relation to the research question (Braun & Clarke, 2013).

## Results

The analytic process generated three themes (see thematic map 1.1 below). The first theme was 'An opportunity for social interaction', within this theme there were two sub-themes: 'Stimulation is offered by the group', and 'Providing a relaxed atmosphere of support'. The second theme was 'Sharing experiences and information', and the third theme was 'Initiating attendance requires strength'.

INSERT TABLE 2 HERE

### **Theme 1 An opportunity for social interaction**

This theme captures the way in which the participants described their experience of belonging to a support group as a source of social support, which had a positive impact on their psychological well-being. The carers described how the group offered them companionship, through sharing experiences which was therapeutic for the carers, whilst attending the groups were both stimulating and provided a relaxed environment for them to be themselves. For some participants the group offered a source of guidance and education on further supporting their family member.

Carers repeatedly reported that social interaction was a particularly important benefit of attending the group. Frequently, carers reported that they valued sharing their experiences with somebody who was going through a similar experience, for example: "It's just nice to know that there are other people that you know with similar problems" (Sue).

Carers indicate that belonging to a group where the members are all in a similar position and experiencing similar events in their relationships and home life was especially important. Belonging to a support group provided the carers with a place to share their experiences, which helped them to feel more positive about their



situation: “I went out of here feeling quite different because there was someone else with a similar problem” (Bob). Bob’s account demonstrates the value of having a shared experience with group members which alleviated low feelings and isolation.

Furthermore, the carers report that the social interaction provided by the group was also of particular benefit to those they care for. For example: “He’s [service user] sort of relaxed enough within the group [...] he actually says that he enjoys it” (Liz). Some participants reported that their family members enjoyed the social interaction offered by the group, even if this did not involve direct conversation: “Ken can’t talk erm he still seems to enjoy the company of others” (Beryl). For some participants, the group offered an opportunity for further learning about the needs of their family members, for example: “the opportunity to do various activities throughout entertainment and that sort of thing and I thought that she wouldn’t enjoy that and as it turned out she did (laughs) which was amazing” (Kate).

### **Subtheme 1.1 Stimulation is offered by the group**

This subtheme captures participants descriptions of attending the group as offering them stimulation. Carers expressed that attending the group is important to them because it gets them out of the house and enables participation in the activities which are run during the group sessions and that this stimulation positively impacts on both themselves and the person they care for.

Frequently participants described a noticeable difference in the behaviour of the person they cared for, which in turn affected their own psychological well-being, if they were unable to attend the group, for example: “The days when we don’t go out and we stop in I notice a difference” (Trish). The carers described the stimulation provided by the group as being of particular benefit to their family member, for

example: “because something’s going on he’s interested he’s alert all the time so for me yeah it’s invaluable really” (Barbara). The stimulation offered by the group was perceived as beneficial and enjoyable for both the dementia patient and the carers: “we enjoy the music but I think it’s very important just to get out” (Trish). Trish’s account suggests that attending the group offered a positive experience that both she and her family member (who had dementia) could enjoy together.

Many of the carers described the group as having a positive impact on their own psychological well-being: “When I come I feel so differently I feel much better” (Jan). Often carers reported that attending the group and the stimulation that it provides was helpful in preventing loneliness and feelings of isolation: “I think we’d find [not attending] quite erm quite stressful really very lonely in lots of ways” (Jan). Frequently the carers reported that the group provided mutual but different forms of stimulation for themselves and their family member, for example: “There’s a couple of people there I’ve got quite close to and it’s really nice to have a chat but Mum just sits there, if there’s a hymn she knows then she’ll join in... I felt [the group] was as much for Mum’s benefit as it was for mine” (Kate).

### **Subtheme 1.2 Providing a relaxed atmosphere of support**

The second subtheme captures the way in which participants described their experiences of attending the groups as providing a relaxed atmosphere, which was underpinned by a shared understanding of dementia within the group which in turn alleviated a need to worry about other peoples’ opinions and judgements about the person they cared for: “It’s almost like being at home you know it’s quite comfortable” (Sue). Whilst in the group session participants described having some fun and an opportunity to relax, without the need to worry about the behaviour of those they care

for, for example: “You know I can just I can relax and just let her [dementia patient] just babble on and just get on with whatever she wants” (Sue).

Participants reported feelings of shame when they attended a place where the nature of their family member’s dementia was unknown: “she [dementia patient] used to come to [external organisation] with me and we’d have a speaker and she’s sat there she’s fast asleep er it’s quite embarrassing and I think it’s uncomfortable for the person... well here whoever is performing or whatever they know so it’s that comfort really” (Trish).

The carers’ narratives demonstrated the stressful nature of caring for their loved one and opportunities to relax are rare. Belonging to a group provided carers with an opportunity to positively reflect on their experiences and laugh with fellow carers: “there’s a serious side to this it’s not nice but you can laugh about it at times with what happens and so it’s quite nice really” (Beryl). Beryl’s narrative indicates that the shared understanding of living with dementia provided group members with a forum to discuss both the serious nature of dementia as well as the value of sharing humorous negative experiences which Beryl continues to describe as a valuable source of strength: “it is lovely and that’s what a lot of what we get out of it really”.

## **Theme 2 Sharing experiences and information**

The second theme captures participants’ description of the educative nature of the group. Some of the carers described information sharing as a particularly positive aspect of belonging to a group. Most participants reported that the group made accessing information quick and easy. Information that participants most valued included providing information on sources of support to further their ability to care for their loved one as the nature of their condition changed alongside the carers’

personal circumstances, “[the group] gives us information and will sort of guide us along on where to go” (Hazel) thereby offering an ongoing source of support.

During the group sessions information is shared between carers on various aspects of life ranging from shared experiences of being a carer to finding out about resources. Some participants described the value of asking questions and sharing experiences with fellow carers, for example: “you’ve sort of got questions and someone has been through something similar which is useful” (Liz). Liz’s account captures the value of receiving information from others who have been through or are going through a similar experience which helped the carers to continue to provide support. However, some younger carers described feeling less connected with the group on account of generational differences and having additional work responsibilities. For example Sue reported: “if I were Mum’s other half if it was husband and wife you know and you’re both at that stage in your life erm but I am not I am a generation younger [I have] my life to lead er I have my work to do and I have all the rest of it”.

Some participants reported that the information and guidance they received from the group helped them to provide better care which was particularly challenging when they lived with their loved one, for example: “when you’re living with somebody you just switch off from it and you can’t you just can’t do it well I can’t” (Sue). The group support appeared to offer the carers an opportunity to reflect on their on-going experiences and provided a forum for enhancing their ability to support their loved one, even when this became more challenging over time.

In addition to carers sharing information between themselves, the group facilitators were perceived as knowledgeable, and able to provide valuable information and

guidance: “I know if I’ve got a particular issue problem then there are people there I could chat to people who could point me in the right direction” (Kate).

### **Theme 3 Initiating attendance requires strength**

The final theme captures the factors that influenced the carers’ decision to attend and join a support group. The carers made reference to the psychological impact of caring and the need for support. Initiating contact with a support group at a time that was right for the carers was particularly significant. Frequently the carers felt overwhelmed following the diagnosis and needed time and space to adopt to their changing circumstances before making contact with a support group.

Whilst attending the group was deemed beneficial by carers to both themselves and those they care for, it is apparent that when the diagnosis of dementia is given it is a traumatic time for all involved. Carers report that at this time they receive a great deal of information and everything can seem overwhelming. Initiating attendance of a new group requires a great deal of inner strength and resources which are often not available, for example: “I did have a lot of literature [about the drop-ins] but I don’t know what it was I just didn’t feel comfortable with it [initially]” (Bob).

Almost all of the carers cited the needs of their family member who had dementia as a mediating factor in their decision to join a support group, rather than for their own needs. Carers typically described a desire to do something extra for their family member which they perceived the group as offering, for example: “Mum’s been diagnosed with [dementia] for about four and a half five years, so, yes and I just thought it was like something like yes I needed to get Mum out to be doing something (Sue). Sue’s account demonstrates that the time since receiving the

diagnosis was as an influencing factor in her decision to join a support group in order to be 'doing something'.

It is important to note that almost everyone interviewed intimated that they needed time to adjust to their new circumstances before they could consider attending the drop-ins support group. Moreover, the few carers that did contemplate attending soon after receiving the diagnosis found the idea insurmountable and reported that attending too soon was detrimental, for example:: "It was at the very beginning but I can't yeah yeah it was too soon" (Trish). Trish further described this experience as too much to cope with: "I remember thinking 'I can't do this' it was just too much", and in some instances joining a group was intimidating: "I tried and I got put off" (Kate).

## **Discussion**

This study provides a subjective evaluation of the experience of attending a support group from the perspective of carers of dementia patients. On the whole participants described attending the support group as a very positive experience. Thus, it seems that attending these support groups has a positive impact on carers' subjective well-being, which in turn is likely to have a positive impact on their health and longevity (Diener & Cahn, 2011). Health of carers is of the utmost important if the UK government are to achieve their aim of enabling dementia patients to live in their own home for longer (Department of Health, 2016), given that caring for a dementia patient places demands on the carer's well-being, social activities and finances (WHO, 2017) as well as placing them at greater risk of experiencing anxiety and depression (Mahoney et al., 2005). Therefore, ensuring carers get time to socialise, relax and enjoy themselves is likely to play a critical part in maintaining their health

and quality of life (Livingston et al. 2013; Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006), and this is particularly relevant in a rural setting (Kaufman et al., 2010). As social interaction was one of the main themes throughout the data it seems the drop-in sessions provided the opportunity to do exactly that i.e. time to socialise, relax and enjoy themselves. This finding extends the findings of Kaufman et al. (2010) in that social support seems to be linked to subjective well-being in a rural setting.

The support group was reported not only as extremely beneficial to the carers, but they also believed that attendance was beneficial to the people they care for. Many carers reported noticing a positive difference in the mood and behaviour of their loved one following group attendance, with opportunities for them to join in with the activities run during the sessions. This subjective benefit of attending the group corresponds with the benefits of an intervention reported by Cooper et al. (2012) that tailored activities for the dementia patients can contribute to improved quality of life for the dementia patient, which in turn improved the well-being for carers.

Another commonly reported benefit of attending the support group was being able to get accurate information about what services and resources are available locally. This fits well with the findings of Elvish et al. (2013) who reported information on local services and encouraging social networks was found to be beneficial. Such information can often be difficult to obtain, even with the use of the Internet. Knowing where to start can be overwhelming at the best of times. Carers tended to be older adults who typically are less au fait and more easily confused with using the Internet (Zickuhr & Madden, 2012). In addition, they can be overwhelmed both physically and mentally by the demands of caring for a dementia patient. Therefore, being able to obtain information from trusted members of staff or other carers who have

themselves accessed the information and/or resources is reassuring and thus reduces stress (Hope, Schwaba & Piper, 2014).

A further recurring theme evident in the data was initiating attendance. Carers reported feeling so overwhelmed at the time of diagnosis that they did not know whether or not they had received information about the group at that point. When they did eventually decide to attend the group, it was often as a result of some informal communication or chance encounter. This is an important finding that may apply to any support group provider, and thus it seems that it may be a good idea that such providers consider their process of contact carefully and ensure timing of the invitation is appropriate.

There were additional factors which might be worth considering when organising entertainment for group attendees e.g. poor eye-sight, poor hearing and poor motor skills. In addition, travel distance was raised by many. Having the group within walking distance was a large determinant of group attendance, especially given that not everyone had access to a car, and public transport in rural areas is generally poor in terms of frequency and coverage. If more groups could be run within walking distance this would benefit the carer and the patient in terms of getting more physical exercise which in turn could help contribute towards improved health and well-being (Booth, Roberts & Laye, 2012; Taylor et al., 2017). Alternatively, it would be advantageous to attendees if support group meetings could be held in places in the community which have existing accessible transport links e.g. town centres rather than villages.

### *Limitations*



These findings offer tentative understanding of carers' experiences of belonging to dementia support groups. However, consideration should be given to the limitations of the sample and the small-scale nature of this qualitative study. All participants and those they care for identified themselves as being of White European origin.

According to the Alzheimer's Society (2012) more than 25,000 people from ethnic groups in the UK are affected by dementia, however, these groups are not represented in this study. Support groups need to consider how they could encourage ethnic groups to attend and how the specific needs of ethnic groups could be incorporated in to the sessions. Furthermore, it is recommended that further research is carried out to investigate the extent to which diverse ethnic groups in the UK engage with dementia support groups.

A further limitation is that the majority of participants were female who were attending with a male dementia patient. This is not representative of the fact that more women than men are diagnosed with dementia in the UK (Alzheimer's Research, 2018). Therefore, it is recommended that future research examine factors which influence males attending dementia support groups with the aim of addressing any barriers in order to encourage greater male attendance at such groups.

The majority of participants in this study reported that they were retired, reflecting the average age of the sample (mean age 70 years). Given that most participants reported that belonging to the support group provided social support by getting them out of the house and that they valued meeting carers in a similar position, these findings may have been shaped by participants' age and stage of life. Some younger carers did speak about the impact of age on their experience of caring and belonging to a support group, citing generational differences in the experiences and needs of carers. However, this finding needs further exploration.

## Implications for counselling practice

This study has evaluated the individual experience of attendees of a dementia support group in a rural setting. Participants' accounts demonstrate that subjective well-being was positively impacted by attending the group, and that those aspects of the group activities found to be similar to features of successful interventions e.g. information sharing (Elvish et al., 2013), and tailored activities for the dementia patients (Cooper et al., 2012) were greatly valued by the participants. As is the benefit of social support (Kaufman et al., 2010). Participants' accounts support the findings of previous research which were efficacious in a real-life setting. Counsellors may benefit from greater understanding of the symptoms of dementia and the potential negative impact on psychological well-being to both the patient and the carer(s), in particular the loss of independence associated with a diagnosis of dementia. Participants reported feeling overwhelmed at the time of diagnosis and receiving information about sources of support in coping with their role as carer. Being aware of services and sources of support available locally which counsellors can sign post carers to may be beneficial given that participants valued obtaining information about sources of support from trusted professionals.

Counsellors should be mindful of the benefits of group-based support given the positive experiences reported by carers in respect of the opportunity to share their experiences of being a carer with fellow group members and finding out about resources. Support groups may enhance well-being and quality of life for both the carer(s) and dementia patients.

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**Table 1: Characteristics of the sample (N = 14)**

Race/ethnicity	White British (13) White French (1)
Age of carer (range)	51-84 (mean: 70)
Age of the person with dementia	70-89 (mean: 79)
Relationship between carer and dementia patient	Spouse (11) Sibling (1) Parent-child (2)

Table 2: Carers' experiences of dementia support groups – themes and subthemes

