A Qualitative Literature Search and Pilot Study of Online Support Groups for Patients With Dementia and Their Carers

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Abstract

The ever-growing group of people living with dementia (PLWD) and their relatives face great challenges. The Covid 19 pandemic has once again placed a particular challenge on this vulnerable group. What started a decade earlier with telephone-based support groups experienced a real push during the pandemic in the form of video-based self-help services. The aim of this qualitative literature search in MEDLINE, EMBASE, CINAHL, and PsycINFO with keywords related to online, support group, caregiver, and dementia was to collect the reported experiences by the end of 2022. Peer reviewed journal papers were included when published and written in English. After the joint decision of two reviewers, it was decided to only include studies that were published in Medline. The results of the literature search are compared with experiences of the participants in a presentation group that was transformed into an online group at the time of the COVID-19 pandemic via Zoom. In search yielded a total of 129 articles. 113 articles described different types of interventions, 30 of which had a randomized design. The qualitative literature search showed on the one hand a high interest in online support groups but on the other hand that the effectiveness and efficacy in randomized trials is much less clear. In addition, we investigated the assessments and experiences of the participants in a presentation group that was transformed into an online group at the time of the COVID-19 pandemic via Zoom. This study demonstrates that PLWD and carers on virtual group meetings can express significant emotive capacity and enhanced connectivity with one another despite a diagnosis of mild to moderate dementia. Further research on entry criteria, concerns about online support services in general and necessary support for use is essential to develop the time- and location-independent possibility of video-based online self-help into an important form of support for both PLWD and their caregivers as an additional support option independent of exceptional pandemic situations.

Introduction

The number of people living with dementia will increase worldwide during the coming years (Ricci, 2019). Dementia has become an increasing public health concern in general, but specifically the future use of and demand for care. Caring for persons living with dementia (PLWD) is a great mental and physical challenge for the carers (Sm-Rahman et al., 2022). Understanding the needs of PLWD living at home and their carers is particularly important to maintain a good quality of life. In most cases, these burdens are long-lasting depending on the course of the disease. Caring often leads to negative psychological, physiological, and financial consequences for these informal carers. Many of them show

high, or moderate to severe, levels of burden (Brodaty et al., 2014). Informal carers are an important resource for the care of people with dementia. Measures that support caregivers and lead to a reduction in burden are therefore very important.

A globally growing group of people living with dementia and their care givers are among the so-called vulnerable

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groups. Both PLWD and carers report that the person with dementia has changed socially (Singleton et al., 2017). While literature research shows that a general expectation of improved circumstances in living with dementia is associated with the use of technologies (Bharucha et al., 2009). Most importantly, it shows that most studies primarily involve family care givers to implement technologies for PLWD. A recent review has described the effect of online interventions on dementia caregivers published between January 2014 and July 2018. It was shown that online interventions targeted at family caregivers can help improve their psychological wellbeing (Etxeberria et al., 2021). The covid-19 pandemic has posed major new challenges for the care of vulnerable people. The protection that these groups of people receive from COVID-19 infection through social isolation puts them ahead of other risks. An international multicentre study has shown that the COVID-19 pandemic affects on neuropsychiatric symptoms in dementia and carer mental health (Wei et al., 2022).

The implementation and expansion of self-help in general will be of great importance even after the restrictions caused by the pandemic. On the one hand, self-help is generally a free and very personal form of support for those affected and their care givers. On the other hand, online offers are increasing in many respects and, in addition to the free offer, also enable affected persons and their care givers to network with like-minded people independent of time and place. Other support services such as mobile accompaniment or day care can only be afforded in many cases once a certain level of care has been reached and which are simply not available nationwide due to the lack of resources. The pandemic has led to further inevitable isolation of patients and caregivers. Carers have reported increased levels of burden, anxiety, depression, and distress during the COVID-19 pandemic (Rainero et al., 2020). Furthermore, the COVID-19 pandemic showed negative effects in terms of quality of life (Cavazzoni et al., 2023).

The aim of this scoping review is to identify studies that report on online support groups related to patients suffering from dementia and their caregivers. The objectives are i) to identify the topics covered in these reports ii) to review the reported experience with online support groups made so far iii) whether and how many intervention studies are available and whether results on effectiveness, acceptability and feasibility are available. Another main goal is to compare how the results from the literature search compare with the results from the focus group and which studies are particularly suitable for making this comparison. The literature search in combination with results from the focus group will yield insights that can help ensure that online focus groups are accepted and provide support for patients with dementia and their relatives.

Methods

Qualitative Literature Research

MEDLINE, EMBASE, CINAHL, and PsycINFO were searched using Medical Subject Headings (MeSH) and keywords related to "support group", "videoconference" or "videobased", "dementia" and "caregiver". After a pre-screening, we decided not to do a quantitative analysis because the available studies are very heterogeneous. Therefore, there was no expectation or possibility of statistical pooling or quality of evidence assessment. Peer reviewed journal papers were included if they were published until the end of year 2022, published and written in English. After the joint decision of two reviewers, it was decided to only include studies that were published in Medline. Studies were only included if both reviewers agreed that the inclusion criteria were met. Eligible reports had to follow standard systematic review procedures with dual independent screening of abstracts and full texts and we only included when both reviewers agreed. Studies were limited to those published in English. This review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009). Data on study participant, methodology, videobased intervention characteristics, and findings related to online support group and dementia were extracted.

Survey of Participants in Ongoing Self-Help Groups

For the qualitative survey, participants ($n = 12$, seven female, five male) were recruited from online self-help groups, which were migrated into the virtual space at the time of the COVID-19 pandemic. For this purpose, participants were informed several times from September 2022 until December 2022 about existing self-help and online self-help groups as well as in the course of dementia-specific events about the focus group interviews. Mainly, they were recruited through a non-random procedure through the choice of a voluntary response sample over existing groups of through PROMENZ, a federal self-help association for the promotion of supported self-help in the dementia sector, founded in 2015 in Austria. As a member of the coordination group of the Austrian Dementia Strategy, the steering group and platform Dementia Friendly Vienna, the German-speaking network of supported self-help groups EmpowerMenz, as well as the "Infoplattform Pflege" of the Federal Ministry of Social Affairs, Health, Care and Consumer Protection, PROMENZ offers numerous international services for PLWD and their care givers with a focus on supported self-help groups online and offline.

Two focus group interviews took place in the form of a one-off survey on two dates in January 2023. In the course of the first appointment, PLWDs and relatives were interviewed who had experienced a shift of support groups into the virtual space in the course of the COVID-19 pandemic. In the course of the second appointment, moderators of those online support groups were interviewed. Participants of these online support groups were surveyed on experiences, limitations, benefits and potential disadvantages.

Procedure

Answers were collected by means of focus group interviews to provide the opportunity for group discussion. The specific focus in relation to the research question was maintained in order to generate as diverse and varied narratives, experience reports and positions on the given topic as possible.

All study participants were informed in advance about the purpose and procedure of the study. In addition, the study participants were informed that they could terminate the study at any time and without giving reasons.

Data Analysis

The focus group interviews were recorded via Zoom (Version 5.12.9 (13190) (2022) and were transcribed pseudonymously using Noota as a conversation intelligence software (Version 3.0, 2023). The text files were revised following the transcription rules based on Kuckartz and Rädiker (2022). Subsequently, the texts were formatted, tagged and imported to InfraNodus (Paranyushkin, 2019). For this paper, the transcripts of the two focus group interviews were merged together to ensure that the commonalities of the topics discussed were reflected in the analysis of the textual content.

InfraNodus is an open-source tool and a method for generating insight from any text or discourse using text network analysis. The method is based on a text network analysis algorithm that represents any text as a network and determines the most influential words in a discourse based on their co-occurrence.

Once a text is represented as a graph in this way, network analysis methods are then applied to detect communities of closely related concepts or topical clusters (topic modeling) and identify the most influential nodes (top keywords) Furthermore, the visual representation of a text and AI-generated topical clusters as a network are used in the process of identification of patterns and structural gaps. This all leads to a more coherent expression of ideas.

Nodes (words) that tend to co-occur together in the same context are called topical clusters. InfraNodus employs a combination of clustering and graph community detection algorithms (Blondel et al., 2008) in order to identify groups of nodes that are more densely connected together than the rest of the network. The Force Atlas algorithm (Jacomy et al., 2014) is used to align them closer to one another on the graph and gives them a distinct colour.

The Jenks elbow cutoff (a 1-dimensional implementation of the K Means algorithm) algorithm is used by InfraNodus to select the most prominent keywords with significantly more influence. The most influential keywords are those with the highest betweenness centrality (the shortest path between two randomly chosen nodes) and the highest degree. The most important keywords are

listed in detail in the appendices and are as follows "Online Connectivity" with "worked," "start" & "wrong," "Virtual Communication" with "zoom," "communicate" & "job," "Tech Savviness" with "passed," "bedroom" & "technically," and "Social Impact," with "home," "disadvantage," and "early." The main concepts are "zoom," "worked," "home," and "split."

Results

Qualitative Literature Research

In Pubmed search key words related to online, support group, dementia and caregiver yielded a total of 129 articles. One hundred thirteen articles describe different types of interventions, 30 of which had a randomized design. Thirty-two out of 129 studies focused on the acceptance of video-based technologies. Twelve of the 30 studies described the study protocol, but no clinical efficacy data yet.

The number of publications shows a continuous increase especially for the years 2021 and 2022. The first publications from 2000 onward examined the telecommunications technology as an aid to family caregivers of persons with dementia (Czaja & Rubert, 2002).

The studies address different questions related to online, online support, dementia, and caregiver. Several studies address the issue of the conditions under which online technologies are adopted by the patients and caregivers identifying perceived social norms as a most strong predictor of health-related technology adoption (Miguel Cruz et al., 2023). Actively involving patients and carers in the decision-making process on whether and how to use online technologies is likely to increase acceptance (Berridge et al., 2022). Online technologies have a high potential for supporting patients and carers especially in rural areas (Santoyo-Olsson et al., 2022) as well as in developing countries (Baruah et al., 2021). The majority of the studies report an improvement in carers' attitudes towards people with dementia and of a relatively high acceptance of both patients and carers.

Results from several studies show that online technologies can have a positive impact on caregivers, for example, in terms of self-efficacy, stress levels, helplessness, or feelings of being supported (Bateman et al., 2017; Gerritzen et al., 2023; Parkinson et al., 2018). The studies so far are too small and too heterogeneous to make definitive judgments on effectiveness.

It became apparent that the randomized studies are also very heterogeneous. This refers to the type of intervention, the participants and the duration of the studies. The type or stage of dementia is not described.

A recent, randomized study on the effectiveness of a web-based social support intervention for caregivers of people with dementia showed no significant improvements for the intervention group relative to the control group for the primary outcomes or any secondary outcome (Christie et al., 2022). A European-Portuguese
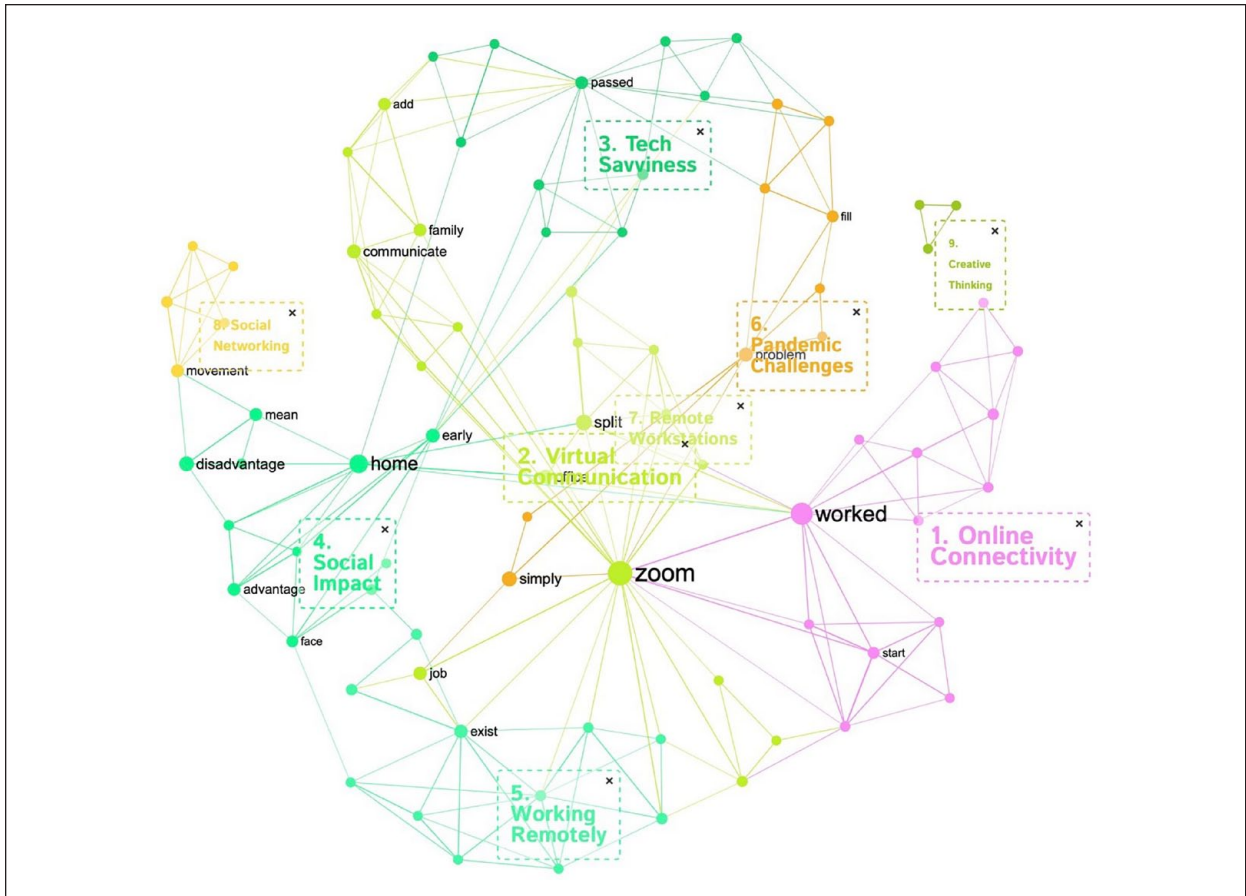
Figure 1. Depicts the structure of the text given by InfraNodus with its main topic clusters and keywords.

version of the WHO's iSupport program was reported to have a good acceptability and promising preliminary results on carers mental health, knowledge, and well-being (Teles et al., 2022). However, the authors concluded that a full-scale RCT is needed to determine iSupport's effectiveness. A randomized controlled trial of the SMART4MD tablet application conducted for persons with mild cognitive impairment and their informal caregivers to improve or maintain quality of life revealed insignificant differences compared to standard care (Ghani et al., 2022). Online cognitive-behavioral therapy with telephone support and psychoeducation both achieved significant benefits over 26 weeks compared with baseline in mental health and mood, but there were no advantages for CBT compared with the psycho-education intervention (Fossey et al., 2021). No significant differences were found between 55 caregivers with 29 in the iSupport group and 26 in the control condition at 3-month follow-up on the primary outcomes (Baruah et al., 2021).

Results on Online Support Groups

As with previous research on online support and online support groups, the results of the focus group interviews

are heterogeneous, too. In order to ensure accurate findings the nodes (the words) with the highest betweenness centrality are therefore identified using InfraNodus ranking algorithm; these are the nodes that appear most frequently on the shortest paths between any two randomly chosen nodes in the network. Those words are crucial for meaning circulation and can be seen as the discourse's meaning junctions; they are shown larger on the graph (Figure 1).

The network structure given by InfraNodus with a modularity factor of 0.68 ($M > 0.65$) is dispersed; the community structure is very prominent, and the influential words are distributed among the communities. Therefore, the discourse covers a variety of topics that are not closely related.

If we look at the keywords of the most important nodes (Tables 1 and 2), we see that both groups already had some previous experience with regard to the use of Zoom and that this term came up very frequently. Although Zoom was not specifically asked about, for all participants in the study this term stood for the video conferences (online video conferencing tools) that took place before and especially during the COVID-19 lockdowns.

With regard to "work" and thus the work situations, both PLWD and relatives had previous experience with

Table 1. Summarizes the 9 Topic Clusters Representing Their Node Percentages, and the AI Generated Categories Using GPT-3.

Topical cluster	Percentage of nodes (%)	Percentage of entries (%)	Category
1	17	18	1. Online connectivity
2	14	12	2. Virtual communication
3	13	12	3. Tech savviness
4	13	12	4. Social impact
5	13	12	5. Working remotely
6	11	6	6. Pandemic challenges
7	8	6	7. Remote workstations
8	6	12	8. Social networking
9	4	12	9. Creative thinking

Table 2. The Most Influential Keywords.

Keyword	Betweenness centrality	Next Jenks elbow point
Zoom	0.5086821238582756	0.5086821238582756
Worked	0.41561276723878343	0.17559971896015256
Home	0.27684934256749977	0.17559971896015256
Split	0.17559971896015256	0.17559971896015256
Disadvantage	0.15176151761517614	0.05630834086118639
Simply	0.14001806684733514	0.05630834086118639
Office	0.12267891197430493	0.05630834086118639
Problem	0.11743450767841011	0.05630834086118639
Early	0.11226538191307839	0.05630834086118639
Communicate	0.11020776874435412	0.05630834086118639

Zoom. When asked about the beginnings of the transformation of self-help into the virtual space, one PLWD answered, "because I simply have a lot to do with Zoom in my job." At the time of the transformation, relatives were also already working in a home office and thus connected via Zoom. "I was in a home office and we had to split up because I also worked a lot via Zoom," describes one relative, referring to the problems of shared workplaces at that time. Both groups saw problems in the use of online self-help in the not always functioning internet connection and the reduction of physical exercise. "But at the same time it's also a disadvantage, because it means you don't get to move around," which allows conclusions to be drawn about the main concept "home."

Referring to the results of the Bert KI model, which was able to analyze both positive and negative moods, it can be summarized that with regard to the beginnings of online self-help, advantages and disadvantages, opportunities, and challenges were found on the side of the facilitators as well as on the side of those affected and their relatives. Creativity, technical savyiness but also the motivation of beginners' spirit as well as tolerance and time for each other ("Most of the time, it was the group that dealt with the screen settings") were reported by both groups as important principles to be able to carry out a transformation of self-help into the virtual space.

Furthermore, the BERT-KI model shows discussed contents as predominantly positive (41%), partly negative (35%), and partly neutral (24%).

Discussion

The qualitative literature search and the pilot study show a high interest in online support groups. The pilot study was able to show under which conditions patients and caregivers are interested in an online group. The accessibility and manageability of the internet is an important prerequisite. In the already existing group it could be shown that this group is very well accepted and formed alternative support options even after COVID-19 conditional restrictions.

The qualitative literature search showed on the one hand a high interest in online support groups but on the other hand that the effectiveness and efficacy in randomized trials is much less clear. Most studies deal with the acceptance, feasibility and accessibility of online groups. As reported by the study authors, the experience of the participants in these groups is quite positive. Whether online groups or presence groups have clear advantages remains open. Probably the accessibility is a crucial question.

Both the literature search and the focus group showed that the participants already had some experience with online media, such as zoom. This could also be a

limitation of the study, since participants may have been selected who have a higher affinity for online media. The question is under what conditions do patients and carers use online media who have little or no experience with online media. Again, the literature search and the focus group show that there should be an experienced mediator for the group who can guide the individual group members at least at the beginning. The literature search also showed that the online group and studies dealing with it increased significantly in the corona-19 pandemic. The participants in the focus group also stated that they were forced to use online media more due to the measures taken due to covid-19 pandemic. The participants stated that they are happy that the covid-19 measures have been relaxed or lifted and that this means that face-to-face meetings are possible again. Nevertheless, a majority of the participants want to continue participating in the online support groups. It could therefore be a limitation of the study that the online groups mainly took place under the covid-19 conditions. Further studies are intended to show how willing people will be to take part in online groups without restricting their freedom of movement. The focus group also showed that members were motivated, creative and experienced in handling technical equipment, which was also confirmed in the literature search. Technical development will continue to increase user-friendliness, but it will still be important to find ways to make people with little online experience less reluctant to use new technologies.

Discussion on Online Group

This study is in line with a recent report demonstrating that participants on virtual group meetings can express significant emotive capacity and enhanced connectivity with one another despite a diagnosis of mild to moderate dementia (Brown et al., 2022).

In relation to the COVID-19 pandemic, the transformation of self-help into the virtual space was advantageous in that the pandemic could be "outsmarted" and time that remained unfulfilled due to closed support services could be filled by various zoom sessions.

The keyword "split" was also one of the main concepts, along with "zoom," "work," and "home." In summary, it can be said that the task in the course of transforming self-help into the virtual space was often to create several work or screen places within one's own four walls.

For medical assistance, both conventional and new technologies should be prioritized to connect PLWD and their caregivers. Telehealth or eHealth services can be a useful tool, where applicable and available, in order to provide distance instructions, monitoring, surveillance, and follow-up treatments (Sm-Rahman et al., 2020).

In both groups, Zoom, the video platform used for online self-help, emerged as having a dominant role, equating it with a family. This allows for the very personal possibility of meeting in virtual space. Worries and doubts

with regard to technology are also shared by both groups, although the evaluation according to the Bert KI model allows the conclusion that these doubts are more likely to have been hidden or could be quickly dispelled in the course of the transformation of self-help into the virtual space. A generational theme also emerges from both groups, which suggests that the children's generation of people with dementia is the user group for online self-help.

It became apparent that although the transformation of online self-help was seen as a necessity due to the COVID-19 pandemic, it may very well offer an alternative means of support for PLWD and their relatives in the future. The prerequisites for this are above all technical details and support in the initial phase. Further research is needed to make the initial phase manageable for both PLWD and their relatives.

Online Support So Far: From Telephone Support to Videoconfernces

In recent years, telephone was one of the first remote interventions for informal caregivers of people with dementia providing social support overcoming the dependency on location. Telephone support groups provide assistance for hard-to-reach caregivers. Caregivers who are traditionally deterred from face-to-face groups because of social constraints, geographic isolation, or physical limitations, or who are homebound because of the needs of the care recipient, are more able to participate in telephone support (Smith & Toseland, 2006). A quantitative review of the efficacy of telephone counseling for informal carers of people with dementia showed that telephone counseling can reduce depressive symptoms for carers of people with dementia and that telephone counseling meets important needs of the carer (Lins et al., 2014). Telephone-based group interventions show effects on quality of life, feelings of burden, caregiver symptomatology, and the depressivity of informal caregivers (Finkel et al., 2007). Compared to face-to-face meetings and other remote-intervention methods (e.g., internet), telephone-based interventions are advantageous because they can be easily accessible, made widely available without concern for technological barriers, are highly flexible in terms of intervention hours, and are low cost.

Support 2.0.—A Necessary Rethink Not Only Due to the Pandemic

Telehealth may be a viable alternative to the provision of care face-to-face for different patients (Scott et al., 2022). Our pilot study suggests that video-based support groups are feasible and have wide acceptance by PLWDs and carers. Our results are consistent with several studies. As the qualitative literature search showed, there are some randomized studies, but it is desirable that the number of randomized controlled trials will increase in

the future. In times of social distancing and worldwide lockdown regulations social life in general shifted to the net and enabled virtual meetings in real time even (Hajek & Konig, 2021). As a result and due to COVID-19, more and more attempts were made to shift services into the virtual space in order to make them accessible to those vulnerable groups both for caregivers and PLWD. In addition, for the introduction of future support services, it was determined that especially long-term interventions can especially support caregivers. The authors also note that most of the interventions studied lasted on average over 4 months. This is a very short time, considering that the time spent caring for and accompanying a PLWD is usually much longer (Cheng et al., 2020).

Video-Based Online Self-Help

Videoconference groups were able to replicate group processes such as bonding and cohesiveness as was stated in a systematic review (Banbury et al., 2018). Furthermore, in this review similar outcomes were reported for those comparing face-to-face groups and videoconference groups. While meta-analyses of telephone-based services for caregivers of PLWD found improvements in quality of life (Belle et al., 2006), caregivers' burden (Lykens et al., 2014) and depressive symptoms video-based groups have been shown to improve mental health in general, as well as self-efficacy and reductions in stress (Czaja et al., 2013) or caregivers burden (Marziali & Garcia, 2011) even before the pandemic (Dam et al., 2016). A modified STrAtegies for RelaTives (START) program delivered online (START-online) was feasible and acceptable for carers, including those living outside of metropolitan areas who might otherwise be unable to access face-to-face programs (Loi et al., 2022). In terms of video-based groups, the focus so far has been on carers and their experiences of support options (Banbury et al., 2019).

Zoom Fatigue

In general, satisfaction with video consultations during the pandemic period was high, with a decrease in independent use with patient age (Bradwell et al., 2022). Videoconferencing was often used with success in the covid-19 pandemic. Now a phenomenon called zoom fatigue is being discussed. "Zoom fatigue" is in some reports interchangeably with the more generic label "videoconference fatigue" and define it as the experience of fatigue during and/or after a videoconference, regardless of the specific VC system used (Doring et al., 2022). A study found that people who spent most of their time during COVID-19 in the home office and thus in video conferences slipped into a comparison with the "good old days" and that technical problems also led to a certain fatigue. Nevertheless, PLWDs describing that COVID-19 impacted on their quality of life, also used

technology for socialization and support (Glassner et al., 2022).

It is questionable whether video-based online self-help for PLWD and their care givers can be said to have the same fatigue effects as any professional online meetings, there is still much to be learned about the general use of videobased support services.

While larger studies are needed to confirm these findings, we suggest that this methodology may be used to support PLWD not only in times of pandemics but also as an addition to other community and home care services. Future research should continue to validate interventions on PLWDs and their carers to identify the persons that would benefit most from online support.

Study Limitations

With regard to the qualitative surveys in the course of the pilot study, there are limitations, which mainly relate to the sample size, the selection of the test persons, and the methodological evaluation. The selection of the sample was a non-random procedure through the choice of a voluntary response sample. The non-randomized design can reflect the experiences of a group, but is limited in comparison to a randomized study as no comparison group is included.

Conclusion

Self-help groups—whether in person or in virtual form - are an important support for both PLWD and their caregivers in coping with the disease as well as in providing psychosocial relief. Our findings emphasize the need to create opportunities for socialization. Online support may be a way to social interaction for PLWDs and carers throughout the progression of their disease. However, our results suggest that online self-help should not be used as the only form of self-help, but very much as an alternative form of support, independent of COVID-19-related restrictions.

In addition, the results of the pilot study and the findings of the literature review showed that there must always be an intensive on-boarding process, moderation, and technical support for the implementation of online self-help. For the expansion of future online support, this means that resources must be created to intensively accompany at least the initial phases of new groups. While the creation of resources is always associated with effort, further studies on online self-help should be conducted in order to clarify the great benefit of these additional support services and thus form the basis for their development and expansion.

Declaration of Conflicting Interests

Ethics Statement

This study was in accordance with the 1964 Declaration of Helsinki and approved by the ethics committee of the University of Innsbruck, Austria (number 1200/2022). Data confidentiality was guaranteed and the study participants were informed that they had the right to withdraw from the study at any time.

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