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'The oxygen of shared experience': exploring social support processes within peer support groups for carers of people with non-memory-led and inherited dementias

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ABSTRACT

Objectives: To explore support processes and behaviours taking place during online peer support groups for family carers of people living with rare, non-memory-led and inherited dementias (PLWRD).

Methods: Twenty-five family carers of PLWRD participated in a series of ongoing online peer support groups on the theme of 'Independence and Identity'. Transcripts from 16 sessions were analysed using qualitative directed content analysis with a coding framework informed by Cutrona & Suhr's (2004) Social Support Behaviour Code (SSBC).

Results: Most of the social support behaviours outlined in the SSBC were identified within the sessions, along with two novel social support categories – 'Experiential Support' and 'Community Support' – and novel support behaviours including 'Advocacy and Collective Action' and 'Uses Humour'. The SSBC code 'Relationship' appeared to be of central importance.

Conclusions: This study sheds light on the unique challenges of the caring context for those affected by non-memory-led and inherited dementias and the significant contributions carers can offer to, and receive from, peers in similar situations. It highlights the importance of services which recognise the value of the informational and emotional expertise of carers of PLWRD and encourages the continued development and delivery of tailored support for these populations.

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Introduction

Dementia is an umbrella term describing a number of different conditions with varied underlying causes, all of which lead to progressive decline in various cognitive functions (Prince et al., 2015). Dementia is associated with substantial economic and social costs for individuals, families and wider society (Prince et al., 2015). Approximately 50 million people worldwide have a type of dementia associated with Alzheimer's disease, accounting for 60–70% of dementias and affecting mostly people over 65 years (WHO, 2020). There are, however, other types of dementia in which non-memory complaints are the leading symptom, and people living with these conditions can experience changes in personality and behaviour (as in behavioural variant frontotemporal dementia (bvFTD)), problems with speech and language (as in the primary progressive aphasia (PPA)), or dominant difficulties in visual and spatial processing (as in posterior cortical atrophy (PCA)) (Crutch et al., 2017; Marshall et al., 2018; Piguet et al., 2011). Some dementias are also directly inheritable such as familial frontotemporal dementia and familial Alzheimer's disease (Greaves & Rohrer, 2019; Ryan et al., 2016).

While calculating the prevalence of these rarer dementias is complicated by their being under-recognised, they are thought to account for ~7% (Brunnström et al., 2009; Snowden et al., 2007) of all dementias and ~10–20% of dementias in

people under the age of 65 (Hogan et al., 2016; Koedam et al., 2010; Kvello-Alme et al., 2019). Despite this relatively low prevalence, non-memory-led and inherited dementias directly affect ~115,000 people in the UK (i.e. 7% of: people with dementia (~59,000) and carers (~45,000) as well as 11,000 individuals at-risk of genetic dementias (Bekris et al., 2010; Greaves & Rohrer, 2019; Ratnavalli et al., 2002).

Most rarer types of dementia disproportionately affect those under 65, bringing with them a range of additional challenges commonly associated with young onset dementia including impacts on family care commitments, employment and finances (J. Carter, 2022).

The atypical symptom profiles and the typically earlier age of onset result in additional, and distinct, challenges for carers of people affected by rare, non-memory-led and inherited dementias. For example, the lack of empathy, apathy and disinhibition that characterise bvFTD is associated with increased carer burden and poorer quality relationships with carers (Karnatz et al., 2021). More generally, the often-earlier age of onset of these conditions can also result in challenges relating to employment and finances and issues with childcare commitments (Millenaar et al., 2016). All of these factors combined can contribute to an impact on independence and sense of identity for carers (Svanberg et al., 2010). These problems can be exacerbated by limited awareness about, and consequent

lack of tailored support for, young onset and non-memory-led dementias within the health and social care sector (J. Carter et al., 2018; Tookey et al., 2021). The often-convoluted diagnostic journey brought about by gaps in services has been shown to contribute to carer stigma, anxiety and frustration (Harding et al., 2018; Roach et al., 2016). Peer support services are therefore vital for those affected by these rarer dementias, often filling the gap between professional services, patients and the public (Shalaby & Agyapong, 2020), although the delivery of condition specific or young onset peer support is largely limited (Sullivan et al., 2022).

Peer support can be defined as nonprofessional psychosocial support given to, or received by, individuals with similar circumstances or lived experiences of distress (G. Carter et al., 2020). It takes many forms including, but not limited to, one-to-one support, peer delivered services and self-help groups, with the latter being the oldest and most widely used model (Solomon, 2004). Peer support increasingly takes place online via social networks, forums and video-conferencing software, and these forms of support have been shown to deliver similar outcomes to face-to-face models, whilst also allowing for increased accessibility and flexibility of delivery (Banbury et al., 2019). Peer support can have positive outcomes for carers of people with dementia (e.g. reduced depression, perceived burden) (G. Carter et al., 2020), however the multicomponent nature of interventions, lack of consensus on outcomes and inherent complexity of groups makes it difficult to untangle mechanisms (Sullivan et al., 2022; Walker & Peterson, 2021).

Shifting the focus to the processes of social support—how it is delivered and received—rather than just the outcomes, may offer insights into the mechanisms of peer support. This, in turn, may help with targeting peer support interventions towards the most relevant outcomes for various populations. In this study we sought to understand the nature of the social support delivered in virtual peer support groups for family carers of people living with rare, non-memory-led or inherited dementias (PLWRD).

Methods

Design

A qualitative directed content analysis was used to explore and outline the support processes and behaviours taking place during tailored video-conferencing (VC) peer support groups for family carers of PLWRD. The study was conducted as part of the Rare Dementia Support (RDS) Impact Study (Brotherhood et al., 2020), with ethical approval granted by the UCL Research Ethics Committee (8545/004: RDS Impact Study).

Sample

Twenty-five family carers of people with non-memory-led or inherited forms of dementia attended a series of experience-sharing peer support groups based on the theme of 'Independence and Identity'. Participants were members of the University College London (UCL)-led Rare Dementia Support service—a national service offering support, advice and information to people affected by rarer forms of dementia. Members are required to be affected by or supporting someone with a rare, non-memory-led or inherited form of dementia. Members were invited via email to take part in a range of experience-sharing and information-giving peer support groups on different

themes, and places were allocated on a first come first served basis and according to preference. Here we report on the experience-sharing 'Independence and Identity' themed support group for family carers. All participants provided informed consent for sessions to be recorded and used for research purposes. In the first instance, four separate 'Independence and Identity' themed peer support groups were established with between five and nine participants in each. After the initial planned 3–4 sessions per group, 20 out of 26 attendees expressed an interest in continuing meeting with their peers, resulting in the four original groups being merged into two continuing groups (of 9 and 11 participants) which continued to meet every four weeks for a further 18 months.

Data collection

Sessions lasted between 1–2 hours and were led by two co-facilitators, with experience of working with individuals affected by different dementias. The first 3–4 sessions for each group included structured prompts from facilitators relevant to the theme, after which the sessions were opened up for more free-flowing, attendee-led discussion. The ongoing merged sessions were less structured and lightly facilitated. Further information on session content and structure is available in [Supplementary File 1](#). Sessions were conducted and recorded using the *GoToMeeting* (LogMeIn Inc., 2016) video-conferencing platform and recordings were uploaded to a secure server. A sample of 16 sessions were selected for analysis. To encourage representativeness, an equal number of sessions from the initial, more structured groups and from the ongoing, less structured groups were selected (eight from each). Additionally, sessions were selected across the lifespan of the groups so that different levels of familiarity were represented, as well as sessions which reflected a range of group sizes. Sessions were transcribed by a third-party transcription service, and the transcripts were anonymised prior to analysis.

Data analysis

Qualitative directed content analysis (Hsieh & Shannon, 2005) was selected to explore the social support delivered in peer support groups as it provides a way of analysing textual data which focuses on the language used, as well as the content and contextually situated meaning present within it, using a pre-existing theoretical framework (Hsieh & Shannon, 2005). It provides the opportunity for the analysis to produce findings which expand upon, or refute, this pre-existing framework, and through analysis, researchers can add elements to the model, delete them or further divide already-existing elements into sub-categories (Hsieh & Shannon, 2005). These deviations can indicate a need to edit current theoretical understanding of a phenomenon or, in instances where the research context is unique, indicate that the deviations stem from the specificity of the context itself. This applicability to unique contexts seemed fitting for this first exploration of naturalistic peer support delivered by family carers of people living with rare, non-memory-led or inherited forms of dementia.

The coding framework was based on the Social Support Behaviour Code (SSBC), a framework for classifying different support behaviours (Cutrona & Suhr, 1992), later expanded upon by Suhr et al. (2004) (see [Table 1](#)). Seven of Suhr et al.'s (2004) support behaviours were removed from the coding

Table 1. The social support behaviour code.

Support category	Behaviours
Informational Support	Suggestion and Advice (offer ideas, suggesting actions) Situation Appraisal (reassess the situation) Teaching (teach how to do something or teach facts) Referral (to other sources of help)
Emotional Support	Relationship (express closeness and togetherness) *Physical affection (hug, kiss, hand hold, touch) *Confidentiality (promise not to tell others) Sympathy (express sorrow and regret for situation) Understanding and empathy ("I understand," self-disclose) Prayer (pray with person) Expresses concern (inquires after well-being) Reassurance (nonspecific comfort) Encouragement
Esteem Support	Compliment (emphasise abilities, say positive things) Validation (agree with and take other's side) Relief of blame (say it's not other's fault)
Tangible Aid	Loan (offer money or material object) Direct task (offer to do something related to problem) Indirect task (offer to do something not related) *Active participation (offer to join in reducing stress) Willingness (express willingness to help any time) *Complies with request (agrees to do something after stressed person requests it)
Negative Behaviours	*Interrupt (changes subject or interrupts other) Complain (talks about own problems) *Criticism (negative comments about other or blaming) *Isolation (will not help other, will not discuss it) Disagree or disapprove (does not agree with other)

Source. (Cutrona & Suhr, 1992; Suhr et al., 2004) *Removed from the analysis, see 'Analysis' section for more details.

framework before analysis as they were deemed inappropriate for this context either due to the online nature of the groups (e.g. Physical Affection) or due to the ground rules for participation which had been agreed to by all participants at the outset (e.g. Confidentiality, Interruption, Criticism).

The transcripts were divided up between four researchers (SRH, SA, AG, CW) and coded using NVivo software, version 12 (QSR International Pty Ltd., 2018). Researchers read each transcript individually, coding incidences of SSBC support behaviours, and noting any behaviours which fell outside the framework. Each member contribution or turn was treated as a unit of data. Single support behaviours could therefore not be coded across multiple turns (e.g. if three members offered consecutive 'Validation', these would be coded as three separate instances of validation). This was decided to ensure that each separate instance of social support was captured and that those which appeared frequently alongside each other would not risk being underrepresented by being grouped across large sections of data. The SSBC codes were initially intended to be applied discretely (i.e. not concurrently), in order to capture the frequency of what the author's considered to be mutually exclusive social support behaviours, within one-minute segments of transcripts of interactions (Suhr et al., 2004), and have since been applied in this way to online forum data (Coulson & Greenwood, 2012). In the current study however, individual contributions were often dynamically and responsively connected to that which came before and that which followed, and our research aims were focused around capturing the context and (potentially) multi-layered meanings within naturalistic peer support conversations, rather than solely the frequency of different support types. For this reason, a decision was made to allow the application of concurrent coding if, once a data segment had been reduced down to as small a meaningful chunk as possible, it appeared that two (or more) types of social support were being delivered simultaneously. For example, if one brief statement appeared to be offering Understanding and Empathy and Relief of Blame at the same time, it could be coded as both, in

order to capture the multifaceted nature of support being offered. To ensure this concurrent coding didn't just reflect a lack of clarity in definitions or conceptualisation of the coding framework, social support behaviours which were co-occurring or overlapping frequently, were noted down by researchers and brought to analysis meetings in order to refine the team's definitions, consider conceptual overlap and refine the coding framework as appropriate. We used both quantitative and qualitative approaches to identify notable co-occurrences—we reviewed any codes for which more than 10% of the data within them was also coded with another code, and the researchers kept reflexive notes on any codes they found themselves struggling to differentiate, or often applying to the same or overlapping segments of data. Any decisions or re-definitions were added to a shared analytic memo, which researchers could continually refer to. When any new codes were added, researchers revisited earlier transcripts to check for instances of these new codes.

Quality assurance

The two researchers who undertook the majority of the coding (SA, SRH) independently coded a sample of 5% of the data which was then reviewed for consistency. The degree of agreement on this 5% sample of coding was assessed using Cohen's κ . Codes which had less than moderate agreement (Cohen's $\kappa < 0.41$) were reviewed to establish consistency in coding and interpretation. As this was a qualitative content analysis we also drew on principles of consensual qualitative research (Hill et al., 2005) to encourage in-depth and critical reflection on the data, which took account of the context and meanings of participants' contributions and researcher interpretations. To enable this, regular meetings for all researchers involved in analysis provided opportunities to discuss any biases, assumptions and inconsistencies in interpretations of the data and coding framework. Any discrepancies were reviewed and discussed until a consensus of full agreement was reached, any decisions were

Table 2. Five verification strategies to ensure rigour in qualitative research.

Strategy	Description	Consideration of strategies in this study
Methodological Coherence	Ensure congruence between the research question and methods	Background: Use of SSBC (model codifying support behaviours, previously applied in a number of peer-support settings) as a theoretical framework from which to direct a content analysis. Methods: Transcripts containing in-vivo spoken data recorded directly from a peer support group for family carers of PLWRD.
Appropriate Sample	Participants who best represent or have knowledge of the topic	Methods: Community-based sample of family carers dealing with non-memory-led and inherited dementias, as well as two experienced peer support co-facilitators. Participants represented a range of dementia diagnoses, disease severities, care environments and geographic areas.
Concurrent data collection and analysis	Iterative interaction between data and analysis	Methods: Memo-writing (Individual researchers kept a log of any emergent codes or existing codes which they were having difficulty defining. Researchers also used these reflexively to log and reflect on personal biases). Meetings (Researchers met once a month to sense-check consistent coding of already-existing SSBC codes, alongside inclusion of new ones. These meetings were also used to note any reflexivity issues. All decisions were noted in a rolling analysis diary, shared by all researchers).
Thinking theoretically	A dynamic, cyclical process of reconfirming emerging ideas in new data	Methods: Once 6 transcripts were coded, a meeting was held to confirm all new emergent codes within the data. The working coding framework was updated to include these new codes. Researchers then went back over the earlier transcripts, coding specifically for the newly added codes, before moving on to the final 10 transcripts. When struggling to define a specific support behaviour, researchers went back to Suhr's et al (2004) paper on the SSBC (as well as other Content Analyses using the SSBC) to help refine definitions of the phenomena being analysed.
Theory development	Deliberate between the micro-perspective of the data and the macro- conceptual understanding	Results: Moving between memos, transcripts, codes, supporting quotes and SSBC literature. Creation of a new framework to represent support processes found within our data (See Table 4). Discussion: Integrating results with existing theoretical and practical literature. Suggestions for future work and methodological implications of working with live spoken data.

Source. (Morse et al., 2002).

documented, and any codes which required revisiting in other transcripts as a result were indicated. The five verification strategies outlined by Morse et al. (2002) to encourage reliability, validity and rigour during qualitative research were considered whilst designing, collecting and analysing data and writing up the current study (see Table 2). This approach to quality assurance was taken instead of participant validation because of feasibility and pragmatic concerns about the challenges of bringing participants together to reflect on the findings in a way that would (i) permit equal opportunities for confirmation/disconfirmation from all members of the group, and (ii) do so in a way that was sensitive to the interactive and relational way in which the data was collected (i.e. inherently acknowledging the value of multiple perspectives and not seeking consensus).

Results

Twenty-five family carers attended the experience-sharing peer support groups based on the theme of 'Independence and Identity'. Sample characteristics are summarised in Table 3. The nature of the different forms of social support expressed within the peer support groups are described below, including the common forms they took, functions they appeared to serve and content they referred to. These include those identified in the original SSBC along with two newly defined categories of support behaviours which were added during analysis (Experiential Support and Community Support), both containing codes which were modified from existing SSBC codes (Shares Experience, Expresses Difference) and others which were novel (Uses Humour, Advocacy and Collective Action, User-led Service). The social support categories of Emotional, Esteem and Experiential Support and the social support behaviour of Advocacy and Collective Action were dominant across the data set. These were prevalent across all sessions, the majority of participants' contributions fitted within them, and they are described in detail below. Within these, the Relationship code co-occurred most often with other SSBC codes, and illustrative

Table 3. Carer participant demographic details.

N=25	Carers
Age in years	
31–40	1
41–50	2
51–60	4
61–70	13
71–80	3
(Data missing)	(2)
Gender	
Female	16
Male	9
Ethnicity	
White British	19
White non-British	2
Arab	1
British Indian	1
Irish	1
Non-British Asian	1
Native English speaker	
Yes	22
No	3
Relationship to PLWRD	
Spouse/partner	23
Adult child	2
Highest education level	
Tertiary	18
Secondary	2
(Data missing)	(5)
Type of dementia of PLWRD	
Familial Alzheimer's disease (FAD)	2
Familial frontotemporal dementia (FFTD)	2
Frontotemporal dementia (FTD)	4
Dementia with Lewy bodies (LBD)	5
Posterior cortical atrophy (PCA)	9
Primary progressive aphasia (PPA)	3

examples of these co-occurrences are also provided below. The social support behaviours within the category of Informational Support were less prominent, and some illustrative examples of the data coded within this category are given below. Finally, we briefly note the types of social support behaviours employed mostly by facilitators, and the SSBC-defined social support behaviours which were not found in the data. The final coding framework based on Suhr et al.'s (2004) model but incorporating

Table 4. Final coding framework.

Support category	Behaviours
Informational Support	Suggestion and Advice (offer ideas, suggesting actions) Situation Appraisal (reassess the situation) Teaching (teach how to do something or teach facts) Referral (to other sources of help)
Emotional Support	Reflection (validate contribution, link to broad related theme) Relationship (express closeness and togetherness) Sympathy (express sorrow and regret for situation) Understanding and empathy ("I understand," self-disclose) Prayer (pray with person) Expresses concern (inquires after well-being) Reassurance (nonspecific comfort) Encouragement
Esteem Support	Compliment (emphasise abilities, say positive things) Validation (agree with and take other's side) Relief of blame (say it's not other's fault)
Tangible Aid	Loan (offer money or material object) Direct task (offer to do something related to problem) Indirect task (offer to do something not related) Willingness (express willingness to help any time)
Experiential Support	Shares experience (describe experience of rarer dementia) Expresses difference (note difference in experience or perspective)
Community Support	Uses humour (laughter, joke, describe amusing situation) Advocacy and collective action (encourage peers with lived experience to instigate change through social action) User-led service (identify opportunities for those with lived experience to inform service development)

Source. (Cutrona & Suhr, 1992; Suhr et al., 2004).

modifications to describe the support behaviours taking place specifically within the context of these peer support groups is presented in Table 4.

Emotional support

Relationship

Contributions coded as Relationship often focussed on gratitude for the shared experiences within the group and the relational bonds facilitated by this. Many recounted a sense of loneliness felt in contexts wherein non-memory-led and inherited dementias were misunderstood and posited the group as a viable and valued alternative to those spaces:

This group is an important part of things for me...I reflect on it sometimes weeks in the past or into the future, and it's like the oxygen of shared experience, it's sort of validating, it means that I'm not alone, however rough it feels.

(Male carer for person with PCA)

These contributions often mentioned a sustaining and helpful sense of community, that 'just listening to everyone is therapeutic' (M; PCA)¹, especially others who were 'in the same boat' (F; FTD), and particularly given the challenging situations people were in—'we're not alone. It's not a nice place to be together, but we are, and we are soldiering on somehow' (F; FAD). The honesty with which members felt able to share experiences of difficult emotions such as guilt, grief and anger seemed an indicator of closeness:

Meeting with a group like this is so different to anything else because you're all people who know exactly what it's about and what it's like and no one else, none of my friends and even family have got a full grip on how demanding and how exhausting it is and how depressing at times.

(Male carer for person with PCA)

...as did the multitude of non-dementia-related topics and life events members shared with each other. The Relationship code was the one which co-occurred with most other SSBC codes, and some illustrative examples of these co-occurrences are provided in Table 5.

Table 5. Examples of data segments with Relationship and other co-occurring code(s).

Quote	Codes
<i>Just listening to everyone else is very therapeutic, and just realising everyone's in a very similar situation, maybe at different stages. But it really helps to feel almost you're not making it up.</i> (Male carer for person with PCA)	<ul style="list-style-type: none"> Relationship Understanding and Empathy
<i>...at least in a group like this, you know there are other people fighting those same battles, and who know where you're coming from, and your perspective on it, hopefully.</i> (Male carer for person with PCA)	<ul style="list-style-type: none"> Relationship Understanding and Empathy
<i>I just want to say to Carmen and Debbie to thank you both for coming on today... it's a wonderful gesture, because it means such a lot to hear you, to take the time out and have the courage to come and join us today.</i> (Female carer of person with FTD)	<ul style="list-style-type: none"> Compliment Relationship

Understanding and Empathy

These contributions tended to foreground shared experiences, feelings, concerns and coping strategies and often mentioned the need to keep busy or distracted, worries about the future and loss of independence, frustrations when navigating services and a lack of emotional and physical energy due to caring demands:

I recognise what you say when you talk about feeling numb some of the time, because you're plodding on, and you don't know what your head is doing at all.

(Female carer for person with FTD)

Understanding tended to stem from shared experiences, 'so much of what people have said there resonates' (M; PCA). Many of these contributions seemed to imply that a collective story about life with an inherited or non-memory-led dementia was being told in the group, e.g. 'that's my story too' (M; PCA), and members frequently encouraged each other to contribute and add their voice to this story. A minority of contributions noted an ability to empathise despite not currently experiencing the same challenges. These tended to come from individuals further along in their dementia journey reflecting back on earlier experiences, or members using non-dementia-related experiences

(e.g. of other health conditions) as a basis from which to draw empathy.

Sympathy

Contributions coded as sympathy were characterised by members expressing sorrow or acknowledging the difficulties another member was experiencing, even if they couldn't personally relate e.g. 'that sounds really difficult'. Sympathy was often expressed in reference to bereavement and challenging experiences with particular symptoms. Sympathy was also expressed towards the person living with dementia.

Reassurance

Members reassured each other that they weren't alone, that their reactions and responses were understandable and acceptable, that they were doing a good job of caring, that it was okay that their experiences differed from one another, and that things would get better (e.g. that they'd find solutions to challenges).

But maybe to reassure Clara², I'm in the same state of panic with housework. And I think I'm just so distracted by trying to keep on top of Mandy's situation that I don't concentrate when I'm doing things.... So, don't be too concerned, Clara, it mightn't be as bad as you think.

(Male carer for person with PCA)

Encouragement

Group members appeared to use encouragement to instil hope and inspire fellow carers to persevere. They were encouraging about others' approaches to caring and caring decisions, for example in pre-empting challenges, creating opportunities to spend quality time with their family member and demonstrating resilience in navigating bureaucracy. They actively encouraged others to take time for themselves and organise respite, to get additional support in place (e.g. entitlements, home help), to make enjoyable plans, and more broadly to keep going and to stay strong.

It [respite break] will be such a relief for you. You will feel greatly refreshed. And I would, if I were you to try and get them regularly booked in so that you've got things to look forward to.

(Female carer for person with DLB)

Esteem support

Compliments

Many contributions expressed admiration for others' caring and coping abilities (i.e. complimenting resilience and perseverance in securing appropriate support from health and social care services). For example:

I'm really going to miss your can-do attitude on here. You're an inspiration in so much that you've done.

(Male carer for person with PCA)

Members also complimented others on continuing to foster a relationship with the family member they were caring for and their efforts to maintain their engagement and dignity. Group members also expressed gratitude to others for sharing tips, strategies and suggestions. Members also complimented others on their courage and bravery in openly sharing their experiences.

Validation

Group members validated each other's accounts of the challenging circumstances they were facing (e.g. balancing multiple family care commitments), various approaches to caring and statements about the importance of seeking respite. Carers also validated the difficult feelings others shared, with one commenting 'we've all got similar dynamics going on inside us' (M; PCA). These included worries about getting ill as a carer, feeling a need to put a positive spin on things, feelings of uncertainty, guilt, sadness, and of being overwhelmed by the demands of caring. Members also validated others' feelings of frustration, both with services and with the family member with dementia they were caring for.

Relief of blame

Group members attempted to relieve each other's feelings of guilt for being angry, annoyed or impatient with the person with dementia they were caring for, actively encouraging each other to share difficult feelings with the rest of the group. They also attempted to relieve blame when others described impeding their family member's ability to be independent (e.g. by taking over and doing something for them), for not being a 'natural carer', for thinking about their own future and for struggling with tasks that they had previously been able to keep on top of. Members also reminded others that they were in a very stressful situation and that it was not required (or indeed possible) for them to be perfect, e.g.:

That's a sign of what a good carer you are, Elaine, if you're feeling the guilt, because some people don't care. You're giving up a lot to look after your husband.

(Female carer for person with FAD)

Informational support

Informational Support contributions fell mostly within the categories of Teaching, Suggestions/Advice and Situation Appraisal. Teaching contributions tended to contain factual information concerning dementia subtypes, symptoms and accessing services (e.g. rights and entitlements). Suggestions and Advice contributions also focussed on symptoms and services, but additionally contained information to support fellow carers' coping (e.g. self-care, arranging respite, practising self-compassion, establishing support networks) and maintaining the person with dementia's engagement (e.g. stimulating activities and technological aids).

Matthew is hopeless in groups of people, and it really distresses him. But what he can do is play cards...So...we will play cards all together and Matthew is quite animated when he plays cards. Whilst he isn't part of the conversation, he feels engaged, because we're all doing a group activity together... So, I guess what I'm saying is that if people can't communicate...then maybe there are other ways that you can stay engaged with them at least in the activity that you choose together.

(Female carer for person with FTD)

Suggestions and Advice contributions were more likely to incorporate member opinion and experience than Teaching ones, and as such were more likely to represent multiple perspectives. For example, some carers advocated for the early introduction of home care while others cautioned against the disruption home care could involve to long-established

household routines. Situation Appraisal contributions were similarly characterised by the offering of different perspectives, wherein members would actively reframe the situation under discussion.

Experiential support

The support category 'Experiential Support' was created to unite three social support behaviours which made use of group members' lived experience. Two of these were modified from the SSBC and a third was created during analysis. The two codes adapted from the SSBC originated in the Negative Behaviours category (Complain, which was changed to 'Shares Experience' and Disagree or disapprove, which became 'Expresses Difference'). These codes were modified as it was felt that contributions which involved talking about one's problems and disagreeing with others' perspectives were socially supportive and did not function, within the context of the groups, as wholly Negative Behaviours, as labelled by the SSBC.

Shares experience

The behaviour 'Complain (talks about own problems)' was reframed as 'Shares Experience' to capture the significant portions of the transcripts in which members told their stories. This adaptation allowed for acknowledgement of the fact that members shared 'problems' but also strategies, lighter moments and non-dementia-related experiences. While sharing experience did not necessarily function as an explicit support behaviour in and of itself, it was key to the peer support process, both prompting and providing opportunities for social support by other members and helping normalise self-disclosure so others might join in.

Expresses difference

The behaviour 'Disagree or disapprove (does not agree with other)' was reframed as 'Expresses Difference' to capture contributions wherein members noted points of difference between their experiences and others', whilst acknowledging that this was often described by members as a group strength. Differing perspectives arose due to differing care situations, localities, disease presentations, and stages in carer journey:

I think respite care for my wife, it wouldn't work, but everyone is different.

(Male carer for person with PCA)

Uses humour

'Uses humour' was created to capture contributions which explicitly aimed to be funny or entertaining (e.g. telling jokes, describing experiences with levity) and contributions which elicited laughter from the group. Themes included descriptions of surprising or unusual coping strategies, self-deprecating jokes about appearing tired, distracted or disorganised, difficulties translating rarer dementia experiences to those unfamiliar with them, the (often extreme) sense of pressure and responsibility experienced by members, and challenging situations members had found themselves in due to the person with dementia's symptoms or behaviours e.g.:

Yes, I recognise that. Especially the toilet story. I've become a really expert toilet unblocker of all sorts of stuff. (Laughter) Oh God. It's

funny thinking about it now. But my God, it's bloody not funny when it's like the ten hundredth thing you've done that day.

(Female carer for person with FTD)

Laughter also often accompanied conversations about TV, hobbies and interests, alcohol use and one particularly lengthy exchange about Christmas puddings.

Community support

'Community Support' was created to capture two emergent support behaviours (Advocacy and Collective Action and User-led Service) which posited the potential for a community of carers, people living with rarer forms of dementia and professionals (united through shared expertise, and experience) to help shape services and conversations around inherited and non-memory-led dementias.

Advocacy and collective action

'Advocacy and Collective Action' captured contributions highlighting the potential for group members, and others with experience of inherited and non-memory-led dementias, to address problems such as geographic disparity, bias towards more prevalent forms of dementia, lack of professional knowledge and a paucity of available legal information within the rarer dementia support landscape. Strategies posited included training for legal and clinical professionals and educating people affected by rarer dementias about their rights and entitlements. Contributions included positive portrayals of carers acting as 'troublemakers' (M; PCA), encouragement to members to keep disrupting the status quo, descriptions of services as insufficient and expressions of hope for future families affected by non-memory-led and inherited dementias:

I think social services or the state help [...] has got a typical profile of the client and [...] we are not fitting into those categories. [...] I think me and Andy are just saying that we are fighting as much as we could to [...] get the best care out of it. If we don't do that, they don't know people [...] like us exist.

(Female carer for person with DLB)

Facilitator contributions (User-led Service, Direct Task, Indirect Task, Referral, Concern, Reflection)

Facilitators, rather than members, made the majority of contributions coded as Direct Task, Indirect Task, Referral and Concern from the SSBC, as well as the newly created Reflection and User-led Service codes.

Codes with no data assigned (Loan, Active Participation, Willingness, Prayer)

No data was coded for three behaviours within the Tangible Aid category of the SSBC (Loan, Active Participation, Willingness) which related to hands-on offers of help, or for Prayer (from the Emotional Support category).

Discussion

In this study we have explored, for the first time, to our knowledge, the processes of social support as they occur in peer

support groups for family carers of people affected by rare, non-memory-led and inherited forms of dementia, using the SSBC as a guiding framework. Our findings highlight the multitude of ways in which carers provide esteem, emotional and informational support to their peers in this context, alongside some of the novel ways peers can provide social support for carers of people with rare, non-memory-led or inherited forms of dementia. Here we discuss the implications of these findings and possible directions for future work to further understand and support the development and delivery of social support for carers of people affected by rarer dementias.

Mechanisms of social support

The groups' contributions and the social support processes utilised shed light on the potential mechanisms underpinning peer support for family carers of people affected by these lesser known forms of dementia. The groups appeared to support the development of a sense of community and connection by allowing space for sharing with others with similar lived experience. This commonality is well recognised as a key component of peer support, helping to reduce isolation and increase social support by reminding attendees that they are not alone (Keyes et al., 2016). In addition, the opportunities to share openly, provide and receive comfort, to be relieved of self-criticism, to teach and learn strategies and to gain a different perspective on their situation may all help to increase carer confidence and self-esteem in coping, along with their emotional and social wellbeing, as found in other studies (Clare et al., 2008; Dam et al., 2017; Núñez-Naveira et al., 2016). The proposed helpfulness of social support coded as Relationship, Shares Experience, Informational Support, Understanding and Empathy and Validation is compatible with Diefenbeck et al.'s (2014) study which identified Yalom's therapeutic group factors of: Group Cohesiveness, Catharsis, Imparting of Information, and Universality as those most prominently delivered within an asynchronous peer support group for carers.

SSBC social support processes – the old, the new, the modified and the missing

Almost all of the SSBC codes were found in the data and those which were not were often attributable to the format of the group. Some SSBC codes previously framed as 'negative behaviours' were modified, and new codes were also created. Taken together, these suggest something unique taking place within support groups for family carers of people living with rare, non-memory-led or inherited forms of dementia. The neutralised negative behaviours perhaps signify (i) the value of hearing peers' difficult stories (i.e. 'complaints'), when these are so commonly under-recognised by others unfamiliar with non-memory-led dementias (McIntyre et al., 2019); (ii) the inevitability, but also value, of differences in experiences (i.e. 'disagreements'), given that everyone is dealing with one of a range of rarer conditions all of which are characterised by atypical symptoms and heterogeneity (Karnatz et al., 2021); and (iii) the collective energy that can be catalysed to push for change (e.g. Advocacy and Collective Action) when existing dementia services and support provision for carers of those affected by lesser known forms of dementia are lacking (Sullivan et al., 2022). The value in the differences in experiences was also exemplified in relation to stage of dementia, as those at a later stage could

deliver Reassurance or Encouragement with credibility, having previously been through a similar experience. The value of the bringing together of people at different stages of the dementia experience more generally is evidenced in volunteer peer support programs involving former carers of people living with dementia (Smith et al., 2018).

The central importance of 'relationship'

The presence of some overlapping and co-occurring codes seems to capture something potentially encouraging about the multifaceted nature of peer support delivered in naturalistic peer support groups like these. Within this, the Relationship code appeared central in its significance, in being the code that co-occurred with most other social support processes. It may be that the support processes it most commonly co-occurred with (e.g. Compliment, Understanding and Empathy), were key contributors in fostering the sense of connection and togetherness the Relationship code captured, and further work to better understand the interrelationship of different social support behaviours and processes within peer support settings is suggested below. On the significance of this sense of connection and togetherness, the peer support groups did indeed seem to offer a unique opportunity for camaraderie for the individual members of these under-represented groups, a chance to create a collective narrative and to amplify one's own experiences alongside others facing similar challenges. The benefits of forming a collective identity with others facing a similar challenge such as a dementia diagnosis has also been documented by Clare et al. (2008). The dominance of the Relationship code in the current study seemed particularly poignant given the sense of isolation, loneliness and stigma often experienced by those dealing with rarer dementias (Sullivan et al., 2022).

Limitations and implications for future research and practice

An important limitation to consider is potential sampling bias in that participants self-selected for an experience-sharing group and were recruited from a university-led support service, meaning participants were already connected with specialised peer and professional support. This type of group may not appeal to all carers, and carer willingness to share is evidently an important factor in the successful delivery of social support in this format. The findings here cannot capture the experiences of those in receipt of no support, for whom specialised peer support may be especially needed and helpful. This study may help future efforts to articulate what groups like this can offer and what prospective members can expect, which may help to maximise inclusion and participation. Another way in which our sample may have been biased is in terms of demographic profile, with participants being predominantly white British and having a high level of education. These factors could impact engagement with support and future work with more representative groups will be valuable. Given the typically earlier age of onset of rarer forms of dementia, future work which takes account of the impact of age of onset on accessibility of and engagement with peer support would be valuable.

One limitation of studying peer support as it was delivered rather than as it was recalled by group members (e.g. in follow up interviews) was the lack of opportunity to ask clarifying

questions or probe about the intentions or reception of contributions. There were many examples of peer support which seemed implicit (e.g. someone sharing a story which the team knew was very similar to the experience of another member). It was not possible within the chosen methodology to fully explore these instances, and as such it is possible the contributions were doing even more in the way of support than was captured by this analytic approach. Drawing on an a priori, existing coding framework (the SSBC) undoubtedly informed and potentially limited our exploration of the various weightings and/or hierarchical importance of different social support behaviours (e.g. Relationship). The complexities in discretely defining and conceptualising these complex behaviours, evidenced by the presence of co-occurring and overlapping codes, may suggest the value of future work from a more inductive perspective in further delineating the essential ingredients and specific mechanisms of peer support. Alongside this, future research, using discourse, conversation or situational analysis, which takes an approach more sensitive to turn-taking and contextual factors, and which offers opportunities for follow up with individuals outside of the group, would be a beneficial next step in developing understanding of how peer support is experienced by group members.

Here, with a focus on capturing the dimensions of peer support, we have looked at contributions made by peers in sessions which were both structured and unstructured, together. Given the differences in these session types—particularly in terms of the increased space and time for peer (rather than facilitator) contributions in the unstructured sessions, along with the non-directed and increasingly peer-led nature of the conversations in those sessions—future work which explores differences in how aspects of peer support that are expressed as dynamics among group members change over time would be beneficial. Additionally, longitudinal exploration of how these peer support mechanisms develop over time as the condition inevitably progresses, may also offer helpful insights regarding the sustainability of support of this kind. Given the particular accessibility of online groups for those caring for family members with rarer forms of dementia, owing to geographical spread and concurrent family or work commitments, examining the barriers and facilitators to online access would also be beneficial.

The labels assigned to the different social support processes used here may enable other support group facilitators to acknowledge the peer support processes going on in their own groups and doing this explicitly may help group members recognise their own contributions and feel valued. Finally, in highlighting the value of a multitude of different perspectives in a peer support group context, this study attests to the value of group-based peer support in general, which is an encouraging contribution given the economic benefits of offering support at a group level and current pressures on mental healthcare and third sector services.

Reflexivity

Reflexivity was an important consideration throughout this study given that members of the research team have direct involvement in facilitating peer support groups, and both professional and personal experience of caring for people living with dementia. Researcher's individual perceptions and interpretations of their own and other's contributions were shared and discussed during regular team meetings to allow for

recognition of any assumptions and biases and to ensure these did not inadvertently impact the trustworthiness of the analysis.

Conclusion

This study is the first study we are aware of to have explored the nature of the social support that family carers of people living with rare, non-memory-led or inherited forms of dementia deliver to their peers in online peer support groups, offering exciting insights into *how* peer support is delivered and works, as opposed to just *if* it does. It has shone a light on the significant contributions carers—particularly those facing the stigma, uncertainty and isolation associated with rarer dementias—can offer to, and receive from, peers in similar situations. In doing so, this study recognises the informational and emotional expertise of carers of those affected by these underrepresented conditions and its immense value and highlights the importance of services which recognise and facilitate the connectedness which comes with such sharing of experiences and expertise.

Notes

1. (Carer gender M/F; PLWRD diagnosis)
2. All names have been changed

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Disclosure statement

The authors have no conflicts of interest to disclose.











Ethical approval

The study was approved by the UCL Research Ethics Committee (reference no. 8545/004). Participants were given sufficient time to read and consider the Participant Information Sheet and informed consent was obtained.

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Data availability statement

The data that support the findings of this study are not publicly available in compliance with ethical and funding requirements but will be uploaded to a data repository for researchers from different institutions to access after the study ends in 2024.

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Appendices

Supplementary File 1. 'Independence and Identity' session structure and content

Independence and Identity session schedule

Overview:



Session 1: Introductions <ul style="list-style-type: none">• Introducing ourselves• Introducing the concepts• Plan for future sessions	Session 2: Carer Independence <ul style="list-style-type: none">• What challenges do you face in maintaining your interests and activities that are important to you?• What are some of the ways you have found to deal with these challenges?
Session 3: Maintaining independence and identity of the person living with dementia <ul style="list-style-type: none">• How is the person with dementia's independence and identity challenged?• What are some of the ways you have found to manage some of those challenges?	Session 4: Carer Identity <ul style="list-style-type: none">• How has your sense of self and identity been impacted?• What has that been like?• How are people managing those changes?

Session 1: Introductions

Welcome and housekeeping (5-10mins)

E.g. confidentiality, house rules, what to expect, giving feedback

Introducing ourselves (10-15mins)

Discussion: Introducing the concepts (30-45mins)

Example prompts:

- What brings you to this group?
- What do we hope to get from the sessions?
- What does 'independence' mean to you/the person you are caring for?
- What does 'identity' mean to you/the person you are caring for?


Wrap up: Plan for future sessions, check-out etc. (5-10mins)

Session 2: Carer Independence

Welcome and check-in (5-10mins)

Context setting and research round-up (10mins):

Example slides:



Why independence?

- We know it can be greatly affected
- Is an important aspect of carer quality of life, burden, wellbeing and other outcomes
- There can be numerous challenges to ensuring it


3. Meeting my own needs (for doing things I enjoy) whilst also caring has been...

- not a problem for me
- quite easy
- a problem at times
- quite difficult
- very difficult

4. Thinking of my ability to do things I enjoy, I have felt...

- free to do them when I want
- restricted in a little way by my caring duties
- restricted to some extent by my caring duties
- restricted a lot by my caring duties
- unable to do them due to my caring duties

Brown, A., Page, T.E., Daley, S., Farina, N., Basset, T., Livingston, G., Budgett, J., Gallagher, L., Fenney, Y., Murray, J., Bowling, A., Knapp, M., Banerjee, S., 2019. Measuring the quality of life of family carers of people with dementia: development and validation of the QoL of Life Research (QoL of Life) scale. *Quality of Life Research* <https://doi.org/10.1007/s11136-019-02186-w>



Why independence?

Personal freedom

Carers described good QoL as being associated with participation in enjoyable activities, and conversely, poor QoL was associated with restriction on activities, lack of choice, freedom, and spontaneity. Most carers experienced some degree of restriction on preferred activities. The sense of restriction was less problematic for participants who enjoyed undertaking joint activities with the person with dementia and those receiving support from others.

Daley S, Murray J, Farina N, et al. Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework. *Int J Geriatr Psychiatry* 2019;34:79-86. <https://doi.org/10.1002/gps.4990>

Why talk about it?

- Acknowledging the impact of changes to your independence
- Hearing about possible strategies from others
- Highlighting needs

Discussion (30-45mins)

Example prompts:

- What challenges do you face in maintaining your interests and activities that are important to you?
- What are some of the ways you have found to deal with these challenges?
- What does independence mean/feel like for you/in your situation?
- How has your sense of independence changed/been challenged by the diagnosis/day-to-day at the moment?
- What is that like for you?

- What would you like to be able to change about it?
- Any strategies/tips for maintaining independence?
- Which activities do you still feel able to do independently/which activities are most important for you to sustain?
- What do they offer you?

Wrap up: Plan for future sessions, check-out etc. (5-10mins)

Session 3: Maintaining independence and identity of the person living with dementia

Welcome and check-in (5-10mins)

Context setting and research round-up (10mins):

Example slides:



Example quotes – how a rare dementia diagnosis can affect independence :

One of my big problems is frustration that I can't do things I want to do. I don't need to do them but because I've always been able to do them it really irks me to have to phone my son up and say, "come and put this together for me"

I would like to go out for walks on my own, I would like to drive a car, I would like to have a life, which I do vicariously and I'm not complaining...but I miss that freedom, when you've been independent as you are now, and as most people are in a lot of their lives, you miss it when it goes...I just wish I could be more functional and get more done.



Example quotes – how a rare dementia diagnosis can affect sense of self and identity :

"Somebody who was perhaps a hundred percent academic and good luck to them doing things that I couldn't do, but who wouldn't know which end of a screwdriver to hold wouldn't miss not being able to do those things, whereas everything you see in this house I built and now I'm just totally useless at all these things, it's so frustrating to me"



Discussion (30-45mins)

Example prompts:

- How is the person with dementia's independence and identity challenged?

- What are some of the ways you have found to manage some of those challenges?
- How is the person with dementia's independence challenged?
- What is that like for them? For you?
- What ways have you found to support the independence of the person with dementia?
- How can the person with dementia's identity be challenged?
- What ways have people found to maintain and support the identity of the person living with dementia?

Wrap up: Plan for future sessions, check-out etc. (5-10mins)

Session 4: Carer Identity

Welcome and check-in (5-10mins)

Context setting and research round-up (10mins):

Example slides:



• Linking up independence and identity

'Now I can't do all the things I would like to do. I can't go off to (town) and go to a theatre, or do any of the cultural things I used to do. So it's changed me totally.'

Daley S, Murray L, Farina N, et al. Understanding the quality of life of family carers of people with dementia: A novel conceptual framework. *Int J Geriatr Psychiatry*. 2019;34:786. <https://doi.org/10.1002/gps.4990>



• Identifying as a 'carer'

**very little research on carer identities*

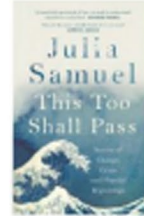
- Many carers do not actually identify or see themselves as carers... carers commonly understand caring as a natural part of an ongoing relationship
- Being a carer is a complex experience that develops over time. On a daily basis it may include providing practical help with, for example, instrumental activities of daily living such as supervision, social stimulation and companionship, help with contacting authorities, financial support and assistance, and even personal care... These are activities that often have a deep impact on the cared-for person, but also on the carer's own everyday life and understanding of self. As the process of becoming a carer involves a life change caused by another person's illness or disability, caring activities should thus be seen as an identity-forming practice.
- Former identities are not lost or eroded but may not be recognised by others – there can be a discrepancy between how a carer sees their identity and how others do. Can make those previous roles and aspects of identity seem like a now invisible self.

Q: How does the process of becoming and being a carer come to influence and affect a carer's understanding of self

Andréasson, F., Andréasson, J., & Hanson, E. (2018). Developing a carer identity and negotiating everyday life through caregiving: an explorative study on identity constructions. In an online Swedish carer community. *Ageing & Society*, 38(11), 2304-2324.

- **Identity changing over time**

- As we progress through life and change happens to us so too do adjustments to our identities
- Change can be forced by circumstances beyond our control – tensions between holding on to past self and adjusting to new situations
- The process of change is supported by experimentation with new actions, connections with new groups, knowledge building to create better understanding and familiarity with this new landscape



- **Identity as a couple**

The co-construction of couplehood in dementia

Victoria J. Mulveyaux
Hertie School, Berlin, Germany

Sarah Bultmann
Hertie School, Berlin, Germany

Jane Simpson
University of York, UK

Craig Murray
University of York, UK

Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood

Oliver Waltham, Jane Simpson, Jonathan Rank & Craig Murray

ARTICLE

Sustaining 'couplehood'
Spouses' strategies for living positively with dementia

INGRID HELLSTRÖM
Erna School University College, Stockholm, Sweden

MIKE NOLAN
University of Sheffield, UK

ULLA LUNDH
Faculty of the Department of Welfare and Care, Linköping University, Sweden




Discussion (30-45mins)

Example prompts:

- How has your sense of self and identity been impacted?
- What has that been like?
- How are you managing those changes?
- How have you noticed those shifts in your individual/couple identity? What makes you aware of them?
- In what ways are you different now? How has this experienced changed you?
- How do these changes show up in the day-to-day, and over the longer term?
- What feelings come with that? What is that like for you?
- How have you responded to those changes in yourself?
- How are aspects of your enduring identities present/evident in the current situation?
- In what ways are you the same, as an individual, and as a couple?

Wrap up: Plan for future sessions, check-out etc. (5-10mins)

Continuing sessions (unstructured, every four weeks)

Check-in (5-10mins)

Lightly facilitated discussion, topic determined by members (30-45mins)

Wrap up: Plan for future sessions, check-out etc. (5-10mins)

Please note: this document is for illustration purposes only and not for onward sharing. Please contact emma.harding@ucl.ac.uk with any questions or requests for further information or advice.

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