

Providing Psychosocial support through Virtual Support Groups to Patients with Parkinson's Disease and their Caregivers: A Scoping Review

Larissa Mailhot, Laura Mulder, and Andrew M. Johnson

Abstract

Individuals with Parkinson's disease (PD) may require substantial support, owing to the significant physical, cognitive, and psychological symptoms that are associated with the disease. Furthermore, caregivers of individuals with PD may struggle with the demands of their responsibilities, which can impact their quality of life and ability to participate in social activities. The purpose of this scoping review was to evaluate the factors associated with providing psychosocial support to individuals with PD and their caregivers through virtual support groups. We applied the scoping review methodology described by Arksey and O'Malley to the 15 articles identified within our literature search. Evidence suggests that virtual support groups provide similar experiences to in-person support groups, demonstrating that they can provide an effective form of support, particularly for individuals who have difficulty leaving their home (possibly due to symptom severity or mobility issues) or who are unable to locate suitable in-person resources in their geographical area. Thus, online support groups appear to serve as an effective form of social support for individuals with PD and their caregivers. The perceived level of benefit derived from online support groups is further influenced by factors such as age, group similarity, and disease severity. Overall, the use of virtual support groups may increase access to social support by addressing accessibility barriers and may be a particularly valuable adjunctive service for individuals living in rural areas, or for whom PD symptoms present mobility challenges.

Background

Psychosocial support involves sharing knowledge, advice, and emotional support, which has shown to be particularly beneficial to individuals with PD and their caregivers (Attard & Coulson, 2012; Bakke, 2019; Chung, 2021; Liberman et al., 2005; Liberman et al., 2006; Loane et al., 2015; Marziali & Donahue, 2006; Mazanderani et al., 2012; Shah et al., 2015). PD is a neurodegenerative condition characterized by physical, cognitive, and psychological symptoms. It can be psychologically demanding for individuals with PD and their caregivers to deal with the unpredictability of physical and mental function associated with PD (Attard and Coulson, 2012). Evidence suggests that virtual support groups can provide an effective form of psychosocial support by improving one's quality of life and ability to accept their condition and cope with challenges, as well as decrease caregiver stress and burden (Attard & Coulson, 2012; Chung, 2021; Liberman et al., 2005; Liberman et al., 2006; Marziali & Donahue, 2006; Shah et al., 2015).

The COVID-19 pandemic shed light on the potential advantages of virtual technology as it can help address accessibility challenges. The physical symptoms of PD (i.e. tremors, muscular rigidity, and poor balance and coordination) can impact one's ability to participate in daily activities, especially as the disease progresses, often resulting in social isolation (Chung et al., 2021). In addition, approximately 40-50% of individuals with PD suffer from depression (Attard & Coulson, 2012). Virtual support groups can help address the psychological symptoms associated with PD and prevent social isolation by providing other opportunities for individuals to engage with peers. Virtual support groups can also address time and geographical constraints that would typically prevent individuals and caregivers from accessing psychosocial support (Chung et al., 2021; Shah et al., 2015). The literature suggests that 40% of caregivers of

individuals with PD do not partake in social or leisure activities, and that they often have fractured interpersonal relationships. Unfortunately, there are limited resources for these caregivers as available support groups often focus on the individual with PD, despite the complexity of caregiver responsibilities (Shah et al., 2015).

There is a substantial and developing literature that supports the importance of providing psychosocial support to individuals with PD and their caregivers (Attard & Coulson, 2012; Bakke, 2019; Chung, 2021; Liberman et al., 2005; Liberman et al., 2006; Loane et al., 2015; Marziali & Donahue, 2006; Mazanderani et al., 2012; Shah et al., 2015). The purpose of this scoping review is to identify factors associated with providing psychosocial support to individuals with PD and their caregivers through virtual support groups to further understand the needs of this population.

Method

A scoping review is a type of literature review that addresses a broader range of topics to identify key concepts and available evidence in a particular area of research (Arksey & O'Malley, 2005). Scoping reviews involve identifying all relevant evidence regardless of study design, methods, and limitations. In addition, the process is sufficiently documented so it can be replicated by others. The aim of this scoping review was to summarize, disseminate, and identify gaps in the research findings using the 5-step framework presented by Arksey and O'Malley (2005).

Stage 1: Identifying the Research Question

This scoping review addresses the following question: *What are the factors associated with providing psychosocial support to individuals with Parkinson's disease and their caregivers through virtual support groups?*

Stage 2: Identifying Relevant Studies

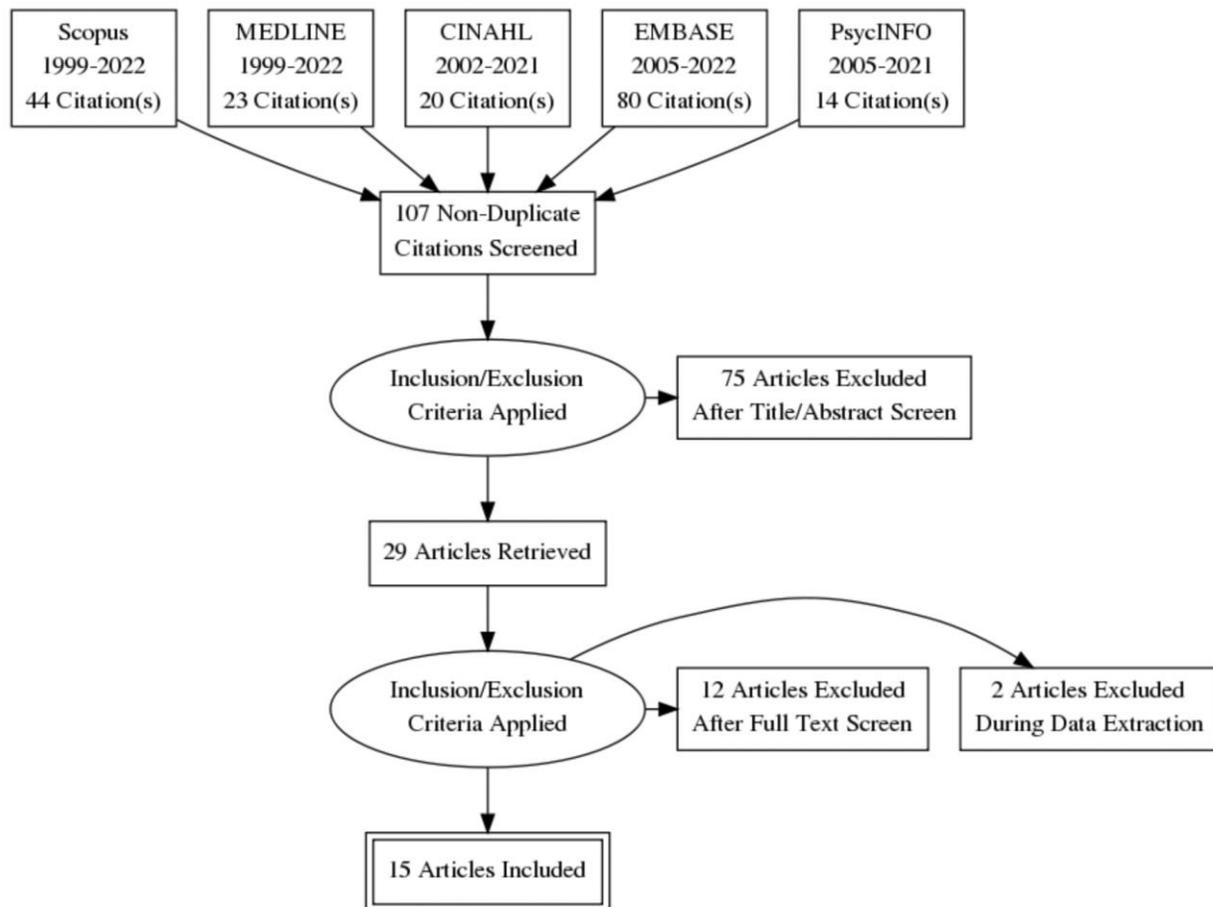
The following databases were searched to identify relevant studies: Scopus, MEDLINE, CINAHL, EMBASE, and PsycINFO. Two researchers independently reviewed each database using the following terms which were searched as keywords and subject headings: (Parkins* OR “Parkinson* disease” OR Parkinsonism OR “Parkinsonian disorders”) AND (“support group*” OR “self-help group*” OR “peer support” OR “group support”) AND (online OR virtual OR internet OR telephone). The search revealed 107 non-duplicate citations. Bibliographies for articles identified as being relevant were also searched to identify more references. Further, we utilized the above search string to conduct a Google search for relevant grey literature. The first ten pages of the Google search were reviewed independently by both reviewers. After independently reviewing the academic and grey literature, the two researchers discussed any inconsistencies in their findings and negotiated until the conflicts were resolved.

Stage 3: Study Selection

Studies were included if they explicitly discussed virtual support groups, in conjunction with PD or caregivers of individuals with PD. Studies were excluded if they focused solely on in-person support groups (i.e., without a virtual option), if the principal participant group was not PD, or if they focused on activity-based support groups. Preliminary findings were also excluded. The researchers used Covidence software to conduct the title and abstract screen and full text screen. They independently decided whether or not studies met the inclusion criteria and then discussed any conflicts that arose during the title and abstract screen and full text screen, until they arrived at a final decision. As shown in Figure 1, during the title and abstract screen, 107 articles were excluded, leaving 29 articles for full text screening. After the final screen, 15 articles were included and organized into a data chart. We included grey literature that provided

insight into the perceptions and experiences of individuals with PD and their caregivers within virtual support groups. Thus, we searched for open online discussion forum posts, news articles, and narration pieces. During the search, the two reviewers only came across open online forums for individuals with PD or caregivers, so those five articles were included in the grey literature section of the paper.

Figure 1. Summary of the search results



Results

Stage 4: Charting the Data:

The data was synthesized, interpreted, and extracted by two reviewers. The core themes identified in the literature by both reviewers were compiled into a data chart. The

researchers followed the themes in the data chart and documented notes about each theme observed in the articles. Grey literature discussion boards were analyzed by both reviewers in a similar manner. The first 15 posts of each discussion board were extracted using the same themes. No identifying information was recorded. The key patterns identified in this scoping review include support group format, group composition, moderator presence, psychosocial support, and health measures.

Individuals with Parkinson's disease

Support Group Format

The support group format was divided into 3 categories: online forums, video calls, and telephone calls.

Online Forums: Online forums provide patients with an opportunity to receive support, and to share experiences, knowledge, advice, and encouragement (Attard & Coulson, 2012; Bakke, 2019; Chung et al., 2021; Loane et al., 2015; Mazanderani et al., 2012). They allow individuals to access informational support at any time, which can help address unmet information needs and improve one's quality of life (Attard and Coulson, 2012; Chung et al., 2021; Chu & Jang, 2022). Lieberman et al., 2005, Lieberman et al., 2006). Within online forums, it is common for participants to discuss treatment-related information (i.e., medications) and Parkinson's disease-specific information (i.e., symptoms) (Chu & Jang, 2022; Wicks et al., 2010). Online forums have shown to be particularly beneficial to individuals with PD who are having trouble accepting their condition and want to set boundaries (Attard & Coulson, 2012; Mazanderani et al., 2012). Specifically, some individuals found it difficult to see others with a greater disease severity face-to-face, so online forums allowed them to create distance (Attard & Coulson, 2012; Mazanderani et al., 2012). Individuals with PD were also more comfortable

talking online about taboo topics (Lieberman et al., 2005; Lieberman et al., 2006). The literature further demonstrated how individuals with PD could derive different levels of consumer value from online forums that are not available in typical health delivery methods such as self-esteem, spirituality, play, and aesthetic (Loane et al., 2015). Even though online forums can provide an effective forum of psychosocial support to patients, there are limitations. Peer-to-peer sharing of treatment and coping strategies can result in the spread of misinformation. Further, online discussion forums increase the risk of disclosing personal medical information, which may expose patients to fraud or even identity theft. These risks (i.e., misinformation and fraud) may be at least partially mitigated by ensuring that medical expertise and gatekeeping is present within the online support forum (Attard & Coulson, 2012; Bakke, 2019). Other limitations include: response time lags; limitations with regards to the symptoms available for discussion; a lack of personalized medical advice; abrupt member departure within the online forum; technical difficulties; absent non-verbal cues, and member diversity (Attard & Coulson, 2012; Bakke, 2019; Lieberman, 2006).

Video Calls: One study was identified that evaluated how a support group for individuals with PD transitioned from in-person to zoom during the COVID-19 pandemic (Ketigian et al., 2022). The zoom meetings allowed participants to maintain social bonds with peers and their community, as well as receive information about the pandemic from health care professionals (Ketigian et al., 2022). The support group was successful at improving mood, reducing isolation, and relieving COVID-19 related stress and anxiety (Ketigian et al., 2022).

Telephone Calls: Telephone calls offer individuals with PD another form of psychosocial support that allows them to set boundaries. The telephone can provide another comfortable

communication medium for individuals who have difficulty seeing others with PD (Mazanderani et al., 2012).

Group Composition

The reviewed studies included both heterogenous and homogenous groups. Homogenous groups were composed of individuals that had shared characteristics outside of their PD diagnosis, such as age and disease severity. On the contrary, heterogenous groups consisted of any individual with a PD diagnosis.

Heterogenous: Even though group diversity was generally viewed positively, available evidence suggests that many individuals with PD found support groups in online formats too diverse (Attard and Coulson, 2012; Lieberman et al., 2005; Lieberman et a., 2006; Mazanderani et al., 2012). Specifically, some individuals experienced identity tensions as they felt that the shared diagnosis within the support group did not provide a sufficient foundation for establishing a meaningful connection among individuals (Mazanderani et al., 2012). In fact, at times, group diversity appeared to cause disagreements because of opposing opinions or viewpoints (Attard and Coulson, 2012). Heterogenous groups were still successful at improving quality of life, but not as successful at improving symptoms of depression as homogeneous groups (Lieberman et al., 2005; Lieberman et al., 2006).

Homogeneous: Homogenous groups appear to provide greater benefits from support group participation than heterogenous groups (Lieberman et al., 2005; Lieberman et al., 2006). Individuals with PD demonstrated substantial improvements in depression, PD symptoms, and quality of life (Lieberman et al., 2005; Lieberman et al., 2006). Members of homogeneous groups were also more committed to their group as they had higher levels of adherence (Lieberman et al., 2005; Lieberman et al., 2006).

Moderator

Most support groups for individuals with PD that were evaluated had a health professional moderator present to facilitate trust, offer expertise, and prevent medical misinformation (Bakke, 2019)

Health Professional: Professional moderators can serve as gatekeepers who provide accurate information and advice. Evidence suggests that individuals value and seek insight from the professional moderator in online forums. Collectively, professional and personal expertise can build trust in an online forum to help online communities thrive. However, potential problems arise when professional and personal knowledge conflict. It appears that the circumstances dictate whether individuals with PD prefer professional or personal expertise, so it is important that moderators assess the quality of information while also respecting patient opinions and experiences (Bakke, 2019). When comparing professional and peer moderators, a study identified that participants express more positive and negative emotions with professional moderators (Lieberman, 2008).

Psychosocial Support

Psychosocial support is important to individuals with PD as it can help them accept their condition, cope with challenges, and provide health benefits (Attard & Coulson, 2012; Chung et al., 2021; Liberman et al., 2005; Liberman et al., 2006).

Shared Knowledge/Experiences: It is important for individuals with PD to share experiences about their symptoms, medications, treatment, emotions, and daily life (Attard & Coulson, 2012; Chu & Jang, 2022; Loane et al., 2015; Wicks et al., 2010). Sharing experiences and knowledge allows online support group members to connect with individuals who may be able to share strategies for coping with PD symptoms. This fosters trust within the community

and reassures members that they are not alone (Attard & Coulson, 2012; Bakke, 2019; Loane et al., 2015; Mazanderani et al., 2012). Participants benefit from learning about other's symptoms and treatments because the knowledge has shown to improve patient's communication with their care team and helped them feel more involved in their treatment decisions (Wicks et al., 2010). Sharing experiences can provide individuals with a greater understanding of PD; however, the level of knowledge obtained is influenced by shared similarities between members (Bakke, 2019; Mazanderani et al., 2012). In order for individuals with PD to fully benefit from sharing experiences, evidence conveys the importance of ensuring that individuals have similarities and can identify with each other (Mazanderani et al., 2012; Loane et al., 2015). Allowing individuals with PD to be selective about their communication medium helps them manage how they identify with others, which further influences how shared experiences are received (Mazanderani et al., 2012).

Advice: It is important for individuals with PD to receive advice from others who are going through similar experiences that can offer unique expertise related to PD management (Bakke, 2019; Chung et al., 2021; Mazanderani et al., 2012). Individuals with PD can offer personal expertise related to their experiences by offering insight and a level of understanding that family, friends, and health professionals cannot provide (Bakke, 2019). Online support group members can offer a range of perspectives, while also reminding individuals to consult doctors (Attard & Coulson, 2012; Bakke, 2019). Providing and receiving advice can also help improve members self-esteem (Loane et al., 2015). Individuals with PD often experience unpredictable symptoms so informational support allows members to ask for advice about these symptoms without time or geographical barriers. Overall, informational sources can be viewed as a more accessible and efficient coping resource that can promptly address individuals' concerns (Ketigian et al., 2022;

Loane et al., 2015). However, evidence conveys the risk of acting on strangers' advice and disclosing health information as this can put individuals with PD in a vulnerable position (Bakke, 2019).

Emotional Support: Emotional support helps individuals cope with PD by providing empathy, reassurance, comfort, security, coping strategies, and care during stressful times (Chung et al., 2021; Lieberman et al., 2006; Loane et al., 2015). Emotional support can improve individuals' ability to cope with symptoms of depression and psychological stress associated with PD. Specifically, emotional support can act as a stress buffer which promotes contentment and improves perceived quality of life (Chung et al., 2021). Members of online PD communities were grateful for their peers who informed, encouraged, and cared for them, despite facing their own difficulties (Attard & Coulson, 2012). Furthermore, online communities allow individuals who are in distress to set boundaries if they feel that they do not have the capacity to offer support to others (Mazanderani et al., 2012). Emotional support can also boost confidence, provide aesthetic value (i.e. valuing contributions), and community value (i.e. contributing and benefiting from discussions) (Loane et al., 2015). In order to optimize the benefits of emotional support, it is important that individuals identify and relate to each other (Mazanderani et al., 2012).

Health Measures

Individuals with PD experience psychological symptoms that appear to benefit from virtual psychosocial support (Attard & Coulson, 2012; Chung et al., 2021; Lieberman et al., 2005; Lieberman., 2006; Loane et al., 2015)

Depression: It is important to address the high rates of depression prevalent amongst individuals with PD. Evidence suggests that online homogenous support groups are successful at reducing symptoms of depression in this population (Lieberman et al., 2005; Lieberman., 2006).

Quality of Life: Sharing experiences and advice with peers has shown to improve quality of life and one's level of perceived control over their condition (Wicks et al., 2010). One recent study indicated that emotional support could increase contentment, which could in turn improve perceived quality of life among individuals with PD (Chung et al., 2021). Both homogenous and heterogenous online support groups have also shown to improve quality of life of individuals with PD (Lieberman et al., 2005; Lieberman., 2006).

Well-being: Along similar lines, Chung et al. (2021) found that online social support can assist individuals with PD by redefining their situation and improving their psychological well-being. Furthermore, this study showed how varying levels of engagement in online support groups can influence the relationship between perceived social support and well-being. Loane et al. (2015) presented evidence that suggests members of online communities can gain satisfaction from providing information that contributes to the well-being of others.

Stress: Chung et al. (2021) also demonstrated how social support from peers can act as a stress buffer by making individuals with PD aware of available coping resources, including social connections and comfort. This study also demonstrated how social support can help peers redefine their situation as less stressful. Further, social support from peers and accurate information from health professional moderators has shown to decrease additional stress individuals with PD experienced during the COVID-19 pandemic (Ketigian et al., 2022).

Anxiety: A study found that individuals who prematurely dropped out of virtual support groups were more likely to experience higher levels of anxiety and fear (Lieberman, 2007). Another study revealed that a virtual support group that provided COVID-19 information from health care professionals was able to alleviate COVID-19 related anxiety in more than 50% of individuals with PD (Ketigian et al., 2022).

Caregivers of Individuals with Parkinson's disease

Support Group Format

The support group format was divided into 3 categories: online forums, video calls, and telephone calls.

Online Forums: Unfortunately, there were no exclusive studies that evaluated online forums for caregivers of individuals with PD. However, evidence is available regarding caregiver participation in forums designed for both individuals with PD and caregivers (Bakke, 2019; Loane et al., 2015). In this mixed format, caregivers can access the experiences of individuals with PD and other caregivers. Individuals with PD can provide caregivers with personal insights to help them better relate to their loved ones, whereas caregivers helped each other cope with challenges by offering emotional support (Bakke, 2019). Online communities can help boost caregivers' confidence, offer reassurance and address unmet information needs (Chu & Jang, 2022; Loane et al., 2015).

Video Calls: Video calls were able to foster environments similar to in-person support groups as caregivers were able to offer empathetic understanding and mutual support to others (Marziali & Donahue, 2006; Marziali et al., 2005). In addition, evidence conveyed a decrease in stress and burden among caregivers in the intervention group. Caregivers also displayed strong adherence to the virtual support group (Marziali & Donahue, 2006).

Telephone Calls: Qualitative feedback portrayed that caregivers found it helpful to talk to others in similar situations via telephone (Shah et al., 2015). However, quantitative assessments showed no statistically significant changes.

Group Composition

Group Composition consisted of heterogenous and homogenous groups. Homogenous groups were composed of individuals that had more shared characteristics outside of caring for an individual with PD, such as similar care recipient characteristics. On the contrary, heterogenous groups consisted of any individual caring for someone with PD.

Heterogeneous: Shah et al. (2015) evaluated a heterogeneous group of caregivers. However, factors related to heterogenous groups were not evaluated.

Homogenous: Marziali and Donahue (2006) matched members of the intervention group based on factors including the level of disability, gender, and age of care recipient. However, factors related to homogenous groups were not evaluated.

Moderator

Most support groups for caregivers of individuals with PD that were evaluated had a health professional moderator present to facilitate meaningful conversations, provide resources, and offer support (Marziali & Donahue, 2006; Shah et al., 2015).

Health Professional: Evidence supports the benefits of clinician-based support group programs (Marziali & Donahue, 2006; Shah et al., 2015). It is particularly beneficial when the clinicians specialize in PD as they can offer more expertise (Shah et al., 2015). Health professionals can offer support, facilitate meaningful conversations, and provide educational resources that help manage stress, health, and preserve capacity to care (Shah et al., 2015). In addition, professional moderators can help caregivers self-reflect and problem solve using adaptive strategies (Marziali & Donahue, 2006).

Psychosocial Support

Psychosocial support is important for caregivers of individuals with PD as it helps them cope with challenges and lower levels of stress (Marziali & Donahue, 2006; Shah et al., 2015).

Sharing Knowledge/Expertise: Caregivers found that sharing their experiences online was just as helpful as in-person support groups (Marziali & Donahue, 2006; Marziali et al., 2005). Participants were able to form connections and bond while sharing stories because they identified with each other (Marziali et al., 2005). In particular, caregivers find it beneficial to discuss the negative emotions they experience, how their relationships have changed, anticipatory mourning, and institutional care (Marziali & Donahue, 2006; Marziali et al., 2005). Overall, caregivers found connecting with others in similar situations beneficial as it helped them persevere through challenges, recognize that they are not alone, and build trust in online communities (Bakke, 2019; Marziali & Donahue, 2006; Marziali et al., 2005; Shah et al., 2015).

Advice: Literature suggests that caregivers benefit from online support groups that provide advice from both individuals with PD and caregivers as the guidance helps caregivers further assist their loved ones (Bakke, 2019). It is common for caregivers to ask about Parkinson's disease in general (i.e., symptoms) and treatment information (i.e., medication effects and side effects) (Chu & Jang, 2022). Online support groups also provide advice on problem solving skills and coping strategies that help lower stress in caregivers (Shah et al., 2015).

Emotional Support: Emotional support is important for caregivers because it offers reassurance that they are not alone and helps boost their self-confidence (Bakke, 2019; Loane et al., 2015; Marziali & Donahue, 2006). Online support groups help caregivers offer each other empathetic communication, understanding, and mutual support (Marziali & Donahue, 2006).

Health Measures

Caregivers of individuals with PD experience psychological symptoms that appear to benefit from virtual psychosocial support (Marziali & Donahue, 2006; Shah et al., 2015).

Depression: Studies that measured depression did not find statistically significant findings (Marziali & Donahue, 2006; Shah et al., 2015)

Stress: Online support groups were shown to effectively reduce caregiver stress and burden (Marziali & Donahue, 2006; Shah et al., 2015). Specifically, one study found that 90% of caregivers felt that their online experience was positive and that the group helped them cope with the stress associated with caregiving (Marziali et al., 2005).

Anxiety: No studies evaluated anxiety among caregivers of individuals with PD.

Grey Literature

There are various resources online about the virtual support groups available for individuals with Parkinson's disease and their caregivers. However, there appear to be limited virtual support groups targeted specifically at caregivers of individuals with PD as only one group was identified. Fortunately, caregivers were also able to participate in Parkinson's disease forums and would receive responses from individuals with PD and other caregivers (dailystrength, 2022; Parkinson's Foundation, 2022; Parkinson's UK, 2022). In the open online forum, members often asked questions about their specific situation (i.e., symptoms, medications, disease progression, coping, caregiving) or shared information about Parkinson's disease that they have gathered online (i.e., clinical trial reports). It was evident that members were able to provide support and advice to their peers. However, at times, peers did not respond to posts or were unable to answer specific questions (Caregiver Action Network, 2022; dailystrength, 2022; NeuroTalk, 2022; Parkinson's Foundation, 2022; Parkinson's UK, 2022). Some members would encourage their peers to speak to their doctor about certain health related questions, but it was clear that groups without health professional moderators would benefit from their expertise (dailystrength, 2022; NeuroTalk, 2022; Parkinson's Foundation, 2022). Further,

not all groups were private as they were open to the public. Open forums provide the public, individuals with PD, and caregivers of individuals with PD with more information; however, they do not provide privacy to the members of the group.

Discussion

The purpose of this scoping review was to synthesize available research and identify gaps in the identified peer-reviewed articles by exploring the factors associated with providing psychosocial support through virtual support groups. Virtual support groups appear to provide effective support to individuals with PD and their caregivers, particularly for individuals with restricted access to resources (Attard & Coulson, 2012; Bakke, 2019; Chung, 2021; Liberman et al., 2005; Liberman et al., 2006; Loane et al., 2015; Marziali & Donahue, 2006; Mazanderani et al., 2012; Shah et al., 2015).

Given the wide range of symptoms and experiences associated with PD, the level of benefit derived from virtual support groups was influenced by situational and contextual factors (Lieberman et al., 2005; Lieberman., 2006). Literature conveys the importance of allowing individuals to be in physical and mental control of their preferred communication medium (Attard & Coulson, 2012; Mazanderani et al., 2012). Thus, it would be beneficial to match individuals to support group formats that align with their individual needs, preferences, and level of access. Specifically, evidence suggests that creating homogenous groups of individuals with similarities (i.e. age and disease severity) can enhance experiences and health benefits (Lieberman et al., 2005; Lieberman et a., 2006; Mazanderani et al., 2012). Furthermore, health professional moderators can facilitate trust, offer expertise, and prevent medical misinformation (Bakke, 2019; Chung et al., 2021; Chu & Jang, 2022; Liberman et al., 2005; Lieberman et al., 2006; Lieberman, 2008). It is also important to note that even though some individuals found

face-to-face contact difficult, there were others who still felt alone in their offline environment because they wanted to meet with group members in-person (Attard and Coulson, 2012). However, limited data was available about whether or not video calls could address the needs of individuals with PD who preferred face-to-face contact.

Virtual psychosocial support can help address caregiver stress and burden (Marziali & Donahue, 2006; Marziali et al., 2005; Shah et al., 2015). Caregiver virtual support groups also appear to benefit from a health professional moderator who facilitates meaningful conversations and offers support (Marziali & Donahue, 2006; Marziali et al., 2005; Shah et al., 2015). Mixed online formats that included individuals with PD and their caregivers appeared to provide the value of PD experiences as well as emotional support from caregivers (Bakke, 2019). However, given that PD support groups typically focus more on the individual with PD, it is important to ensure that caregivers still receive emotional support that relates to the challenges associated with their responsibilities. Even though evidence demonstrates the benefits of virtual support groups for caregivers of individuals with PD, there is currently few resources available for this population. Specifically, more information is needed regarding the individual factors that can help tailor programs to the needs of caregivers.

Limitations

Some limitations should be acknowledged within the present review. First, scoping reviews typically include a wide range of data regardless of the quality of the evidence, which can influence the validity of the findings. However, to strengthen the quality of the findings, we presented the academic and grey literature in separate sections and excluded preliminary findings. In addition, there were fewer available sources regarding caregivers of individuals with PD, which could also impact the generalizability of the findings within this population.

Conclusion

This review supports the health and accessibility benefits of psychosocial support through virtual support groups for individuals with PD and their caregivers, and suggests that there may be substantial benefits associated with tailoring virtual support groups to individual preferences and needs (Attard & Coulson, 2012; Bakke, 2019; Chung, 2021; Liberman et al., 2005; Liberman et al., 2006; Loane et al., 2015; Marziali & Donahue, 2006; Marziali et al., 2005; Mazanderani et al., 2012; Shah et al., 2015). Specifically, the benefits of virtual support are optimized through homogenous groups and the presence of a health professional moderator (Bakke, 2019; Chung et al., 2021; Liberman et al., 2005; Liberman et al., 2006; Liberman, 2008; Mazanderani et al., 2012).

Future Directions

It is evident that more research is required among caregivers for individuals with PD. In particular, it would be beneficial to assess the individual and contextual factors that influence the benefits derived by this population from virtual support groups. Furthermore, although support group homogeneity was suggested as a strength for focus groups, future research should explore whether this homogeneity should extend to the inclusion of caregivers in virtual support groups. Specifically, it would be interesting to explore the relative impact of support groups that include a mix of individuals with PD and their caregivers. It would also be beneficial to further assess the dynamic of virtual support groups composed of both individuals with PD and caregivers to see if both groups derive equal benefits.

Moving forward, is it important to offer a number of different programs that consider the diverse situational and contextual factors of individuals with PD. In order to optimize programs, more information is needed regarding the benefits of online video calls for individuals with PD

who want more face-to-face interactions. To further optimize accessibility, solutions could be explored to address physical limitations (i.e. hand tremors) that impact individuals ability to participate in discussion forums.

References

1. Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
2. Attard, A., & Coulson, N. S. (2012). A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behaviour*, 28(2), 500–506. <https://doi.org/10.1016/j.chb.2011.10.022>
3. Bakke, A. (2019). Trust-Building in a Patient Forum: The Interplay of Professional and Personal Expertise. *Journal of Technical Writing and Communication*, 49(2), 156–182. <https://doi.org/10.1177%2F0047281618776222>
4. *Caregiver Help*. (2022). Caregiver Action Network. <https://www.caregiveraction.org/community/disease-specific-caregivers/parkinsons-disease/caregiver-help>
5. Chu, H. S., & Jang, H. Y. (2022). Exploring Unmet Information Needs of People with Parkinson's Disease and Their Families: Focusing on Information Sharing in an Online Patient Community. *International Journal of Environmental Research and Public Health*, 19(5). <https://doi.org/10.3390/ijerph19052521>
6. Chung, S., Kim, E., & Houston, J. B. (2021). Perceived online social support for

Parkinson's disease patients: The role of support type, uncertainty, contentment, and psychological quality of life. *Communication Quarterly*, 69(3), 259–279.

<https://doi.org/10.1080/01463373.2021.1940232>

7. Ketigian, L., Piniella, N., McGivney, K., Lui, S., Dukat, A., Jung, M. K., Gallagher, R., & Leder, A. (2022). Transition and Sustainability of an Online Care Model for People With Parkinson's Disease in Response to the COVID-19 Pandemic. *Frontiers in Public Health*, 9(February), 1–10.

<https://doi.org/10.3389/fpubh.2021.772805>

8. Lieberman, M. A. (2007). Psychological characteristics of people with Parkinson's disease who prematurely drop out of professionally led Internet chat support groups. *Cyberpsychology and Behavior*, 10(6), 741–748.

<https://doi.org/10.1089/cpb.2007.9956>

9. Lieberman, M. A. (2008). Effects of disease and leader type on moderators in online support groups. *Computers in Human Behavior*, 24(5), 2446–2455.

<https://doi.org/10.1016/j.chb.2008.02.018>

10. Lieberman, M. A., Wizlenberg, A., Golant, M., & Minno, M. Di. (2005). The Impact of Group Composition on Internet Support Groups: Homogeneous Versus Heterogeneous Parkinson's Groups. *Group Dynamics: Theory, Research, and Practice*, 9(4), 239–350. <https://doi.org/10.1037/1089-2699.9.4.239>

11. Lieberman, M. A., Winzelberg, A., Golant, M., Wakahiro, M., DiMinno, M., Aminoff, M., & Christine, C. (2006). Online Support Groups for Parkinson's Patients. *Social Work in Health Care*, 42(2), 23–38.
https://doi.org/10.1300/J010v42n02_02
12. Loane, S. S., Webster, C. M., & D'Alessandro, S. (2015). Identifying Consumer Value Co-created through Social Support within Online Health Communities. *Journal of Macromarketing*, 35(3), 353–367. <https://doi.org/10.1177%2F0276146714538055>
13. Marziali, E., Donahue, P., & Crossin, G. (2005). Caring for others: Internet health care support intervention for family caregivers of persons with Alzheimer's, stroke, or Parkinson's disease. *Families in Society*, 86(3), 375–383.
<https://doi.org/10.1606/1044-3894.3435>
14. Marziali, E., & Donahue, P. (2006). Caring for Others: Internet Video-Conferencing Group Intervention for Family Caregivers of Older Adults With Neurodegenerative Disease. *The Gerontologist*, 46(3), 398–403.
<https://doi.org/10.1093/geront/46.3.398>
15. Mazanderani, F., Locock, L., & Powell, J. (2012). Being differently the same: The mediation of identity tensions in the sharing of illness experiences. *Social Science and Medicine*, 74(4), 546–553. <https://doi.org/10.1016/j.socscimed.2011.10.036>
16. *NeuroTalk Online Support Groups*. (2022). NeuroTalk.

<https://www.neurotalk.org/parkinson-s-disease/?s=4e22216221c8bcb8651b83172773f3ce>

17. *Parkinson's Disease Support Group*. (2022). Dailystrength.

<https://www.dailystrength.org/group/parkinson-s-disease?page=1#discussion-3821347c>

18. *Parkinson's UK Forum*. (2022). Parkinson's UK. <https://forum.parkinsons.org.uk>

19. Shah, S. P., Glenn, G. L., Hummel, E. M., Hamilton, J. M., Martine, R. R., Duda, J. E., & Wilkinson, J. R. (2015). Caregiver tele-support group for Parkinson's disease: A pilot study. *Geriatric Nursing*, *36*, 207–211.

<https://doi.org/10.1097/HNP.0000000000000004>

20. *Welcome to PD Conversations!* (2022). Parkinson's Foundation.

<https://www.pdconversations.org/s/>

21. Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., Bradley, R., & Heywood, J. (2010). Sharing health data for better outcomes on patientslikeme. *Journal of Medical Internet Research*, *12*(2), 1–12.

<https://doi.org/10.2196/jmir.1549>