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Online peer support: views and experiences of people with young onset dementia (YOD)

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ABSTRACT

Objectives: This study explores (1) which platforms people with YOD use for online peer support, (2) reasons for using or not using online peer support, and (3) how to optimise potential benefits and accessibility.

Methods: A mixed-methods online survey was conducted including fixed-choice and open questions. Participants were people with YOD recruited through dementia organisations, Join Dementia Research and the NHS using convenience sampling. Fixed-choice questions were analysed with Chi-square test of significance and free-text responses with thematic analysis.

Results: A total of 69 completed surveys were analysed. Zoom was most popular for online peer support, followed by Facebook and Twitter. Positives included sharing social support, joining from home, and the option to choose a preferred platform. However, it can be difficult to follow the conversation or understand others. Many were unaware about online peer support and some felt uncomfortable talking to strangers online. To improve access and benefits of online peer support organisations and healthcare professionals should advertise and signpost more and groups should have a clear description.

Conclusion: Online platforms facilitate social support and make peer support accessible to those who do not have access to in-person options. Future research and practice should focus on raising awareness about online peer support.

Introduction

Dementia is commonly associated with older age and people with YOD often face misconceptions, stigma, and a lack of understanding from their social environment. As a result, people may avoid disclosing their diagnosis (Busted et al., 2020; Milby et al., 2017), and reduce social activities and engagement, increasing the risk of social isolation. This can negatively impact a person's sense of self, agency, and control, and their feelings of self-worth (Bannon et al., 2022; Cations et al., 2017; Greenwood & Smith, 2016; Spreadbury & Kipps, 2019).

There is a growing consensus that psychosocial support, including peer support, is essential to help people with YOD and their supporters adapt to the unique challenges they face (McDermott et al., 2019; Oyebode, 2022; Vernooij-Dassen et al., 2021). This builds on the Social Health Framework, which consists of three domains: (1) 'people's capacity to fulfil their potential and obligations', (2) 'the ability to manage life with some degree of independence despite a medical condition', and (3) 'the ability to participate in social activities including work' (Huber et al., 2011). In their review, Greenwood and Smith (2016) found that for people with YOD peer support can be especially valuable in addressing the unique challenges that they experience. Through peer support people can exchange social support, their experiences of what it is like living with YOD, and information (Keyes et al., 2016; Pierse et al., 2022). Peer support can help people to feel socially connected and create a sense of belonging. It has been identified as an important source of support that can contribute to a more positive post-diagnostic experience and help people to identify other support services (Cations et al.,

2017; Stamou et al., 2021). Additionally, it introduces people to opportunities to be involved new activities, have a positive and meaningful contribution and use their skills and abilities, for example in research, advocacy, or policymaking (Gerritzen, Kohl, et al., 2022; Oliver et al., 2020). This can give people a sense of purpose and hope again (Gerritzen, Kohl, et al., 2022). Thus, peer support has the potential to contribute to every domain of Social Health.

However, accessibility to age-appropriate peer support services for people with YOD varies widely across the UK (Mayrhofer et al., 2018). Time and money spend on traveling (long distances) and dementia symptoms may also make it more challenging for people to engage with in-person support groups when there is none in their local area (Cations et al., 2017). Moreover, during the COVID-19 pandemic much of our communication moved online, including health and social support services for people with dementia (Giebel, Cannon, et al., 2021). Online peer support may offer a solution, as there is no need to travel and people can join from the comfort of their own home.

Research on how people with dementia use online platforms for peer support suggests that the known benefits of peer support, such as social support and exchanging information, can also be present in online settings (Clare et al., 2008; Craig & Strivens, 2016; Gerritzen, Kohl, et al., 2022; Rodriquez, 2013; Talbot & Coulson, 2023; Talbot et al., 2020). Talbot and Coulson (2023) found that people with dementia shared their experiences of receiving their diagnosis and adapting to a life with dementia with their peers on an online forum (Talbot & Coulson, 2023). Craig and Strivens (2016) found that a Facebook

group for people affected by YOD can be informative and allow people to get input from beyond their usual social networks. The current study aims to get insights in the views and experiences of people with YOD regarding online peer support. The findings of this study will contribute to the development of a Best Practice Guidance on online peer support for people with YOD (Gerritzen, McDermott, et al., 2022).

Objectives

This study aims to explore (1) which platforms people with YOD use for online peer support, (2) the reasons why people with YOD use or do not use online peer support, and (3) how to optimise the potential benefits and accessibility of online peer support for people with YOD.

Methods

This is a mixed-methods survey, including both fixed-choice and open questions. Mixed-methods surveys are particularly helpful to capture a range of perspectives and experiences and allow people from a wide geographical area to take part, being particularly suitable for exploring under-researched areas (Braun et al., 2021; Braun et al., 2017). Because the views and experiences of people with YOD regarding online peer support are an under-researched area, a the mixed-methods survey was selected. This paper follows the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach, 2004). Additionally, the COREQ guidelines for qualitative research were consulted (Tong et al., 2007). This study received ethical approval from the London Bromley Research Ethics Committee (reference number: 21/LO/0248).

Survey development

The survey content was informed by informal consultations with people with YOD and health and social care professionals, literature research (Gerritzen, Lee, et al., 2022a, 2022b), and previous qualitative research (Gerritzen, Kohl, et al., 2022). First, informal consultations with people with YOD and health and social care professionals were held to get more insights into potential benefits and challenges of online peer support. Second, an extensive literature study on online peer support for people with chronic, neurodegenerative conditions was conducted, which provided insights on successful elements of online peer support (Gerritzen, Lee, et al., 2022a, 2022b). Third, this survey was developed using findings from a focus group study exploring how people, who were part of an existing peer support group, experienced using videoconferencing platforms for their meetings during the COVID-19 pandemic (Gerritzen, Kohl, et al., 2022).

The online survey was built in the Jisc Online Surveys platform (Jisc Online Surveys, 2022). The research team developed the first draft of the survey. Three Patient and Public Involvement (PPI) members (two people with YOD and one family care) provided input on the content for both the type of questions and the answer options. All three had experience with research projects, and one person with YOD had experience with online peer support. In the initial version, the survey mostly consisted of open questions. After receiving PPI feedback, multiple choice options were added to most of the open questions, with the option to leave a free-text response as well.

The survey had tailored questions for current, past, and non-users of online peer support. The demographic questions on gender, age, time since diagnosis, living situation, employment status, ethnicity, and experience with online peer support were for everyone. Based on their answer to that last question (current, past, or non-user), participants were directed to specific questions. People who were past users were asked why they stopped using online peer support. After that they answered the same questions as the users. These questions included which platforms people used for online peer support and where they found out about these, and for how long and how frequently they engaged with online peer support. Participants were also asked about their experiences, potential challenges, and how online peer support could work better for them. Non-users were asked why they do not engage with online peer support, where they would go if they wanted more information, and if they would consider engaging with online peer support. Finally, all participants were asked if they would recommend online peer support to others.

All three PPI members viewed, pretested, and approved the adjusted version of the survey. They also provided feedback on the qualitative findings. The PPI members were reimbursed for their significant contributions according to the payment guidance for researchers and professionals by the National Institute for Health Research (NIHR, 2022).

Participants and recruitment

People were eligible to take part in the survey if they (1) received their diagnosis before they were 65, and (2) could read and understand English. People did not have to be 65 or younger at the time they took part. The survey was UK focussed but people could take part internationally. People were reminded that if they filled in the survey on behalf of a person with YOD, they should answer the questions from the perspective of the person with dementia (including the demographic questions). People living in care facilities were excluded from this study, as this population is already in daily contact with other people with dementia and are more likely to be in the more advanced stages of dementia, during which the nature of symptoms can make it more difficult to use technology and engage in online communication.

The survey was an open survey, meaning that anyone who clicked the link could access it. The aim was to recruit 75 participants. Through the recruitment message and the Participant Information Sheet at the beginning of the survey, only people with YOD were invited to take part. The recruitment approach selected for this study was convenience sampling. Participants were recruited through (a) 22 different NHS Trusts across England, (b) dementia organisations (Young Dementia Network, Dementia UK, Alzheimer Society, Dementia Engagement and Empowerment Project (DEEP)), (c) Join Dementia Research (an UK-wide service where people can sign up and take part in dementia research), and (d) the University of Nottingham and Institute of Mental Health, using their social media channels (including LinkedIn and Twitter), websites, and newsletters. To support recruitment, the research team posted more frequent reminders on social media channels, and asked the recruiting organisations to repost the study in their newsletters, on their website and social media channels, and if possible send out a reminder to people in their network. People could choose to fill in the survey online, request a paper copy, or go through the questions over a phone or videocall with EVG. The survey was open from the 20th of August 2021 until the 13th of February 2022.

Consent and data processing procedures

Participants of the online survey were asked to read the Participant Information Sheet, which was presented after clicking on the link to the survey. This included information on the purpose of the study, the approximate time needed to complete the survey (30 min), which data would be collected and stored (and for how long), and who the main researcher was. At the end participants were asked to confirm that they read and understood the information by ticking a box. Only after this, they could continue to the questions. Participants filling out a paper copy of the survey were asked to read the study information before proceeding to the questions. It was made clear in the Participant Information Sheet that completion and submission of the survey was taken as informed consent. Participants who wanted to could contact a member of the research team to go through the study information over a phone or videocall.

Participants could choose to fill in the survey anonymously. At the end people who wanted to could leave their name and contact details to receive updates about this study or future opportunities to be involved. Survey data was stored in a password secured account on Jisc Surveys, under the license agreement with the University of Nottingham. After the survey closed, the data was uploaded into a password secured online storage space of the University of Nottingham. Study data will be kept for 7 years and personal information such as contact details will be kept for up to 12 months. After this the data and personal information will be permanently deleted.

Data analysis

The multiple choice responses were analysed in SPSS. Due to the small sample size the Fisher Exact test was used. The free-text responses were analysed using the thematic analysis method by Braun and Clarke (2021) consisting of six phases. During phase 1 EVG read the free-text responses multiple times and wrote down things that seemed to be patterns across the data or stood out. These insights were discussed with OM, an experienced qualitative researcher. During phase 2 EVG went back to the data and refined initial thoughts and ideas that came forward in the discussion with OM in phase 1. During this phase EVG developed codes: specific and detailed segments of the transcript that could be relevant. During phase 3 EVG went back to the data and generated initial themes. In this phase, themes have a broader meaning than codes. For phase 4 EVG went back to the data and applied the initial themes. The aim was to see if the themes captured the important elements of the data and whether it showed how the themes relate together. During phase 5 EVG, OM and MO discussed and refined the initial themes. The reasons refinement was needed was that the description of the themes was not always clear and that some themes and subthemes were too similar. After refinement EVG applied the new themes to the data. Finally, during phase 6 EVG took the lead in the write up with detailed input from OM and MO (Braun & Clarke, 2021).

Results

We obtained 79 completed surveys. Of these, ten were removed as they were duplicates, resulting in 69 completed surveys being included. Of these, 6 were filled out on paper. If people filled out the survey multiple times, the one filled out on the earliest date was included. An overview of the participant characteristics is presented in Table 1.

Table 1. Participant characteristics.

Male (%)	43 (62.3%)
Female (%)	26 (37.7%)
Age mean (min-max) (SD)	60.6 (42–69) (5.4)
Time since diagnosis	
Less than 1 year (%)	17 (24.6%)
1–2 years (%)	21 (30.4%)
2–3 years (%)	16 (23.2%)
More than 3 years (%)	15 (21.7%)
Living situation	
Living with partner (%)	42 (60.9%)
Living with partner and family (e.g. children) (%)	18 (26.1%)
Living with family (e.g. children, siblings) (%)	1 (1.4%)
Living alone (%)	7 (10.1%)
Other (%)	1 (1.4%)
Paid employment	
Yes (%)	8 (11.6%)
Ethnicity	
White – British/European/other (%)	65 (94.2%)
Experience with online peer support	
Never used	47 (68.1%)
Used before, but not currently	6 (8.7%)
Current user	16 (23.2%)

Quantitative results

No link was identified between online peer support use and age (under 60 or 60 and over); gender; time since diagnosis; time of diagnosis (during the COVID-19 pandemic or before); living situation (living with others or alone); or employment status. For some questions people could select multiple answer options that applied to them.

Experiences of current and past users

There were 16 current and 6 past users. Reasons people stopped using online peer support were because they had a negative experience (n = 2/6, 33.3%), or they did not like it (n = 1/6, 16.67%). Others noticed that the platform was too difficult to use (n = 2/6, 33.33%), or that the impact of their dementia symptoms made it difficult to use technology (n = 2/6, 33.33%). Finally, for two people the service was discontinued by the provider (n = 2/6 33.33%), or they did not have enough time for it (n = 1/6, 16.67%). Among users and past-users Zoom was the most frequently used audio-visual platform for online peer support (n = 17/22, 77.3%), followed by Microsoft Teams (n = 3/22, 13.6%), Skype (n = 2/22, 9.1%), and GoToMeeting (n = 1/22, 4.6%). Text-based platforms for online peer support included social media (Facebook and Twitter) (n = 14/22, 63.6%) email (n = 8/22, 36.4%), and WhatsApp (n = 5/22, 22.7%).

Of the current and past users, half had used online peer support for more than one year (n = 11/22, 50%). How frequent people engaged with online peer support varied. Most engaged once (n = 6/22, 27.3%) or more (n = 7/22, 31.8%) per week. Others did so less frequently, namely once (n = 4/22, 18.2%) or 2–3 times (n = 2/22, 9.1%) per month. Most people identified their online peer support through dementia organisations, such as Alzheimer Society, Young Dementia Network, or Dementia UK (n = 15/22, 68.2%) or DEEP/Dementia Voices (n = 6/22, 27.3%). Only 13.6% (n = 3/22) were signposted by their physician. Others learned about online peer support through other people with dementia (n = 6/22, 27.3%), and Twitter (n = 2/22, 9.1%).

Positives of online peer support. Most people liked to share experiences with others (n = 18/22, 81.8%), be part of a group (n = 16/22, 72.7%) and generally to meet new people (n = 15/22, 68.2%) and build friendships (n = 11/22, 50%). Through online peer support, people were also able to

learn more about dementia ($n=15/22$, 68.2%), what support is available to them ($n=12/22$, 54.6%), and research opportunities ($n=11/22$, 50%).

Challenges and limitations of online peer support. Nine participants mentioned that they miss being together in person ($n=9/22$, 40.9%), and one person was unsure who they can trust online ($n=1/22$, 4.6%). Others shared that it can be difficult to understand people ($n=7/22$, 31.8%) or follow the conversation ($n=9/22$, 40.9%). Two people shared that they do not always get a reply to their message ($n=2/22$, 9.1%). Aspects that could make online peer support work better were a simpler design in general ($n=6/22$, 27.3%), specifically for the computer or laptop ($n=5/22$, 22.3%), or for phones and tablets ($n=5/22$, 22.3%). Finally, four people ($n=4/22$, 18.2%) shared that online peer support should be easier to find. Despite the limitations and suggestions for improvement, the majority ($n=19/22$, 86.4%) would definitely recommend online peer support to others, and the remaining 13.6% ($n=3/22$) would consider recommending it.

Experiences of non-users

There were 47 non-users. Most people shared that they do not engage with online support because they never heard about it before ($n=20/47$, 42.6%) or they did not know where to look for support ($n=12/47$, 25.5%). Others do not like to talk to other people with dementia ($n=7/47$, 14.9%), or do not like to talk to others online whom they do not know ($n=11/47$, 23.4%). Similarly, four people shared they are concerned about their privacy ($n=4/47$, 8.5%). Finally, others said they are not able to use a computer, tablet, or phone ($n=10/47$, 21.3%).

For more information about online peer support most people would go to dementia organisations ($n=20/47$, 42.6%), whereas only 14.9% ($n=7/47$) would go to their physician. Others would go to friends or family ($n=11/47$, 23.4%) or other people with dementia ($n=4/47$, 8.5%), or they would consult Google ($n=8/47$, 17%) or social media ($n=5/47$, 10.5%). However, there was also a group of people ($n=16/47$, 34%) who had no idea where to look for more information on online peer support. Finally, the survey asked the 47 non-users if they would consider engaging with online peer support. The majority would consider it, with 26.1% ($n=12/46$[1]) answering 'yes' and 47.8% ($n=22/46$) answering 'maybe'. Only 26.1% ($n=12/46$) indicated that they would definitely not engage with online peer support.

Qualitative results

During the first phase of the analysis process, elements that stood out were the importance of peer support in people's lives after receiving the diagnosis and the positives that it brings people. Additionally, the important role of the facilitator in making it a safe and enjoyable experience for everyone was also noticed. For those who do not use online peer support, it stood out that some felt that they had enough support for friends and family, or that they were unsure where to find more information or what to expect. Four overarching themes and eight subthemes were identified (Table 2).

Theme 1: the emotional and psychological importance of peer support after a diagnosis

Many people shared their positive experiences of online peer support, and how it has helped them after receiving their diagnosis. People mentioned that their online peer support network 'brings back a purpose to life' and that their peers gave them hope. Some got involved in research, advocacy, and policy making activities. People also appreciate the opportunity to share experiences and learn from others, and that support was there for them when they needed it.

> I looked forward to it every week. Always had a laugh but also learnt a lot from others who have been living with dementia for a number of years. But they were all an inspiration to live well. (Male, 65, living with partner)

> I look forward to seeing these amazingly cool people each week. Like me, they were busy, successful, productive parts of society and now, life is completely upside down. But we're still us. We have things to share and ways to encourage each other. And we don't have to complain or pretend to be cheery, we just understand. (Female, 50, living alone)

Social connectedness, empathy, and mutual understanding. Overall, people mentioned that their online peer support group made them feel less alone and isolated. They experienced a great amount of support, acceptance and understanding from their online peer support network. People felt that they did not have to explain everything, because they could tell that the others really understand. Through online peer support, people could have a laugh together, cry together, and build new friendships.

> It was nice and friendly and we all had issues with online, but we supported each other and didn't have to worry that we might be rushed or judged. (Female, 59, living with partner and other family members)

Theme 2: advantages of online peer support

Some participants lived rurally and for them online was the only way in which they could meet other people with YOD or a similar diagnosis. For this group, online peer support overcame geographical barriers. People also mentioned that it can be convenient to join from home, and that it can feel less daunting than meeting a group of new people in person.

> It's a good first step towards trying a group in person as people feel freer to leave whenever it suits them if the meeting is becoming uncomfortable. People may find it more relaxed joining from their own front rooms. It also gives people a chance to check into several different groups and find the one which appeals best to them. (Female, 59, living alone)

Online peer support also offers different formats that can accommodate different needs and preferences. People shared their experiences with text-based options, such as social media,

Table 2. Overarching themes and subthemes.

Overarching theme	Subtheme
1. The emotional and psychosocial importance of peer support after a diagnosis	• Social connectedness, empathy, and mutual understanding
2. Advantages of online peer support	• Convenience of joining from home • Overcoming geographical barriers
3. Barriers that may stop people from engaging with online peer support	• Lack of awareness of and signposting to online peer support • Low perceived need for online peer support Online peer support not meeting someone's needs, abilities, preferences, or expectations
4. Ways to make online peer support work better	• Coping with challenges of using technology and online communication Navigating interpersonal online relationships

as well as audio-visual options such as Zoom. Through online peer support people were able to find a platform and mode of communication that suited their own preferences and needs.

> Sharing tips and hobbies brings a purpose back to your life. When you give up work you lose that sense of purpose. Holding crafting Zooms to share with others what crafts we can still do. (Female, 57, living with partner)

> Out of all the online peer support I prefer text-based rather than things like Zoom. I don't know what to say on Zoom. (Male, 42, living with partner and other family members)

Theme 3: barriers that may stop people from engaging with online peer support

Some of the barriers that stopped people from using online peer support included people not wanting to focus on the diagnosis too much or not wanting to meet other people with dementia.

> I'm very scared about the future and this puts me off talking to people with dementia. I don't want to possibly see my future. (Male, 61, living with partner)

Lack of awareness of and signposting to online peer support.

Many people were not aware that online peer support was an option, or where to find more information. At the same time, many people who did not use online peer support before were open to considering it.

> I don't know if I want to become obsessed with my condition and talking about it all the time […] but part of me is interested to hear other people's stories if they might make me feel more positive and hopeful. (Female, 54, living with partner and other family members)

In the free-text responses, four people mentioned that they got enough support from family and friends, and that this was why they did not engage with peer support.

Online peer support not meeting someone's needs, abilities, preferences, or expectations.

Many people missed in-person interaction or preferred to meet in-person and do activities rather than only talk online. Some mentioned there was limited input from other people with dementia, while this was something that they were expecting or hoping for, and that meetings were too detailed or too specific about medication, but they wanted something where they could have a chat with other people with dementia. Others mentioned that their dementia symptoms were hindering them to use technology or to engage in online communication. This was sometimes directly (as illustrated by the quote below) but also indirectly, for example by only stating that they were unable to use a computer.

> I find that I cannot meet people and interact online, it is just too confusing. I have PCA which means that I have visual problems and I find I can't tell where I'm supposed to look. It is impossible for me to use any tech devices or platforms on my own. (Female, 54, living alone)

Theme 4: ways to make online peer support work better

Many people shared how they managed challenges, and they suggested ways in which online peer support can work better for them and people with YOD in general. One of the main

suggestions is to have a skilled and experienced facilitator, who listens well and does not speak too much. Additionally, not having too many people in the meeting at once and establishing some ground rules were mentioned. Furthermore, practical support, such as receiving a link to the meeting on time, and having a guide with simple instructions on how to use the platform were suggested.

> I have attended some meetings which have not been well facilitated resulting in people living with dementia not being able to speak with each other. The facilitator runs the meetings by bombarding us with questions. It is so important to have a good facilitator who allows conversations to flow. (Female, 66, living with partner)

> If there are too many on a Zoom call I find it hard to see the person who is speaking, all the boxes confuse me slightly. (Female, 57, living with partner)

Navigating interpersonal online relationships.

Participants shared the previous negative experiences they may have had. In a few cases this included verbally abusive (spoken or text-based) behaviour from someone else with dementia who was part of the online peer support group. Other people experienced meetings that were not well facilitated, during which they felt that people with dementia did not get enough opportunities to speak, where the facilitator spoke too much, or where dominant members of the group took over.

Navigating challenges of using technology and online communication.

People shared how experienced challenges with navigating online platforms and communicating with others online. These included finding it more difficult to concentrate or follow the conversation, or having too much background noise when in a video meeting. For some it was difficult to build a connection with people online.

> It's difficult to keep a conversation online with people you have never met in person. Also, sometimes the only link to each other is our diagnosis, which perhaps isn't the best reason to engage in conversation. (Female, 58, living with partner and other family members)

Discussion

This study shows that people with YOD can have positive experiences with online peer support. Moreover, through online peer support people experienced the known benefits of peer support, such as social support, exchanging information and experiences, and feeling more positive after the diagnosis (Keyes et al., 2016; Pierse et al., 2022; Stamou et al., 2021). People described their online peer support network as their lifeline after a sometimes traumatic diagnostic and post-diagnostic period, where they experienced a severe lack of support and empathy from healthcare professionals. For some who had no access to local peer support groups or who were unable to travel, online peer support was the only way in which they could get in contact with other people with dementia.

However, this study also shows that in the UK many people with YOD are unaware that online peer support services exist, or they do not know where to look for more information and support. This is in line with our earlier work, in which people with YOD shared that they were unaware that there were peer support groups specifically for younger people (Gerritzen, Kohl, et al., 2022). This also adds to earlier research by Giebel et al.

(2021) showing that people with dementia and their families often experience a lack of information from healthcare professionals, as well as a lack of support in identifying and accessing suitable support services.

Additionally, people with YOD often experience a mismatch between the services and information that are available to them and what they need and want (Cations et al., 2017). This study illustrates that this is the case for online peer support services as well. For example, a person mentioned that in a meeting they attended there was a lot of input from professionals, but that they were really hoping for more input from others with dementia. Some also felt that they or others did not get enough opportunities to speak, for example because some of the group members took over the whole meeting, or the facilitator was talking too much. This is concerning, as research shows that negative experiences with health and social care services, for example because these are not age-appropriate, can result in people losing trust in (Giebel et al., 2021) and a reluctance to use formal dementia services (Cations et al., 2017). This highlights the importance of having a clear description of the peer support group, who it is for, and what people can expect from it. Similarly, it shows the importance of a skilled facilitator or moderator, who allows for the conversation to flow, ensures that everyone gets a chance to speak, and adapts towards the needs and wishes of the group (Gerritzen, Kohl, et al., 2022; Gerritzen, Lee, et al., 2022a, 2022b).

Furthermore, some people expressed they are hesitant to engage in peer support, for example because they do not want to talk about their dementia with others, or they are anxious about seeing others who are in a more advanced stage of the condition. This is also common in online peer support for people with Multiple Sclerosis (Garabedian et al., 2020). It may be helpful if people can get more information about the group and who the group is meant for (e.g. people who were recently diagnosed). Facilitators may consider having a one-to-one meeting with someone beforehand, so that they can check together with the person with YOD if the group would be something for them. During this meeting, the facilitator can also address any concerns someone may have, for example around privacy and online safety. For people who feel uncertain about whether peer support is something for them, or who find it daunting, online peer support could be a smaller step than an in-person group. Online peer support can be offered in different formats and depending on the platform, people can engage with it at a time, pace, and frequency that works for them. While for some online peer support is about developing new friendships and getting involved in various activities (Gerritzen, Kohl, et al., 2022), for others it can be simply reading about or listening to other people's experiences and getting information (Steadman & Pretorius, 2014).

Some people did not engage in online peer support because they have privacy concerns, or generally do not feel comfortable talking to people online they do not know. Others indicated they do not engage with online peer support because they felt that they had enough support from family and friends and did not need peer support. This raises the question whether people may not always be aware of what peer support, online and in-person, entails and could bring to them. Peer support is unique and can go beyond the support that friends and family can give, simply because they do not have experience of what it is like to have a dementia themselves (Gerritzen, Kohl, et al., 2022; Kingod et al., 2017). Peer support can contribute to every dimension of Social Health.

It offers a variety of social and creative activities to engage with and allows people to share social support and experiential knowledge, and build reciprocal relationships (Keyes et al., 2016; Pierse et al., 2022). Additionally, it can help people to identify relevant support services as well as new opportunities to be involved in research, advocacy, and policy making (Cations et al., 2017; Stamou et al., 2021). This is particularly important for people with YOD, as a YOD diagnosis has a significant impact on the person with YOD (Oyebode, 2022) and the family as a whole (Bruinsma et al., 2022).

Limitations

When interpreting the findings of this study it is important to consider the time when the data was collected. The data was collected during the COVID-19 pandemic with national lockdowns being in place on and off. During this period, online communication and the use of videoconferencing platforms such as Zoom increased, including using such platforms for health and social care services (Giebel, Cannon, et al., 2021). During this period, some in-person peer support groups adapted and moved their meetings online (Gerritzen, Kohl, et al., 2022). This may have influenced the number of people who are online peer support users in this survey. On the other hand, some who received their diagnosis during the COVID-19 pandemic had a negative experience. As a result this group may have felt more reluctant to use formal dementia services, including peer support (Cations et al., 2017; Giebel et al., 2021).

The sample size was smaller than anticipated, despite the survey being open for recruitment for almost six months. In the first three to four months recruitment was relatively slow. To support recruitment, the research team posted more frequent reminders on social media, and asked the recruiting organisations to repost the study in their newsletters, on their website and social media channels, and if possible send out a reminder. However, one should consider the current sample size in the light of comparable survey studies including people with YOD. Recent surveys including only people living with a YOD diagnosis had comparable sample sizes (e.g. Mayrhofer et al. (2021) ($n=55$, United Kingdom) and Draper et al. (2016) ($n=88$, Australia). Surveys with larger sample sizes tend to include both people living with a YOD diagnosis and family members (e.g. Cations et al. (2022) and Stamou et al. (2021)).

When advertising the survey through social media, little is known about the population that is reached and who could have filled in the survey, increasing the risk for sampling bias (Andrade, 2020). Therefore, the survey was also advertised among more targeted populations through the NHS services, dementia organisations, and Join Dementia Research. Similarly, it is unknown how many supporters completed the survey on behalf of the participants with dementia. All supporters were asked to answer questions from the perspective of the person with dementia and minimise their own opinions. Nevertheless, it remains unknown if this was always the case, to what extend the person consulted with the person with dementia, and how this may have influenced the results.

Finally, research shows that the time between the onset of symptoms and the diagnosis can be 3–5 years in YOD (Draper et al., 2016; Loi et al., 2022). Therefore, we may have missed people who received their diagnosis after the age of 65, but whose symptoms started before (Carter et al., 2022).

Methodological reflections

Based on the PPI input it was decided to have fixed-answer and open questions. It can be difficult to think of an answer to an open question, and one of the PPI members raised that there would be the risk of getting little input. Fixed-choice questions may prompt people to think more about the topic while the option for a free-text response provides an opportunity to share one's thoughts and experiences in more detail. However, a limitation is that it is not possible to ask the participants to elaborate on their answers, or to ask participants for clarification.

The survey was mainly distributed through online sources. As a result, it may have mostly targeted people who were able to use technology and online communication platforms. Additionally, as the survey was distributed through dementia organisations, NHS services, and Join Dementia Research, it may have mainly targeted people who already were getting support or who knew where to look for it. Future research may consider other sources for recruitment, for example community centres.

The research team had no direct contact with participants. However, the survey was advertised on the professional social media channels of the research team (Twitter and LinkedIn) which could potentially have influenced participant selection.

Recommendations

Many people with YOD lack access to age-appropriate (peer) support (Cations et al., 2017; Mayrhofer et al., 2018). Reasons identified in this study are that there is either no local peer support available, people are unaware of online options, or people do not know where to look for more information. There is a joint responsibility for organisations offering (online) peer support and healthcare professionals to better advertise and signpost to (online) peer support, so that people with YOD know that it is an option that is there for them. One way to increase awareness of what online peer support entails, where people can find more information, and how they can get involved, could be through a best practice guidance on online peer support. This could also be a tool for organisations that offer online peer support to advertise their group, and it could be a way for healthcare professionals to better signpost to online peer support.

Furthermore, the current and previous studies (Gerritzen, Kohl, et al., 2022; Gerritzen, Lee, et al., 2022a, 2022b) show the importance of having skilled facilitators (in case of peer support through video meetings) and moderators (in case of text-based platforms) to ensure that online peer support is a safe space for everyone and that people have a positive experience. Organisations offering online peer support for people with YOD should consider providing support and training materials for facilitators and moderators. Future research could further explore the impact of group size and duration of the meeting. The group size depends on the type of platform. For discussion forums, on average only 1% of the forum members is responsible for the majority of content, indicating that a large membership is needed to ensure that the group is active (van Mierlo, 2014). For peer support meetings in videoconferencing platforms such as Zoom, groups tend to be smaller, for example around 8–12 members (Gerritzen, Kohl, et al., 2022). Future research could identify who the key stakeholders are in providing (online) peer support for people with YOD and how to implement and integrate (online) peer support as a key component in post-diagnostic support and what guidelines are required.

Conclusion

Peer support is a valuable source of post-diagnostic support for people with YOD. The known benefits, such as social support and exchanging experiential knowledge and information, are also present online. For those in rural areas or without access to age-appropriate in-person support groups, online peer support may be the only way to meet peers. However, many people with YOD are unaware that online peer support exists or do not know where to look for more information. Furthermore, online peer support does not always meet the needs and wishes of people with YOD, which could result in people having a negative experience. Online peer support groups and networks should have a clear description on the purpose of the group and who it is for. Organisations offering online peer support for people with YOD and healthcare professionals have a joint responsibility to clearly advertise and signpost to online peer support, so that everyone with YOD knows that this is an option that is there for them. Future research could focus on how to implement and integrate (online) peer support as a key component in post-diagnostic support.

Note

1. One person who filled in a paper copy did not fill in this question, which is why here the total is 46 responses instead of 47.

Disclosure statement

The authors report there are no competing interests to declare.

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