Carers Transition Group: A personalised group that reflects the changing needs of spousal dementia carers in transition

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Abstract: *Spousal dementia carers face loss, ambiguous grief, and guilt during their partners transition into long-term care (LTC) (Gibson et al., 2019). The Carers Transition Group is an effective group intervention for spousal dementia carers who are facing the tumultuous transition of their partners entering LTC. A support needs assessment tool based on the CSNAT (Ewing et al, 2013) was used to identify individual and group carer support needs and assure that group sessions accurately reflect the same. Mutual support with other spousal dementia carers coupled with psychoeducational and psychosocial interventions both inside and outside of group sessions led to overall positive outcomes.*

Keywords: *dementia, carers, transition, long-term care, nursing home, residential care, social work, groupwork*

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Introduction

According to the World Health Organisation (2023), more than 55 million people are living with dementia globally, with dementia identified as the seventh leading cause of death and a major cause of dependency and disability among older people. Women are identified as disproportionately affected, as they experience both higher mortality and disability adjusted years due to dementia, as well as providing 70% of the caregiving (WHO, 2023). In Ireland, an estimated 55,000 people are living with dementia (DSiDC, 2022), with approximately 60,000 informal carers providing care for persons with dementia (PWD) in their communities (O'Shea, et al., 2018). The adverse effects that dementia has on a carer's holistic health and well-being has become of increasing concern for health care professionals (Cherry et al., 2013). The combination of cognitive impairment and behavioural difficulties often associated with dementia can make caring for the person a very challenging experience, with poorer physical and mental health often reported by carers (Teahan et al., 2017). The progressive nature of dementia, strain of caring for the person around the clock and limited access to fragmented support services are cited as factors which influence the decision to admit a relative to long-term care (Argyle, et al., 2010). Data suggests that 32% of people with dementia in Ireland are likely to be on the cusp of moving to long-term care (O'Shea & Monaghan, 2017). The process of transition often evokes strong emotions and conflicts for carers, such as sadness, guilt, a sense of failure and relief (Argyle, Downs and Tasker, 2010). This paper explores groupwork as an intervention for supporting spousal carers and fostering resilience during the transition to long-term care (LTC) [1]. Research indicates that spouses can gain emotional validation, a sense of belonging and opportunity to gain perspective through regular contact with other spousal carers in support groups (O'Shaughnessy, et al., 2010).

Impact of the dementia journey on spousal carers

Spousal carers of PWD 'face unique challenges as they adapt to the demands of caring whilst experiencing significant losses in their couple relationship', (O'Shaughnessy, et al., 2010: 237). When looking at the relationship between the PWD and the caregiver, the dynamics of the relationship are very important (Kneebone & Martin, 2003). As echoed by Balkie (2002), the couple relationship in dementia is both intimate, but also one that potentially faces interpersonal and intrapersonal stresses arising throughout the dementia caregiving journey. Lau, et al. (2017: 451) further emphasise both the importance and the misunderstanding around the dyadic relationship in their discussion of Thomas Kitwood's work, noting that it is 'a common misconception about dementia caregiving is that the relationship is a one-way drive involving the caregivers giving without the carer recipients reciprocating,' (p. 451).

Managing stressful situations within the relationship can also have a bearing on the morbidity statistics for the caregiver and the quality of life of the person living with a dementia (Monteiro et al., 2018, Myhre et al., 2017). The ambiguous loss caused by the duality of a spousal carers partner being physically present yet psychologically absent due to dementia and the profound impact this has on spousal carers is well documented by Boss (2010). The gradual demise of a life partner, (the most important adult attachment) is well recognised as being more stressful than that of a parent or other family member (Cherry et al., 2013). Spousal dementia carers are more likely to be older (and possibly more frail), to co-habit with the person and therefore experience more day-to-day tasks of caring and associated stressors, and also have fewer opportunities for respite. Spousal carers generally experience higher levels of carer burden and poorer mental health (Teahan et al., 2018). A systematic review by Chan et al., (2013) highlighted that being a spousal dementia carer and the experience of depression were the highest predictors for complicated grief.

Participants of a small-scale qualitative study conducted by Gibson, et al., (2019) who cared for their spouses with dementia prior to their death, described feelings of grief throughout their caregiving journey. They highlighted intense experiences as most impactful during transitional phases, with the time that their spouse moved to long-term care described as the greatest period of grief. 'This decision often followed the realisation and recognition of their spouses' decline in health and their own limitations to care for their spouse', (Gibson, et al., 2019: 5). Withdrawal from social activities, either due to carer stress or physical exertion associated with caregiving was identified by participants, and is also our tacit experience with the cohort of spousal carers who attend the Carers Transition Group. Changing relationships, building new relationships with LTC staff, confronting their evolving carer role and emotional distress due to feelings of guilt and loss are some of the main issues facing spousal carers with a partner in LTC (Duggleby, et al., 2022). Loneliness has also been identified as a key element causing emotional distress in spousal dementia carers and one that does not necessarily improve once their partner enters LTC (Holton, et al., 2023).

There is some research into the support needs of family, and in particular, spousal dementia carers (Brooks, et al., 2022), which has identified a diverse spectrum of support needs: lack of psychological preparedness and knowledge about dementia (in particular disease progression and end of life), and the confusion and stress in accessing the LTC system as contributing factors to carers' psychological distress during this period. A small-scale study by Fitzpatrick and Grace (2019) in the Australian context, highlighted that dementia carers valued the support, information and resources provided by social workers and other healthcare staff during the transition to LTC.

Groupwork as a supportive intervention

Most research into effective group interventions for spousal dementia carers is predominantly focused on interventions that diminish caregiver burden and delay entry into LTC (Dickinson, et al., 2017) and take place whilst the PWD is being cared for at home. There is limited research on group work interventions specific to this cohort at this turbulent time of transition (Brooks, et al., 2022; Duggleby, et al., 2011). And as noted by Dickinson, et al. (2017), multi-component interventions have been found to be effective with dementia carers, however, it is not always clear which components are the most effective and why. Most recent research into group-based interventions for dementia carers has used burden as a measure to determine effectiveness, whilst other smaller studies have used well-being as an outcome measurement (McLoughlin, 2022). Quantitative data from group interventions for dementia carers has been mixed, however, McLoughlin (2022) noted that one intervention study found highly favourable reviews of group interventions, which clashed with mixed findings about well-being. In fact, the review conducted by McLoughlin (2022) found that with the exception of group CBT interventions [2], the effectiveness of psychoeducational or support group interventions on improving dementia carer well-being were mixed.

A study by O'Shaughnessy, et al. (2010: 254) indicated 'that peer group support provides emotional containment and information as carers learn from each other'. One participant described the support group as engendering feelings of understanding, security and acceptance from other group members. While another spouse described her peer support group as providing support, understanding and gained perspective on her own situation through comparison with other group members. An ethnographic study by Lauritzen, et al. (2022: 1225) [3] conducted with carers of PWD at home highlighted how peer interaction within a support group 'strengthened the carers' sense of self' and aided the development of positive changes in carers' social and personal self-images to fulfil their needs. Participants also expressed finding the relationship with the dementia coordinator helped them to feel worthy of support by the health care system (Lauritzen, et al., 2022). The study, however, highlighted the carer's need for group support to be more focused on their perceived emotional and support needs, rather than on the care recipient's situation, and cautioned that some participants felt drained by the negative experiences expressed by other participants (Lauritzen, et al., 2022).

Carers Transition Group (CTG)

The Carers' Transition Group (CTG) is focused on prevention of complex grief, promotion of resilience, improvement of well-being and support needs outcomes for the carer and facilitating positive outcomes for the dyad as a whole during the transition into LTC. Development of the Carers Transition Group (CTG) grew out of an identified need for added emotional and educational support for spousal dementia carers during the transitional period between in-home care and placement in a LTC facility due to the aforementioned challenges (Allen & Flynn, 2017). All group members are spousal carers of PWD who are currently patients of a Mental Health Service for Older Persons [4] and are currently in LTC or in the process of transitioning into LTC. The CTG is a closed group and participants are identified by a member of the inter-disciplinary team. The CTG is comprised of 6 sessions, running for 5 weeks consecutively with a break of three weeks between the 5th and

6th sessions. The composition of the most recent CTG was made up of 7 members: 3 women, 4 men. Not all members were able to participate in all 6 sessions, due to illness or caring obligations. The group was facilitated by two social workers and a clinical nurse specialist, who have extensive training and tacit experience in supporting grief and loss in the dementia journey. A co-facilitator with lived experience also works together with the main group facilitators to connect session themes to their own experience.

Whilst the CTG has been running for approximately 10 years, it was recently restructured to reflect the most up to date research into family/spousal dementia carer support needs and interventions for this cohort. The CTG is a psychoeducational and psychosocial support group for spousal dementia carers. Its objective is to improve spousal carers' knowledge about issues specific to this transitional period and to identify ways to improve carer well-being through reflection and self-care to improve outcomes for both the PWD and the spousal carer. The structure of the group and focus of the sessions reflects both past experience in facilitating the CTG and research into specific spousal carer needs during this period (Duggleby, et al., 2022; Brooks, et al., 2022) and the most up to date evidence-based interventions for this cohort (Duggleby, et al., 2014; Duggleby, et al., 2020; Peacock, et al., 2021). Each session focused on a specific theme, such as communication with LTC staff to improve behavioural and well-being outcomes for their partner when transitioning into LTC, or the importance of self-care and creation of personal goals.

Ample time was given at the beginning of each session to allow members to share their own personal story and that of their partner and their experiences in caring for their partner at home and/or in LTC. Table 1-A (below) outlines the structure of the CTG and highlights elements included in each session and the tools used both during the session and as 'homework'. In addition to facilitation and discussion of topics, group members also receive narrative and expressive writing exercises created specifically for spousal dementia carers in this period of transition (Peacock, et al., 2021), educational resources about dementia and evolving relationships during this transitional period (Henderson & Thom, 2005), mindfulness and self-care resources and tools, and signposting to further supportive and practical resources in the community.

To enhance discussion and meet the psychoeducational and psychosocial needs of individual members, facilitators sent emails between sessions to connect members to outside resources in the community and offer further tools and exercises based on topics of self-care and transition/grief that members could work on in their own time. Additionally, co-creation meetings involving the co-facilitator helped to highlight session focus and enhance communication between groups; as a result sessions took place every three weeks to allow for ample time for reflection. Furthermore, where members missed sessions often due to caring demands, the facilitators followed up by phone and connected them with resources and supports as required. This flexible, person-centred approach allowed participants to continue their journey whilst away from the group, further underscoring the benefit of a hybrid format.

Spousal dementia carers support needs assessment tool

As noted previously, a focus on carer burden or carer well-being may not be an effective method of intervention measurement (McLoughlin, 2022). For the CTG, a support needs assessment tool was developed based on the Carer Support Needs Assessment Tool (CSNAT) (Ewing, et al., 2013), which was originally developed for palliative care family carers and has been shown to be an effective person-centred, carer led support needs assessment tool for dementia carers who are caring for their loved ones in the community (Auon, et al., 2018). The support needs assessment was self-administered by all members at the first and final groups. The purpose of the tool was dual in nature: 1) to ensure the individual sessions and tools utilised therein accurately reflect the specific needs of the group and 2) to ensure the group meets the individual needs of all members. Whilst not meant to be a stand-alone outcomes measure, the tool does provide a clear picture of the support needs of each individual spousal carer as they move through their caring journey and together with the group questionnaire evaluation, a clear understanding of the group's effectiveness is formed. Six participants completed the support needs assessment tool both at sessions 1 and 6. The majority of participants' support needs reduced greatly from session 1 to session 6. This reduction in support needs, however, also appears to be reflective of where each individual is in the caring journey, as those

Table 1: Topics, and resources and tools

Week 1 Topic: Getting to know you & the group

- My Story – Our Story Writing exercise helping spousal carers reflect on what they are experiencing currently
- Spousal Dementia Carers Support Needs Assessment Tool

Week 2 Topics: Transitioning to Nursing Home Care – The Carer's Journey & How to communicate with nursing home staff

- This is me Life Story document to help spousal carers communicate with nursing home staff about their partner and how they can best care for him/her.
- Life for Caregivers after Placing a Relative with Dementia in a Nursing Home Guide for carers from Living Well with Dementia and TCD
- VIDEO Edith's Story About Edith's journey as a carer for her husband and his transfer to a nursing home.

Week 3 Topic Self-Care, Supports, Coping Strategies & Goal Setting

- What helps me? Hand-out to help identify supports and coping strategies.
- My goals for ME Hand-out to develop personal wellness related goals.

Week 4 Topic:Hope & Continuing to care whilst living apart

- Everyday Hope Hand-out to help identify sources of hope during the caregiving journey.
- Reclaiming Yourself – Writing Journal tool to help process emotions during the challenging transitional period, both as a carer and a spouse.

Letting Go Without Giving Up – Guide to continuing the journey as a carer for one's partner whilst they are in nursing home care

Written Instructions & Video on Simple Hand Massage

Week 5 Topic: Keeping on top of your well-being & Living with Hope

- Wellness Wheel Exercise – Identifying personal strategies for improved well-being in various spheres of the spousal carer's life.
- Connecting with Hope video Spouses and Family with Family Member with Dementia in LTC
- Seeds of Hope Video Asking for help to bring hope alive
- Group Evaluation & Identification of issues to cover in final group session (handed out for return before final session)

Week 6 Topic: Wrap up focussed on continuing the focus on self-care, resilience & mindfulness

- Mindfulness March Calendar - small daily mindfulness activities whose partner has settled well in LTC communicated they require little to no support, whilst those still caring at home or whose partner has just moved into LTC require more support.

Group evaluation

At the end of the 5th session, group members were asked to complete a group evaluation and return it to the service in anticipation of the 6th and final session. The group evaluation tool asked participants' questions about the quantity and length of sessions, size of group, whether they felt understood and were also asked to rate the effectiveness of facilitator communication. Six (6) out of the seven (7) participants completed the group evaluation tool. All six (6) participants noted that the group was beneficial and felt the size of the group was *'just right'*. The number and timing of the sessions was also highlighted by several participants: one participant felt that a *'monthly drop-in would be good'* after completion of the 6th session, whilst a continuation or extension of the group was noted as being necessary by another. *'I could see the need for such a group therapy tp (sic) continue long after admission to nursing home care. The conflict between staying strongly involved with one's partner in care and trying to live a life outside doesn't seem to diminish.'* Two (2) out of the six (6) participants felt the number of sessions was insufficient. In fact, all participants agreed there was a need for a 'booster' session and as a result, after completing the final 6th session, it was agreed to hold a session approximately three months later.

Feedback was overwhelmingly positive regarding session content, group size and structure and facilitator communication. The majority of participants felt the tools and resources were Helpful, Quite Helpful or Very Helpful. All participants felt that all six sessions were either Quite Helpful or Very Helpful. Several participants commented that simply hearing the experiences of others was comforting as they were often so similar to their own. Participants also appreciated that sessions were tailored to needs expressed in the assessments and others expressed during group sessions. One participant noted that the sessions were *'very personalised - not just theoretical'*, which she found *'very supportive and reassuring.'* One of the most effective and powerful elements of the group was the supportive nature of the group and the ability of all group participants to feel connected and understood by the other members, due to the fact they all have a spouse with dementia who is currently or about to be in LTC. When asked to list what they found to be *'the most beneficial thing about attending the group'*, every respondent noted that meeting and sharing emotions and experiences and feeling understood with people in similar circumstances was the most beneficial element. During the 'booster' group session, participants remarked that it was the sensation of not having to explain one's situation, of being intrinsically understood, that created a feeling of reassurance and led to the ability to be emotionally vulnerable. The advancing nature of the disease opened existential conversations about spirituality, life and death. All of which seemed to flow naturally due to the foundation of understanding and security built by the group. It was decided by the group members that they would like to continue to come back to the group every few months to meet with each other and 'check-in'.

Discussion

While the negative consequences of caregiving are well documented, how some carers mitigate negative effects and even thrive as a consequence of their caring experience is less well understood (O'Dwyer, et al., 2017). 'Spouses can find meaning in their care, acquire new skills and feel close to the person with dementia through their caregiving journey', (Gibson, et al., 2019: 2). It is precisely at this moment of transition and evolution where support can help spousal carers to 'build a new life' as both a carer and spouse (Duggleby, et al., 2011). The experience of participating in a group with others experiencing similar life challenges and tasks is found to be validating, empowering and liberating, as group members realise they are not alone and that others share their feelings, experiences and reactions (Gitterman and Knight, 2016). Social work group work practice is illustrated as providing a 'natural means to exploit client's strengths and maximise their resilience and growth' (Gitterman & Knight, 2016: 457). Through their experience of walking in the same shoes as one another, group members have a keener understanding of the challenges and stressors of one another's lives (Knight and Gitterman, 2014). This credibility affords them the ability to provide a unique and valuable insight and support to one another. The mutual aid derived from walking in the same shoes as others is central to the understanding of why the group work modality exemplifies a strengths-based approach to practice that cannot be replaced by individual casework (Gitterman & Knight, 2016). However, the facilitators were cognisant of the benefit for some participants in receiving additional one-to-one psychological support to process difficult emotions or where they may be at greater risk of developing complex grief (Holland et al., 2009). For example, when a participant's spouse died whilst she was participating in the group, one-on-one grief counselling and usage of narrative therapy tools to develop purpose after the death of their partner were used (Peacock, et al., 2021).

CTG members will be at varying stages in their caregiving journey. Those earlier on in their journey may be inspired by the progress of others, while those further ahead may be inspired to continue their journey as they share their insights and are reminded of their progress. Carers whose spouse has already moved to long-term care and are 'still standing' have given hope to others whose loved ones are awaiting the move. Group members however also used the group process to express the challenges in communicating with nursing home staff and to express difficult emotions associated with the transitional phase. Therefore, whilst the diversity of journeys and experiences in dealing with adversity is recognised as having the potential to increase the group members' resilience (Gitterman and Knight, 2016), the timing of a groupwork intervention must be given careful consideration as some participants may feel drained by the negative experiences expressed by other participants (Lauritzen, et al., 2022).

The CTG's design is not static in nature; rather, it is reflective of the individual, changing needs of group members. As such, individual group elements and narrative therapy exercises are added to each session depending on the specific supportive needs of group members. A 'toolbox' of resources was identified that could be drawn from based on group and individual needs. Pauline Boss's book 'Loving Someone Who Has Dementia' and the importance of discussing ambiguous loss were found to be particularly impactful for participants and so added to the group content and resources. As previously noted, where participants missed sessions, this was often due to stresses associated with caregiving, such as lack of someone to assume the caring role whilst they attended the group or the sudden entry of their partner into hospital. Telehealth interventions to support dementia family carers during the transition phase (Brooke et al., 2024), may present options to address some of these barriers. Telehealth may also present a more convenient modality for those living in more rural settings with potentially less access to transport than the cohort in the current study.

Conclusion

There is little research and development on support group interventions specific to this cohort in Ireland. Our experience in developing and facilitating a Carers Transition Group (Allen & Flynn, 2017) has underscored the need for further research and development of supportive services for this cohort that will provide psychoeducational and psychosocial support throughout the caring journey whilst also reflecting the Irish context. Spousal dementia carers require support on dementia education, navigating the Nursing Home Support Scheme (NHSS), choosing a nursing home, transitioning into a new life after their partner moves into LTC, end-of-life care in dementia, as well as conflicting emotions related to ambiguous and complicated grief, guilt and loss (Brooks, et al., 2022; Duggleby, et al., 2022; Holton, et al., 2023; Gibson, et al., 2019; Lauritzen, et al., 2022). Such varied and evolving support needs require ongoing assessment and attention that reflects each carer's individual situation throughout the caring journey. Tacit knowledge indicates that exploring and supporting family dynamics and psychological supports are also important factors that enable better transition to long term care. This will have a beneficial effect on the person living with dementia as well as the carer to support their transition. Future research should focus on development of support groups that meet identified spousal dementia carer needs (Brooks, et al., 2022; Duggleby, et al., 2022; Gibson, et al., 2019; Lauritzen, et al., 2022) that are reflexive to the changing needs of both individual carers and the group, as a whole. Because of the nature of spousal dementia caregiving, any group work intervention must allow for members to miss sessions without missing out on valuable group content and the psychosocial benefits of the supportive group environment, therefore connection in between sessions and the consideration of other modalities of delivery, such as videoconferencing should be considered.

Notes

1. The term long-term care (LTC) used in this study refers to nursing home or residential aged care, that is distinct to respite, where someone may go for a brief period to provide respite for caregivers.
2. Which found that CBT interventions are not an effective way to improve dementia carer well-being.
3. Which explored how support group participation meets carers of PWLD (17 out of 25 of which were spousal carers) perceived needs for information, social and emotional support.
4. Mental Health Service for Older Persons is located at Carew House, St. Vincent's University Hospital, Dublin.

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