Online peer support for people with Young Onset Dementia: development of a Best Practice Guidance

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"Finding them was just one of the true highlights of my life" – Person with Young Onset Dementia, interview study

"For those who understand, no explanation is necessary, for those who don't, no explanation is possible" – Person with Amyotrophic Lateral Sclerosis, systematic review

Abstract

Introduction: Peer support can be very valuable for people with Young Onset Dementia (YOD) (diagnosis before the age of 65). People with YOD face unique challenges compared to older adults and often experience stigma. YOD can have a negative impact on someone's sense of self, identity, and social roles in the community. Peer support provides social opportunities where people experience mutual understanding and empathy because they are all experiencing similar challenges. People also exchange practical information on dementia and signpost support services. In the United Kingdom, availability of age-appropriate, in-person peer support services is inconsistent, and many people may miss out on the potential benefits. Online peer support could be a solution, as it overcomes geographical barriers and offers a variety of platforms and modes of communication. The aim of this thesis was to develop a Best Practice Guidance on online peer support for people with YOD, and specific guidelines for peer support facilitators.

Methods: This thesis followed the Medical Research Council (MRC) guidelines on complex interventions and focused on the development stage, including different sub-studies. First, a systematic literature study was conducted, followed by 4 focus groups, an online survey with 69 respondents, and 9 interviews. All participants were people living with YOD. Finally, participants, professionals, and researchers provided input on the Best Practice Guidance.

Findings: For many people with YOD (online) peer support is a lifeline and gives hope and a sense of purpose. Some were hesitant to engage in peer support, for example because they were anxious about seeing others in an advanced stage, or they did not know what to expect. Others were unaware of online peer support options and how they could get involved. This indicates a need for better advertisement and signposting. The Best Practice Guidance provides (1) people with YOD with information on what online peer support entails, (2) group facilitators with guidelines on how to optimise online peer support for people with YOD, and (3) healthcare professionals with an opportunity to signpost to online peer support.

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Statement from funder

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Publication and dissemination

Associated publications

1. Gerritzen, E.V., McDermott, O., & Orrell, M. (2022). Development of Best Practice Guidance on Online Peer Support for People With Young Onset Dementia: Protocol for a Mixed Methods Study. *JMIR Research Protocols, 11*(7). 10.2196/38379

2. Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Parkinson's Disease: a narrative synthesis systematic review. *JMIR Aging, 5*(3). 10.2196/35425

3. Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Multiple Sclerosis: a narrative synthesis systematic review. *International Journal of MS Care, 24*(6). 10.7224/1537-2073.2022-040

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6. Gerritzen, E.V., McDermott, O., & Orrell, M. (2023). Online peer support: views and experiences of people with Young Onset Dementia. *Aging and Mental Health.* 10.1080/13607863.2023.2205833.

Additional publications

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3. Harding, E., Rossi-Harries, S., Gerritzen, E.V., Zimmerman, N., Hoare, Z., Proctor, D., Brotherhood, E., Crutch, S., & Suárez-González, A. (2023). "I felt like I had been put on the self and forgotten about" - lasting lessons from the COVID-19 on people affected by rarer dementias. *BMC Geriatrics, 23*(1). 10.1186/s12877-023-03992-1

Presentations

1. Neal, D.P., Atefi, G., Gerritzen, E.V., Garcia, L., Boots, L., & Orrell, M. (2023, 29 June – 2 July). *Develop, implement, and evaluate technology for social health in dementia: lessons in best practice from the European DISTINCT network* [workshop]. 2023 IPA [International Psychogeriatric Association] International Congress. Lisbon, Portugal.

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Abbreviations

ALS: Amyotrophic Lateral Sclerosis

BPG: Best Practice Guidance

CHERRIES: Checklist for Reporting Results of Internet E-Surveys

COREQ: Consolidated criteria for reporting qualitative research

CPMS: Central Portfolio Management System

DISTINCT: Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology

EWGPWD: European Working Group for People with Dementia

INDUCT: Interdisciplinary Network for Dementia Using Current Technology

IPA: International Psychogeriatric Association

MRC: Medical Research Council

MS: Multiple Sclerosis

NICE: National Institute for Health and Care Excellence

PD: Parkinson disease

PCA: Posterior Cortical Atrophy

PPI: Patient and Public Involvement

PPA: Primary Progressive Aphasia

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

WHO: World Health Organisation

YOD: Young Onset Dementia

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1. Introduction

1.1 Prevalence and definitions

Dementia is "a syndrome – usually of a chronic or progressive nature – that leads to deterioration in cognitive function. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement". Besides the cognitive symptoms, people with dementia can also experience changes in mood, behaviour, and emotions (World Health Organisation, 2022). Globally, more than 55 million people are living with dementia. This number is expected to rise to 78 million in 2030 and 139 million people in 2050 (World Health Organisation, 2022). A similar trend can be observed in the United Kingdom (UK). Whereas more than 1 million people in the UK were living with dementia in 2018, this is expected to be more than 1.9 million people in 2050 (Alzheimer Europe, 2019). In light of these rising numbers, dementia is a growing public health concern globally and in the UK.

When the onset of dementia is before the age of 65 it can be defined as Young Onset Dementia (YOD) (van de Veen et al., 2022). It is estimated that globally 3.9 million people live with YOD (Hendriks et al., 2021). In 2018 almost 53,000 people were living with YOD in the UK (Alzheimer Europe, 2019). However, this figure may not include all people with YOD, because for YOD the time between symptom onset and receiving the diagnosis can be 3-5 years (Draper et al., 2016; Loi et al., 2022; van Vliet et al., 2013). In their recent analysis of the Recorded Dementia Diagnosis dataset, Carter et al. (2022) provide insights into how cases of dementia are recorded in England and how this is contributing to the underestimated numbers of YOD. The Recorded Dementia Diagnosis dataset includes data from all GP practices across England. A limitation of this dataset is that it only presents figures on the current age of people with dementia, but it does not show their age at diagnosis (Carter et al., 2022; NHS Digital, 2022). This means that the current figures do not show the number of people who were diagnosed before they were 65 but are now older than 65, or who received their diagnosis after the age of 65 but who already experienced symptoms before that. Carter et al. (2022) found that half of those with dementia who are currently

between 65-69 years of age were diagnosed before they were 65. Of these people, 5% had been living with dementia for more than 12 years, a quarter had been living with dementia for more than five years, and about half had dementia for three years or less (Carter et al., 2022). Considering these figures, Dementia UK estimates that currently 70,800 people are living with YOD in the UK (Dementia UK, 2022).

There are different terms to describe dementia at a younger age (van de Veen et al., 2021). One of those is 'early-onset dementia'. A limitation of this term is that it could be confused with the early stages of dementia rather than the relatively young age at diagnosis (van de Veen et al., 2022). Another term that is used in for example the National Health Service (NHS) is 'working-age dementia'. This term makes sense for countries where the retirement age is 65, indicating that people who receive their dementia diagnosis before the age of 65 are still of working age. However, retirement ages are shifting and are up to 67 now in some countries. In this case someone who is 66 or 67 would also be classified as working age, but not as having working-age dementia. During the Early Onset Dementia taskforce meeting of the International Psychogeriatric Association (IPA) in The Hague in 2011, the taskforce agreed to use the term 'Young Onset Dementia' (Koopmans et al., 2014). Therefore, this is the term that will be used in this PhD thesis.

1.2 Unique challenges of YOD

1.2.1 Diagnostic process

Because dementia is commonly associated with older age, a diagnosis in mid-life is often unexpected and comes as a shock to the person with dementia and their families (Greenwood et al., 2016; Oyebode, 2022; Rabanal et al., 2018). There is a lack of awareness of YOD among both healthcare professionals and the general population (Pijnenburg et al., 2022). People experiencing dementia symptoms may not attribute these to dementia, or it is only in hindsight that they realise that something was not quite right (O'Malley et al., 2021; Oliver et al., 2019). Part of this may also be denying the symptoms and that they could be related to dementia (Chaplin et al., 2014; O'Malley et al., 2021), or people feel

uncertain about the symptoms and whether they should seek help (Spreadbury et al., 2017). As a result, people may only seek help once the symptoms become too severe (Oyebode, 2022).

Additionally, it can be difficult for general practitioners to recognise the symptoms with which people present themselves as dementia (Hendriks et al., 2022; O'Malley et al., 2021). Research shows that the earliest symptoms with which people with YOD go to the general practitioner are in most cases cognitive symptoms, such as memory problems. Other symptom categories include affective symptoms, including depression and anxiety, and behavioural symptoms, including physical and verbal abuse and socially inappropriate behaviour. These last two symptom categories were more common among people with YOD compared to older adults. It can be difficult for general practitioners to recognise these symptoms as dementia, because there is some overlap with other conditions such as depression or burnout, which are more common in this age group than dementia (Hendriks et al., 2022). This relates to fact that some rare forms of dementia, such as Frontotemporal Dementia (FTD) (Sampson et al., 2004), Posterior Cortical Atrophy (PCA) (Crutch et al., 2017) and Primary Progressive Aphasia (PPA) (Marshall et al., 2018) are relatively more common among younger people compared to the older population (van de Veen et al., 2021). These conditions tend to present with non-memory led symptoms, such as changes in behaviour and personality in FTD (Bruinsma et al., 2022a), vision impairments in PCA (Harding et al., 2018), and difficulties with speech and language in PPA (Crutch et al., 2017). An overview of different dementia sub-types is provided in Appendix 1.

Additionally, research shows that among primary care physicians stigma around dementia still exists. This can lead to general practitioners not attributing certain symptoms to dementia. At the same time, family members or people with the symptoms may not feel taken seriously. This can result in people avoiding seeking further help (Herrmann et al., 2018). These factors result in a longer diagnostic process (Pijnenburg et al., 2022), which is often experienced as stressful and burdensome by people with YOD and their families. Additionally, many people experience a lack of empathy and support when receiving the diagnosis, and a lack of right information, in the right amount, at the right time

(O'Malley et al., 2021). All these factors can contribute to a negative and stressful diagnostic process, and as a result people may lose trust and be more reluctant to use formal dementia services in the future (Cations et al., 2017).

1.2.2 The impact of a YOD diagnosis on a person's identity and sense of self

People with YOD are often in a different phase of their life compared to older adults with dementia (Millenaar et al., 2017; Oliver et al., 2019). People with YOD are more likely to be in employment at the time of their diagnosis, and the work environment is often the first place where changes in behaviour and cognition are noticed (Chaplin et al., 2014; Griffin et al., 2015; Johannessen et al., 2011). Difficulties at work and a YOD diagnosis can lead to (forced) early retirement. This has both financial (Galvin et al., 2017; Harris et al., 2004) and social (Greenwood et al., 2016; Johannessen et al., 2011) consequences, as there is a loss of income as well as a loss of contact with colleagues. Moreover, the loss of work can be a personal loss, as work is associated with involvement in meaningful activities, a sense of self and one's identity (Chaplin et al., 2014; Greenwood et al., 2016; Roach et al., 2014).

Due to their age people with YOD have different roles and responsibilities within their families and communities, for example towards dependent children or older parents. People with YOD explain that there is a sudden shift from being an active and valuable member of their communities to losing all of that because of the dementia diagnosis (Harris et al., 2009; Oyebode, 2022). People often find themselves balancing between their identity as a worker and having certain roles and responsibilities within their families and communities, versus being a person with dementia. The contrast between the two identities is increased because dementia is associated with older age, frailty and losing independence (Oyebode, 2022; Spreadbury et al., 2017).

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1.2.3 The impact of YOD on the family

A YOD diagnosis can have a significant impact on the family. Overall there is often a shift in roles and responsibilities, where partners and children take over tasks that the person with YOD can no longer do, and as the condition progresses take on caring responsibilities (Bruinsma et al., 2022b; Chirico et al., 2022; Wiggins et al., 2023). Spouses experience feelings of grief and loss, as they shift from being a husband or wife to being a carer (Chirico et al., 2022). Accepting that their parent has dementia at such a young age can be difficult for children (Chirico et al., 2022). Following the diagnosis, changes in personality and behaviour, a lack of interest in things that are important to them, or the person with YOD forgetting things such as names and birthdays, can be particularly difficult to accept for young people (Sikes et al., 2022).

From the perspective of the person with YOD, changes in family structures can be experienced as losing one's identity as a parent or partner (Busted et al., 2020; Harris et al., 2004; van Vliet et al., 2010). Busted et al. (2020) found that people with YOD worry about being a burden to their spouses and the family as a whole. They experience feelings of guilt for not being able to help with certain household tasks or have the in-depth conversations that they used to have (Busted et al., 2020). Wawrziczny et al. (2014) found that often the person with dementia is aware of their symptoms and the things that they cannot do in the same way as before, but that they try to hide this and not to talk about it, in an attempt to reduce the burden on their partner. Over time, the person's wish to remain autonomous and independent can clash with their partner's desire to support them and avoid distressing situations, which can cause significant strain on the relationship (Wawrziczny et al., 2014).

For those who have children, some noticed the emotional impact their diagnosis has on their children, resulting in feelings of guilt as well (Busted et al., 2020). Findings of Harris et al. (2009) show that sometimes practical support, for example picking up the kids from school because the person with dementia cannot drive anymore, can have an emotional impact on the person with dementia. Additionally, Roach et al. (2008) found that people with YOD worry about being a financial burden to their families, as they cannot work anymore and family savings might be needed for their care.

1.2.4 The impact of YOD on a person's social network

People with YOD often experience stigma and a lack of understanding from their social environment. First, dementia in general carries stigma, as it is associated with losing independence and a lack of capacity (O'Connor et al., 2018). Second, dementia is associated with old age, adding to the stigma that younger people experience (Pipon-Young et al., 2011). As a result, people may decide not to disclose their diagnosis with others (O'Connor et al., 2018), try to hide their symptoms (Busted et al., 2020), or avoid social situations and interactions. This can increase the risk of social isolation and loneliness among people with YOD and their families (Oyebode, 2022). Additionally, people with YOD often experience a decrease in their social contacts and report losing touch with friends (Greenwood et al., 2016; Harris et al., 2004; Johannessen et al., 2011; Spreadbury et al., 2017). This has an impact on their social network and the levels of support they get from others. The Convoy Model of Social Relations (section 1.3) and the Social Health Framework (section 1.4) provide further discussion on this.

1.3 The Convoy Model of Social Relations

1.3.1 Social networks, connections and support

The Convoy Model of Social Relations is a framework that aims to describe a person's social network, how it influences their sense of wellbeing and how social networks change over the life course (Antonucci et al., 2004). The Convoy Model of Social Relations can help understand how a YOD diagnosis can impact a person's social network and what the consequences of this can be on the person's wellbeing. Research shows that having a supportive social environment is important for people with YOD, as it can help them adapt to a life with dementia and maintain a sense of wellbeing (Johannessen et al., 2018; Rabanal et al., 2018). Social connections and networks are a fundamental part of human life. Being surrounded by others can support us in coping with adverse life events and protect us against the negative impact these events can have on our mental and physical health. Such environments and networks can foster social support. Social support can be defined as "the perception or experience that one is loved

and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations" (Taylor, 2007).

According to the Convoy Model of Social Relations (Kahn et al., 1980) people are surrounded by a network of others, social convoys, that are dynamic over the life course. People in a person's network can be at different levels of closeness to them: close (outer circle), closer (middle circle) and closest (inner circle). Through the Hierarchical Mapping Technique people can identify the people that are in their social network and at what level of closeness they are (Figure 1.1) (Antonucci, 1986; Fuller et al., 2020).

Figure 1.1 Convoy Model of Social Relations, Hierarchical Mapping Technique (Antonucci, 1986; Fuller et al., 2020)
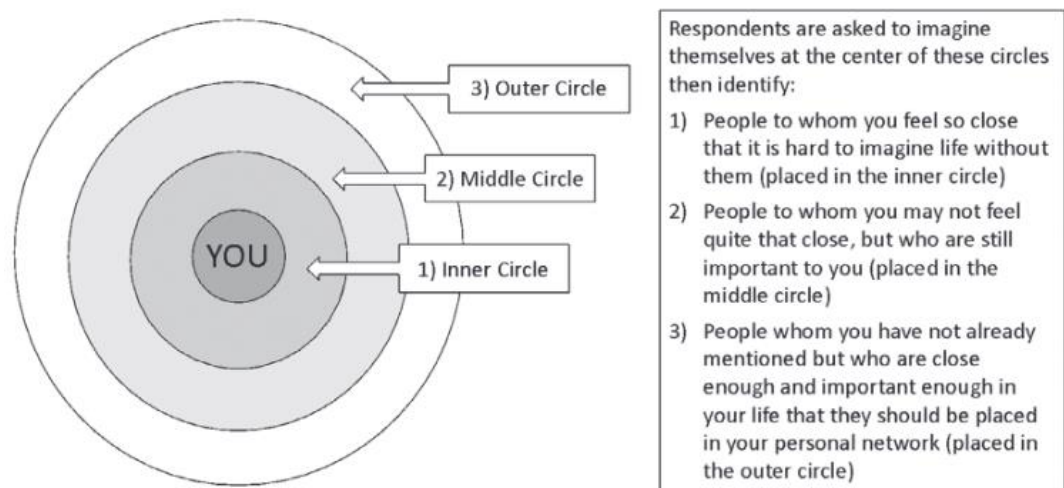
1.3.2 The Convoys of Care model

Within the healthcare field, the Convoy Model of Social Relations was the foundation for the Convoys of Care model, developed by Kemp et al. (2013). Instead of social convoys, or social networks, the Convoys of Care model describes care convoys, or care networks. These care networks are around an individual and include both formal and informal carers. As with social networks, the individuals within someone's care network can also be of different levels of closeness to the person. Care networks have an impact on a person's sense of

wellbeing and quality of life (Kemp et al., 2013). The Convoys of Care model has shown to be useful in dementia research, for example in developing a better understanding of meaningful engagement and care in care homes (Kemp et al., 2023). Furthermore, Hackett et al. (2023) used the Convoys of Care model to demonstrate how the COVID-19 restrictions put the care networks of people with dementia under significant pressure, resulting in a disruption of care and family engagement, which in turn had a negative impact on people's mental health, quality of life, and overall wellbeing.

1.3.3 The different components of the Convoy Model of Social Relations

The Convoy Model of Social Relations states that social networks and social connections are influenced by personal and situational characteristics (Antonucci et al., 2004) (Figure 1.2). Personal characteristics are for example age, gender, religion, and socio-economic status. Situational characteristics include for example social norms and expectations. Both personal and situational characteristics change over the course of life, and therefore social networks are dynamic as well (Kahn et al., 1980).

When a person receives a dementia diagnosis in their midlife, this significantly impacts their social network, or social convoy, and their personal and situational characteristics. For example, personal characteristics can get disrupted when someone is forced to give up work because of their dementia diagnosis, which impacts the socio-economic status of that person and their family (Harris et al., 2009; Oyebode, 2022; Spreadbury et al., 2017). Within the situational characteristics, a someone's roles and responsibilities within the family and their social network can change (Greenwood et al., 2016; Harris et al., 2004; Johannessen et al., 2011; Spreadbury et al., 2017). The model in Figure 1.2 also shows that personal and situational characteristics impact one another. Following our previous example, a change in someone's socio-economic status due to loss of employment can disrupt a person's role as a financial provider for the family.

Figure 1.2 Convoy Model of Social Relations (Antonucci, 1986; Fuller et al., 2020)
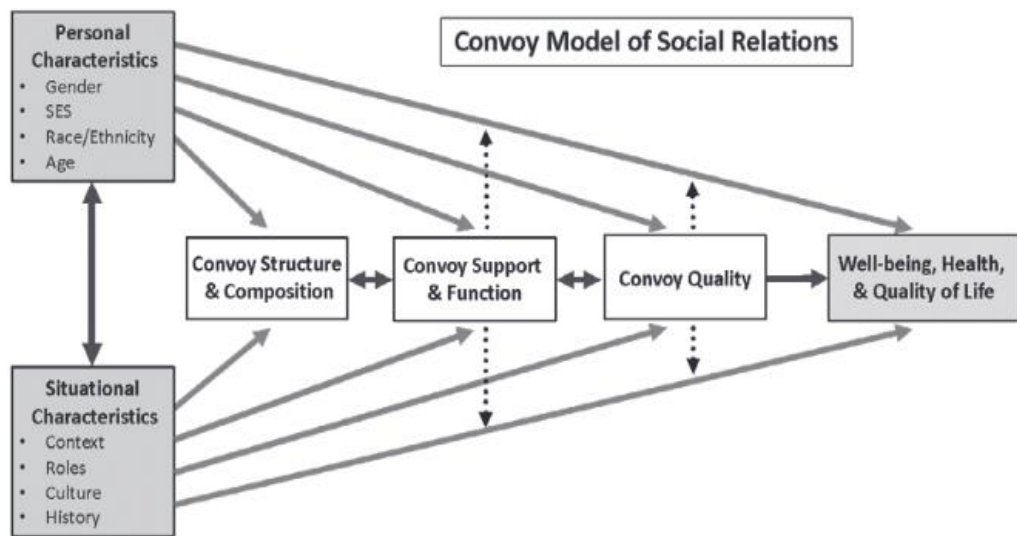
When looking further at the model in Figure 1.2 one can see how the personal and situational characteristics influence the structure, function, and quality of one's social network. First, structure relates to aspects such as size of a person's network, who is in it (e.g., family members, friends, or neighbours), how frequently the person has contact with people in their network, and whether the people in a person's network are geographically close or not. Second, support and function refer to someone being able to receive support from others, but also to provide support. This includes different forms of support, such as social and emotional support, but also tangible support. Finally, quality can be described in how someone perceives the relationship and how satisfied they are with it. For example, whether they perceive the relationship as helpful or supportive. All these elements combined influence a person's health, wellbeing, and quality of life (Kahn et al., 1980). Thus, as a YOD diagnosis influences someone's personal and situational characteristics, this also has an impact on the structure and composition of their social network, on the type and level of support that they receive from and are able to provide to others, and on the quality of their relationships.

1.3.4 The Convoy Model of Social Relations and technology

In their more recent work Antonucci et al. (2017) explored the Convoy Model of Social Relations in the context of current technology, and new ways of communication and building and maintaining social networks. They concluded that while such technology brings new opportunities, it also comes with challenges. On the one hand new communication technologies, such as social media and videoconferencing platforms, can make it easier for people to contact others more frequently, particularly those who are not geographically close to them. However, the authors also warrant that these forms of communication can be perceived as less personal compared to in-person communication. This can lead to more harmful communications, due to the perceived distance and that it is not always possible to see the other person's reaction (for example in text-based platforms such as Facebook and Twitter). The authors suggest that these challenges need to be addressed in future research (Antonucci et al., 2017).

1.4 The Social Health Framework

The Convoy Model of Social Relations links with the Social Health Framework. The Social Health Framework challenges the definition of health as stated in the Constitution of the World Health Organisation, which defines health as "a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity" (World Health Organization, 2005). The social health framework looks at health from the perspective of "the ability to adapt and self-manage", rather than a "complete" state of wellbeing (Huber et al., 2011). It includes three dimensions: (1) the ability to fulfil potential and obligations, (2) the ability to manage life with some level of independence, and (3) the ability to participate in social activities and work (Huber et al., 2011). Dröes et al. (2017) applied the social health framework to dementia. They found that people with dementia can still perceive health and wellbeing and live meaningful and satisfying lives when they try to find a balance between the limitations that they experience because of their dementia, and the abilities that they still have. Thus, when they try to adapt to a life with dementia and find ways to maintain independence. To maintain their social health, people with dementia need strong

social networks that support them while also enabling them to be independent and autonomous (Dröes et al., 2017).

1.5 Care and support services for people with YOD

Due to the chronic and progressive nature, people living with dementia need ongoing support (Hellström et al., 2017; Knight et al., 2017). Researchers agree that there is a need for psychosocial support for people with YOD and their families, to help them adapt to the unique challenges that they face (McDermott et al., 2013; Oyebode, 2022; Oyebode et al., 2016; Vernooij-Dassen et al., 2021). Specialised YOD support services are associated with more continuity and higher quality of care, and higher levels of satisfaction among people with YOD and their families (Stamou et al., 2021b). In their qualitative meta-synthesis Bannon et al. (2021) found that people with YOD want care and support services to respect their autonomy and skills. They need services that also support their families and that help them staying socially connected (Bannon et al., 2021). These findings are supported by the Angela project, a UK-wide study into the needs of people with YOD, which shows that people with YOD want care and support services that support their autonomy, independence, and sense of self and identity. Furthermore, it is important that services support the family as a whole and allow the person with YOD to remain connected with their social network (Stamou et al., 2023).

Despite the importance of age-appropriate support services for people with YOD, the systematic review of Mayrhofer et al. (2018) shows that support services for people with YOD still vary widely across the UK. One of the reasons why there are such big differences in post-diagnostic and age-appropriate support services between regions in the UK is that there are different routes through which someone can receive a YOD diagnosis. Findings of a UK-wide survey show that people were diagnosed through memory clinics, neurology clinics, older people's mental health services, and only one-fifth of the respondents received their diagnosis through a specialised service for YOD. Among this group, only half reported receiving ongoing care from the YOD specialised services (Stamou et al., 2021b). Additionally, services are often

short-term as a result of project-based funding, or services are being offered as part of pilot studies (Mayrhofer et al., 2018). This makes it difficult for people with YOD to locate age-appropriate support services (Rabanal et al., 2018).

1.6 Peer support

Different definitions of peer support exist in the literature. Solomon (2004) describes peer support as "social emotional support, frequently coupled with instrumental support, that is mutually offered or provided to others sharing a similar condition". Mead et al. (2001) describe it as "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful". Darby Penney (2018) describes peer support as "the kind of deeply felt empathy, encouragement, and assistance that people with shared experiences can offer one another within a reciprocal relationship", a description that is also included in the work of Shalaby et al. (2020). Finally, in the work of Keyes et al. (2014) 'peers' are defined as "people who identify with one another on the basis of experiences surrounding a specific diagnosis, which may or may not be the only aspect of their lives in which there is a commonality of experience".

Peer support has the potential to have a positive contribution to a person's social network and all three dimensions of social health. First, peer support can be a way for people with YOD to stay socially connected and reduce the risk of isolation (Pierse et al., 2022). Besides offering a space for social connection, peer support creates opportunities to be involved a variety of activities, such as creative and music-related activities, or involvement with advocacy, research and policymaking, allowing people to choose something that is meaningful to them. This relates to the dimension 'the ability to participate in social activities and work' of the Social Health Framework (Huber et al., 2011). In the Convoy Model of Social Relations it links to the convoy structure (new people in one's social network) (Kahn et al., 1980). Second, through peer support people can both receive and provide support and share unique knowledge they have because of their own personal experiences of living with YOD. Such experiential knowledge can include hints and tips on how to manage dementia in daily life,

as well as information about support services (Dennis, 2003; Kingod et al., 2016). This relates to the dimension 'the ability to manage life with some level of independence' of the Social Health Framework (Huber et al., 2011), and to the support function in the Convoy Model of Social Relations (Kahn et al., 1980). Third, the reciprocal nature of peer support and the opportunity to support others can increase feelings of empowerment (Barak et al., 2008; Keyes et al., 2014; Kingod et al., 2016). This relates to the dimension 'the ability to fulfil potential and obligations' in the Social Health Framework (Huber et al., 2011) and again to the support function in the Convoy Model of Social Relations (Kahn et al., 1980). Additionally, the work of Rabanal et al. (2018) and Stamou et al. (2021a) shows that peer support can make the post-diagnostic experience more positive and can help people with YOD to identify age-appropriate support services.

1.7 Online peer support

The UK is among the countries with the highest levels of internet access in the world (Petrosyan, 2022). The proportion of the UK adult population that uses the internet has been growing over the last decade. In 2013, 83.3% of the UK adult population were internet users, which grew to 92.1% in 2020. Within the age group of 35-64 a similar trend can be observed. In 2013, 89.1% of this age group was an internet user, which went up to 97.2% in 2020 (Office for National Statistics, 2021).

People with YOD often experience difficulties in accessing local, age-appropriate support services, including opportunities for peer support (Mayrhofer et al., 2018; Stamou et al., 2021b). As a result, a large group of people with YOD may miss out on the benefits of peer support, which could negatively impact their post-diagnostic experiences and social health. Considering the wide use and accessibility of the internet, a potential solution could be online peer support, as it overcomes geographical barriers and offers a wide variety of platforms offering different forms of communication (Moorhead et al., 2013; Prescott et al., 2020). Moreover, research suggests that the known benefits of peer support, such exchanging social support, friendship building,

and sharing information, can also be present in online platforms (Kingod et al., 2016).

1.7.1 The development of online platforms and technological devices

The literature has demonstrated that 'technology' is a challenging concept to define. The analysis of definitions of technology by Carroll (2017) explains that technology has a specific function and that it is designed for a specific purpose. For the purpose of this PhD thesis I focus on technology that allows people to access online platforms that can be used for communication with others.

A key event in the development of online communication platforms happened in the early 1990s when the World Wide Web was introduced (Gillies et al., 2000; Greenstein, 2015). Online communities already existed before, for example through private networks and systems for bulletin boards. However, the World Wide Web opened up the Internet for the wider public, and with that it opened up opportunities for people to form online communities, search for a wide variety of information from different sources, and with that become more informed about their health condition (Eysenbach et al., 2004). Eysenbach et al. (2004) describe online peer support communities as "venues where people with common interests meet virtually to share experiences, ask questions, or provide emotional support and self-help. Virtual communities are social networks formed or facilitated through electronic media".

The Internet as a source for health-related information

Research shows that the internet is a popular source to seek for health-related information, including information on symptoms, prognosis and treatment options (Medlock et al., 2015; Zhao et al., 2017). This is also true for the UK. In 2020, 60% of the internet users used the internet to search for health-related information (Office for National Statistics, 2020). In a case study by Kantor et al. (2018a) someone who was diagnosed with Multiple Sclerosis in the 1990s shared their experiences with the Internet and online peer support around their diagnosis and how this changed over time. They highlighted that one of the key

benefits that the Internet and online communities offered was the access to information and relevant experiences of others. Where people used to have to rely on their doctor for medical information, they now had access to information and peers from all over the world who could share their personal experiences and hints and tips (Kantor et al., 2018a).

A platform that understood this desire for information and patient education was PatientsLikeMe, which became available in 2006. On PatientsLikeMe people can create a personal profile where they provide information about their condition, the symptoms they experience, and the medications or treatments they use. All this information is displayed graphically on the user's profile. PatientsLikeMe has searching features so that users can identify others with similar or relevant experiences. PatientsLikeMe has a variety of features that allow users to communicate with each other: a discussion forum, which is accessible to all members, private messages, or through comments on other users' profile pages, which are visible to everyone (Frost et al., 2008).

Online support communities and social media
Besides searching for health-related information, people with different health conditions also use the Internet to learn from experiences of others. The launch of MySpace in 2003 and Facebook in 2004 marked the beginning of Social Media as we know it today (Kaplan et al., 2010). In 2020, 71% of the internet users in the UK used the Internet for instant messaging with others, for example through WhatsApp or Skype, and 70% used the Internet for social networking, for example on Facebook or Twitter (Office for National Statistics, 2020). Although it is widely known which platforms are examples of social media, research shows that social media is a challenging concept to define. Some of the definitions focus on the way messages and communication is constructed in social media (Carr et al., 2015). For example, Russo et al. (2008) define social media as "those that facilitate online communication, networking, and/or collaboration". Other definitions focus on the concept of users being the ones generating the content (Carr et al., 2015). For example, Kaplan et al. (2010) define social media as "a group of internet-based applications build on the

ideological and technological foundations of Web 2.0 and that allow the creation and exchange of User Generated Content". A limitation of these definitions is that they do not make a distinction between social media and other platforms and technologies used for communication, for example email (Carr et al., 2015). Based on previous work and definitions, Carr et al. (2015) describe social media as "Internet-based channels that allow users to opportunistically interact and selectively self-present, either in real-time or asynchronously, with both broad and narrow audiences who derive value from user-generated content and the perception of interaction with others".

A recent systematic review by Chen et al. (2021) shows that people use social media to exchange and search for health-related information, support groups, and to track and share health-related updates. The authors found that in online support communities people shared information and experiences, and emotional support and encouragement. Online communities also provided people with a network of peers who had a similar health condition, which created a sense of belonging (Chen et al., 2021). Social media includes a variety of platforms, such as social networking sites (e.g. Facebook, Twitter), professional networking sites (e.g. LinkedIn), and chat boards and discussion forums (Carr et al., 2015). Boyd et al. (2007) define social networking sites as "web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system". Kaplan et al. (2010) differentiate between social networking sites and content creation communities, for example YouTube. The difference is that for content creation communities people do not necessarily have to create a profile to be able to view the content on the platform (Kaplan et al., 2010). Furthermore, Kaplan et al. (2010) also consider blogs to be social media. Blogs, short for weblogs, are personal internet pages where people share anything that is personal or relevant to them, for example their experiences with a specific health condition. Blogs can include text-based content, but also videos or images. Usually the content of the blog is managed by one person, but readers of the blog often have the option to leave comments, allowing for interaction between the author and the reader (Kaplan et al., 2010).

Smartphones

Before the introduction of smartphones and tablet computers, people relied on personal computers to make use of the Internet. However, with the introduction of smart phones and tablet computers, people did not have to be at home at their computer anymore to be able to reach out to others online. With these new technological devices online peer support communities and social media became accessible at any time of the day and at any place (Rosen et al., 2013). In a qualitative study Wang et al. (2014) explored how people use smartphones for personal use. They found that smartphones are integrated into people's daily lives, and some of the main uses of smartphones are communication and social networking. With a smartphone people felt more connected and people noticed they communicated more frequently with friends and family. Additionally, they engaged more frequently with social networking sites such as Facebook, which made them feel more informed about what is going in in the lives of family and friends. Smartphones can support a wide variety of platforms and apps, which can all support different forms of communication, such as communication by text, voice messages, photos and videos. In this way people can find a form of communication that is convenient for them and that suits their needs and wishes (Wang et al., 2014).

1.7.2 Benefits, challenges and limitations of peer support on online platforms

Overcoming physical and geographical barriers

One of the main advantages of online platforms is that they overcome geographical barriers (Austrom et al., 2015; Coulson et al., 2007). As accessibility to age-appropriate, local peer support services for people with YOD varies widely across the UK (Mayrhofer et al., 2018; Mayrhofer et al., 2021b), online platforms could make peer support more accessible to those who do not have a YOD peer support group in their local area. For example, some support groups specifically for people with a rarer form of dementia are facilitated by Rare Dementia Support in London (Mayrhofer et al., 2021b; Stevens-Neck et al., 2023). Online platforms could make such peer support meetings accessible for people who are unable to travel or attend meetings in-person, for example due

to the nature of symptoms they experience (Barclay et al., 2022), due to other responsibilities such as work or caring for or supporting others (McCabe et al., 2015; McLoughlin et al., 2023), or for financial reasons (Matthias et al., 2016). Finally, people can feel more comfortable and relaxed when being in their own home (Banbury et al., 2018; Rubya et al., 2017).

Access to a wide range of information and experiences

Online platforms provide people with the opportunity to expand their network and receive input from others that they would otherwise not have met. Online platforms can be accessible to people regardless of where they are in the world. In this way, people can learn from the experiences of others who are outside of their regular social circles (Coulson et al., 2007; Walther et al., 2002). This can make peer support through online platforms particularly suitable for people with relatively rare conditions, such as YOD, because they may be less likely to meet someone with the same or a similar condition in their local area (Delisle et al., 2017). Furthermore, a recent systematic review by Johansson et al. (2021) demonstrates that online peer support communities can contribute to feelings of empowerment. They found that through online communities people became better informed about their health condition, which can help them in their consultations with their doctor, and online support communities provided people with the opportunity to help others and share their experiences (Johansson et al., 2021). However, especially on asynchronous platforms such as discussion forums or social media groups, the amount of information and messages can also feel overwhelming and it can be difficult for people to navigate through this and identify relevant information (Coulson, 2013; Malik et al., 2010; Steadman et al., 2014).

Having options and choosing own levels of involvement

There is a wide variety in online platforms that can be used for peer support, and these all offer different options and modes of communication. For example, social networking sites such as Facebook and Twitter allow for asynchronous (not in real time) communication through text-based posts and offers options to

share images, videos, and audio files (Prescott et al., 2020). For these platforms people do not need to be active in the online platform at the same time, but instead posts are saved and people can read, write, or respond to posts in their own time and at their own pace. These platforms can also adopt synchronous (real time) communication, for example through Facebook Live sessions, or when members are active at the same time and engage in a real-time conversation through posts (Mustafa et al., 2015). An advantage of platforms that offer the option for text-based, asynchronous communication is that someone can send a message at any time of the day, right in the moment when they have a question or need support (Ziebland et al., 2012). However, a challenge of asynchronous platforms is that people can also experience a lack of responses to their posts (Attard et al., 2012).

Another type of online platforms that can be used for peer support is videoconferencing platforms, such as Skype, Zoom and MS Teams. These platforms are different in nature compared to the before mentioned asynchronous, mainly text-based, platforms, because there is real-time, verbal and audio-visual communication (Banbury et al., 2018). The opportunity to hear and see others can contribute to a positive experience (Banbury et al., 2018), and can also help to read other people's body-language and see facial expressions. It can be also be comfortable for people to be in their own home for the peer support meeting, and when not having to travel, it becomes more feasible to meet up more frequently compared to in-person support groups (Austrom et al., 2015). In a video meeting people also have the option to turn off their camera or mute themselves if they want to (Banbury et al., 2018). However, meeting in videoconferencing platforms also comes with some challenges. For example, it can happen more easily that people talk over each other and the conversation might feel less natural due to having to take turns and muting oneself when not speaking (Banbury et al., 2018; McLoughlin et al., 2023). Additionally, in online meetings or online support communities it can be more difficult to notice how someone is doing if they are being a bit quiet, whereas in a face-to-face meeting it can be easier to go up to someone outside of the group and ask if they are doing ok (Rubya et al., 2017). Although people can hear and see each other through

the video meeting, it can still feel less personal, relaxed and informal than in-person meetings (McLoughlin et al., 2023).

This variety of different platforms allows people to choose something that meets their own needs and preferences. Additionally, with online platforms it can be easier for people to choose their own level of engagement compared to in-person settings. For example, on discussion forums or social media groups people can choose how often they want to look at the forum and whether they want to interact with others or simply just read the posts (also called 'lurking') (Steadman et al., 2014). Similarly, in video meetings people often have the option to mute themselves or turn off their cameras.

Anonymity

Some online platforms allow people to remain relatively anonymous and choose the amount of personal information they share. Such an anonymous space can make people feel freer and safer to share their feelings or experiences (Hargreaves et al., 2018). The anonymous nature of some online platforms may be particularly appreciated by people with stigmatised conditions (Rains, 2014). Additionally, not everyone with YOD may feel ready to share their diagnosis and experiences with others. Online peer support allows for people to engage in peer support from the comfort of their own home, potentially lowering the barrier to join a peer support group. However, the anonymous nature of some online platforms also comes with some potential risks and limitations. Sometimes people can experience a lack of connection with the other members due to the limited personal information, which can make it more difficult for people to be open (Coulson, 2013; Kantor et al., 2018a). The anonymous nature can also make people feel freer to share certain harmful comments that they would not share as easily in an in-person setting, due to the perceived distance (Antonucci et al., 2017; Turner, 2017).

Exposure to unwanted, misleading, or harmful information

In online platforms, sometimes people can be exposed to unwanted information. For example, reading stories of those who experience different or more severe symptoms or are further in their progression of the condition can be experienced

as triggering (Coulson et al., 2016; Perkins et al., 2020; Talbot et al., 2023). Another well-known negative aspect of for example discussion forums is that people tend to mainly share negative experiences or difficulties. The reason for this can be that when experiencing difficulties, people feel the need for support and therefore reach out to their online support network. As a result, the content can feel quite negative and make others feel bad for the other person or feel more negative, worried or less hopeful about their own situation (Coulson, 2013; Malik et al., 2010).

There is also a risk of being exposed to misleading or harmful information or advice (Turner, 2017). It can also be challenging to judge the accuracy and trustworthiness of the information they find online, for example on social networking sites or discussion forums (Coulson, 2013; Malik et al., 2010) Suarez-Lledo et al. (2021) found that there is a particular risk for misinformation on social media regarding a range of health-related topics, such as medical treatments, health interventions, drugs and medication, and vaccination. Furthermore, people may experience a lack of replies to their posts, or due to the limited personal information experience a lack of connection with other members (Attard et al., 2012).

Digital exclusion

With online peer support there is a risk for digital exclusion, as it is only accessible to those who are able to use technology have the financial resources for the necessary devices (Turner, 2017). Some have to rely on the library to access a computer and use the internet because they do not have the financial resources to purchase a computer or smartphone, and to pay for internet access (Greer et al., 2019). Furthermore, due to the nature of symptoms, using technological devices and engaging in online text-based or verbal communication can be challenging for people with dementia. While some may have support from a family member or friend, others may not and can therefore be at risk of missing out on the benefits of technologies (Talbot et al., 2022).

1.7.3   Online peer support and dementia

People with dementia use a variety of platforms to express themselves, share their personal stories and exchange experiences, for example through blogs (Brooks et al., 2022; Castaño, 2022), discussion forums (Rodriquez, 2013; Talbot et al., 2023), and social networking sites such as Facebook (Craig et al., 2016) and Twitter (Talbot et al., 2020). These studies show that through online networks people with dementia share their experiences of what it is like to live with dementia, hints and tips on coping with challenges in daily life, as well as social and emotional support. Through this, people created a sense of community, despite not being physically close. Furthermore, Craig et al. (2016) and Talbot et al. (2020) found that people use Facebook and Twitter for advocacy and raising awareness.

While the before mentioned studies explore what kind of platforms people use and the posts that they share, most did not directly assess how people experience engaging with the platform and how it impacts their daily lives. The previous research also does not provide insights into the views and experiences of those who cannot or do not want to engage with online peer support, and what the potential barriers are that they face. Furthermore, the previous research focusses on text-based platforms. During the COVID-19 pandemic videoconferencing platforms such as Zoom became increasingly popular and were also used for health and social care services (Giebel et al., 2021a). Finally, the previous research focusses on the dementia population in general and not on YOD specifically.

2. Aims and methods

The methods presented in chapter were published as a journal article: Gerritzen, E.V., McDermott, O., & Orrell, M. (2022). Development of Best Practice Guidance on Online Peer Support for People With Young Onset Dementia: Protocol for a Mixed Methods Study. *JMIR Research Protocols, 11*(7). [10.2196/38379](10.2196/38379)

2.1 Aims

This study aimed to identify facilitators and barriers to online peer support for people with YOD and to produce recommendations for people with YOD and peer support facilitators. The recommendations will be collated in (1) a Best Practice Guidance on online peer support for people with YOD, so that people have access to evidence-based and tailored information about online peer support, and (2) guidelines for facilitators of online peer support, so that they have access to tailored and evidence-based information to improve online peer support for people with YOD.

This study aimed to answer the following research questions:

1. How do people with YOD use and experience online peer support?
2. What makes online peer support meaningful for people with YOD?
3. How can online peer support for people with YOD be optimised?

2.2 Methods

This mixed-methods study consisted of four phases and followed the guidelines of the Medical Research Council (MRC) on complex interventions (Skivington et al., 2021). This study focussed on the development stage of the MRC framework and develops a plan for the feasibility/piloting, evaluation, and implementation stages. Each phase consisted of multiple sub-studies. Phase 1, 2, and 3 contributed to the development of the best practice guidance, including the guidelines for facilitators. Phase 4 consisted of disseminating the best practice guidance and guidelines and developing a plan for a potential future pilot study, evaluation, and further implementation and dissemination. An overview of all four phases can be found in Figure 2.1.

Figure 2.1 Towards the development of a Best Practice Guidance (BPG) on online peer support for people with YOD using the MRC framework
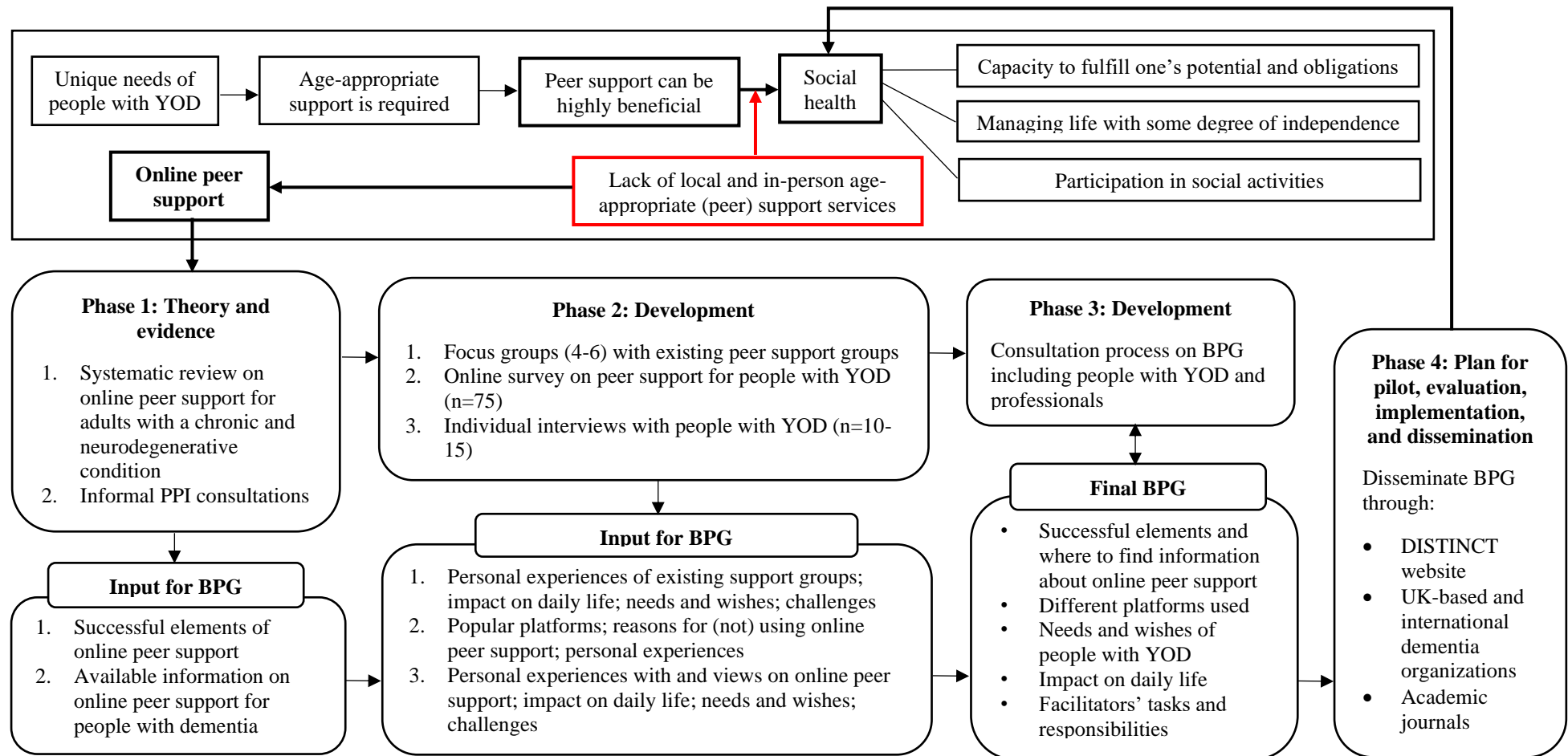
2.2.1 Phase 1: Theory and evidence

The aim of this phase was to get a better understanding of how people with YOD experience and view online peer support, what overall challenges they face, and how facilitators of peer support view using online platforms. Furthermore, this phase aimed to review the existing academic and grey literature on online peer support. The findings set the foundation for the next phases and informed the first draft of the best practice guidance. This phase consisted of a narrative synthesis systematic review on online peer support for adults with chronic neurodegenerative conditions (chapters 3-5) and informal consultations with people with YOD and peer support facilitators.

Narrative synthesis systematic review

Through a scoping search in online databases and Google Scholar, few studies on online peer support and dementia were identified which all focussed on text-based platforms (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2023; Talbot et al., 2020). A larger body of scientific literature on online peer support has been published for other neurodegenerative conditions, in particular Parkinson's disease (PD), Multiple Sclerosis (MS), and Amyotrophic Lateral Sclerosis (ALS). The World Health Organisation (WHO) emphasizes the importance of identifying and sharing techniques or methods that work in certain situations, contexts or groups, which can support the development, adaptation and implementation in similar contexts and populations. These techniques and methods can be defined as 'best practices' (Serrat, 2017; World Health Organization. Regional Office for Africa, 2017). PD, MD and ALS have similarities with YOD as they are chronic and neurodegenerative in nature and are also prevalent among people under 65, who can experience similar challenges as people with YOD (ALS Association, n.d.; Johns Hopkins Medicine, n.d.; Oliver et al., 2019; Parkinson's UK, n.d.) (ALS Association, n.d.; Huntington's Disease Association, n.d.; Johns Hopkins Medicine, n.d.; Oliver et al., 2019; Parkinson's UK, n.d.).

Parkinson's disease

PD is a chronic and progressive neurodegenerative condition which is characterised by motor symptoms such as tremor, bradykinesia, and rigidity. Many patients also experience non-motor symptoms, for example sleep disturbances, depression, and constipation (Halli-Tierney et al., 2020). PD significantly impacts the lives of people with the diagnosis and their families (Ambrosio et al., 2019; Beaudet et al., 2015). Due to its chronic and neurodegenerative nature people affected by PD need ongoing care and support (Beaudet et al., 2015). Besides the physical symptoms associated with PD, receiving the diagnosis and living with the condition also has an emotional impact. This includes anxiety for the future, difficulties managing the condition in daily life, and the impact on the family (Hellqvist et al., 2020). PD can also impact people's social lives and how they are involved in different roles, such as their role within the family, social circles, or at work. Receiving a diagnosis of PD and living with the condition can result in withdrawal from such social roles, increasing the risk for social isolation and loneliness (Perepezko et al., 2019). In 2018 in the UK more than 145,000 people were living with PD, of whom 19,690 were younger than 65 (Parkinson's UK, 2018). These findings show that PD can impact one's life in a similar way as dementia, and that PD also affects people in their midlife.

Multiple Sclerosis

MS is a chronic neurodegenerative condition that causes damage to the central nervous system (Multiple Sclerosis Trust, 2021). MS significantly affects the lives of people who have it as well as their families' (Holland et al., 2011). People with MS experience cognitive changes, leading to difficulties processing and learning new information and solving problems (National Multiple Sclerosis Society, n.d.). In addition, people with MS often experience depression and anxiety, increasing their risk for social isolation and loneliness (Al-Asmi et al., 2015). Physical symptoms of MS can include impaired mobility and balance, problems with bladder and bowel function, and sexual dysfunction. All symptoms can affect a person's family life (e.g. becoming more dependent on family members for care) (Holland et al., 2011), social life (e.g. being unable to

continue practicing hobbies or sports) (Cowan et al., 2020), and employment (e.g. reducing work hours or leaving one's job) (Strober et al., 2018). These findings show that MS can affect a person's life in a similar way as dementia. Most people are diagnosed with MS in their 20s and 30s. Due to its chronic nature it therefore mainly affects people in their early and mid-adult life (Multiple Sclerosis Trust, 2021).

Amyotrophic Lateral Sclerosis

ALS is a motor neuron disease that affects the lower and upper motor neurons (National Institute of Neurological Disorders and Stroke, 2022). Typically, people are around 60 years old when they get diagnosed (Talbott et al., 2016). As the condition progresses people can experience difficulties with speaking, eating, moving and breathing (National Institute of Neurological Disorders and Stroke, 2022). Additionally, people with ALS can experience forms of cognitive impairment, including difficulties in recognising emotions in others, interpreting social situations (Beeldman et al., 2016) and apathy. Due to the nature of symptoms and the rapid progression of the condition, people with ALS need ongoing care and support (de Wit et al., 2017). People with ALS cope with an increasing loss of control and dependency on others and often fear being a burden (de Wit et al., 2017; Matuz et al., 2015; Oh et al., 2017; Weeks et al., 2019). Matuz et al. (2015) found that higher perceived social support and coping skills can reduce depressive symptoms, and that effective coping strategies and health behaviours can reduce the impact of stress. These findings show that people with ALS and people with dementia can experience a similar impact of the condition, particularly due to the growing feeling of dependency on others. Considering the typical age of diagnosis of ALS, it shows that it affects a similar age group as YOD.

Patient and Public Involvement

During the design process of this study people with YOD, carers, and health and social care professionals working with people with YOD were consulted. Senior members of the research team have extensive clinical experience in working with

people with YOD as well as experience with Patient and Public Involvement (PPI) and co-creating research projects. Throughout the study there were regular PPI consultations with people with YOD and health and social care professionals to discuss progress of the study and study documents. All participants who wanted received the initial findings of the study in which they took part and had the opportunity to provide further input on the findings before they got published.

2.2.2 Phase 2: Development

The aim of this phase was to identify the needs and wishes of people with YOD regarding online peer support, and what kind of information they wanted in the best practice guidance. This was done by gathering experiences from people with YOD who used online peer support and those who did not. To do that, this phase consisted of three sub-studies: (1) focus groups with existing peer support groups for people with YOD, (2) online survey for people with YOD, and (3) interviews with people with YOD.

Sub-study 1: Focus groups with existing peer support groups (chapter 6)

This study consisted of focus groups with existing peer support groups that had their meetings online. During the COVID-19 pandemic many support services for people with dementia were disrupted and had to move online (Giebel et al., 2021a). Videoconferencing platforms such as Zoom and MS Teams became more popular. The focus groups were held on MS Teams or the group's usual meeting platform and aimed to provide insights into how people with YOD experienced peer support through video meetings, how this impacted their daily life, and what the impact was of moving the meetings online. This study also explored pros and cons of peer support through video meetings, differences with in-person peer support, and potential challenges and how to overcome these.

Participants

People were eligible for this study if they (1) were living with a dementia diagnosis, (2) received their diagnosis before they were the age of 65, (3) understood English, and (4) were part of an existing peer support group that had experience with online meetings. Groups did not have to be online only groups, they were also eligible if they used to meet in person but moved their meetings online during the COVID-19 pandemic. People did not have to be younger than 65 at the time they took part in the study.

People living in a care facility were excluded from this study, because this population has daily contact with other people with dementia and is thus already involved in a form of in-person peer support, which can reduce the need and wish for remote, online peer support. Additionally, people living in a care facility are more likely to be in the more advanced stages of dementia, when the nature of symptoms can make it more difficult for people to use technology and engage in online peer support.

Recruitment

Existing peer support groups were recruited using convenience and purposive sampling. With convenience sampling the study was advertised through dementia organisations, research networks, and academic institutions. Group facilitators and members could contact the research team if they were interested. With purposeful sampling the professional network of the research team was consulted. The aim was to conduct 4-6 peer support groups, as data saturation tends to occur after 4-6 focus groups have been conducted (Hennink et al., 2019). The number of people in each focus group depended on how many members of each peer support group wanted to take part.

Data collection and analysis

The focus groups were screen- and audio-recorded using the recording function of the videoconferencing platform and an external University of Nottingham approved recording device and were transcribed verbatim. Additionally, the

facilitator took take field notes. The transcripts were analysed thematically with an inductive approach using the procedures outlined by Braun et al. (2021a), and were performed in NVivo.

Sub-study 2: Exploratory survey (chapter 7)

An online survey explored the different types of online peer support that people with YOD use, benefits and challenges of different online platforms, and positive as well as potential negative experiences people may have had. Furthermore the survey explored why people did not engage in online peer support and identified potential barriers. This survey was informed by the findings of Phase 1 and sub-study 1 and set the foundation for sub-study 3. The survey was developed in Online Surveys (https://www.onlinesurveys.ac.uk/) and includes fixed-choice and open questions. At the beginning of the survey participants answered questions on baseline characteristics (e.g. age, gender, time since diagnosis) and their experience with online peer support. At the end of the survey participants were asked if they wanted to be involved in future parts of the study. Those who answered 'yes' could leave their contact details. In this way, this study was used as a pool for recruitment for sub-study 3. Those who answer 'no' could complete the survey anonymously.

Recruitment

This study had the same eligibility criteria as sub-study 1, minus the fourth criteria saying that people had to be part of an existing peer support group. Participants were recruited using convenience sampling through (a) NHS services, (b) dementia charities (e.g. Dementia UK, Dementia Engagement and Empowerment Project (DEEP)), (c) research networks (e.g. Join Dementia Research, Rare Dementia Support), and (d) academic institutions (e.g. University of Nottingham). Furthermore, the survey was advertised through social media and the professional network of the research team. The aim for the sample size was 75 participants, based on expertise within the research team.

Data collection and analysis

Participants could take part independently by following the link to the survey. Alternatively, they could request a paper copy or go through the survey verbally with EVG. This study collected both qualitative and quantitative data. The qualitative data were analysed using thematic analysis following the procedures outlined by Braun et al. (2021a). This consisted of six phases: (1) familiarising with the data, (2) coding the data, (3) developing initial themes, (4) developing and reviewing themes, (5) refining, defining and naming the themes, and (6) writing up. The analysis was performed in NVivo. The quantitative data were analysed in SPSS using the Chi-Square test of significance.

Sub-study 3: Interviews (chapter 8)

The interviews with people with YOD build on the findings of sub-studies 1 and 2 and gathered further insights into (1) reasons to engage or not engage in online peer support, (2) the impact of online peer support on daily life, (3) needs regarding online peer support, and (4) barriers to online peer support and how to overcome these.

Participants and recruitment

By using purposive sampling, a sample from the participants from sub-study 2 who answered 'yes' to the question whether they would like to be involved in future parts of the study, were invited for an individual interview. The sample was as diverse as possible in terms of baseline characteristics, time since diagnosis, and experience with online peer support.

Data collection and analysis

The individual interviews were conducted over a phone or video call (on MS Teams), depending on the participant's preference. The interviews were recorded using an external University of Nottingham approved recording device or the recording function of MS Teams, and were transcribed verbatim. The

transcripts were analysed thematically with an inductive approach following the procedures outlined by Braun et al. (2021a) and were performed in NVivo.

2.2.3 Phase 3: Development (chapter 9) and Phase 4: Dissemination (chapter 10)

The development of the Best Practice Guidance followed a consultation process. A draft of the Guidance and guidelines was shared for feedback with (1) everyone who took part in the study and said they were interested in being involved in future parts of the study, (2) dementia organisations and (3) professionals working with people with YOD. The aim was to disseminate the best practice guidance and guidelines locally (UK) and internationally through dementia organisations and services, research networks, and academic institutions. Furthermore, a plan for a potential future pilot study to test the best practice guidance and guidelines and further implementation and dissemination was developed.

2.3 Ethics and dissemination

This study received ethical approval from the London Bromley Research Ethics Committee (21/LO/0248) (Appendix 2) and followed the Declaration of Helsinki, 1996; the principles of Good Clinical Practice (GCP), the UK Department of Health Policy Framework for Health and Social Care, 2017 and the DEEP (Dementia Engagement and Empowerment Project) Ethics Gold Standard for Dementia Research (DEEP, 2020). The findings were disseminated through journal articles in scientific peer-reviewed journals, presentations at conferences and other events.

2.3.1 Informed consent

All participants provided informed consent before participating in any part of the study. Participants of the online survey were asked to confirm that they read and understood the study information and that they were happy to proceed before they could continue to the questions. Participants who filled in a paper copy or

went through it verbally were asked to do the same. Completion and submission of the survey were taken as consent. For participants taking part in an individual interview or a focus group, consent was be taken remotely. This was due to the wide range of geographic locations of participants and COVID-19 restrictions. There were three ways through which participants could provide consent: (a) signing a paper consent form and sending it back to the researcher, (b) signing a digital consent form and sending it back to the researcher, or (c) going through a verbal consent process with EVG over a phone or video call. EVG followed training on the Mental Capacity Act (Department for Constitutional Affairs, 2007).

2.3.2   Data collection and storage

The interviews and focus groups were conducted remotely through MS Teams, the support group's usual meeting platform, or a phone call. The interviews and focus groups were audio recorded with a University of Nottingham approved recording device, or audio- and screen-recorded through the videoconferencing platform. The recordings were transcribed verbatim by a professional transcribing company that has an agreement with the University of Nottingham, or the automatic transcription function in MS Teams. Once the transcripts were completed the recordings were deleted. The transcripts left out any information that could identify the person. The recordings and transcripts were stored on a password-secured online storage space of the University of Nottingham.

2.4 Conclusion

People with YOD often experience different challenges than older adults with dementia and therefore need age-appropriate support. Peer support can contribute to a more positive post-diagnostic experience and every dimension of the social health framework. However, many people with YOD experience a lack of age-appropriate (peer) support services in their local area, indicating that online peer support could be a solution. While research into online support for people with dementia is increasing, it remains unknown how users experience this, how it impacts their daily lives, and what elements make it meaningful. This

study aimed to explore how people with YOD use and experience online peer support, and how online peer support could be improved. It was intended that the findings would lead towards the development of best practice guidance on online peer support, providing people with YOD with tailored and evidence-based information about online peer support. The guidance also included guidelines for peer support facilitators aiming to improve existing and developing new online peer support opportunities.

3. Narrative synthesis systematic review: online peer support for people with Parkinson's Disease

The findings presented in this chapter were published as a journal article: Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Parkinson's Disease: a narrative synthesis systematic review. *JMIR Aging, 5*(3). 10.2196/35425

3.1 Aims

This narrative synthesis systematic review aimed to (1) explore the benefits and challenges of online peer support for people with PD, and (2) identify successful elements of online peer support. Elements of online peer support were deemed successful if studies identified positive outcomes for the people engaging in online peer support.

3.2 Methods

3.2.1 Narrative synthesis

The method that was selected for this systematic review is the narrative synthesis. With a narrative synthesis the presentation of the findings is mainly words- and text-based. It is a useful method to synthesise the data in a clear and structured manner and to identify elements of best practice (Popay et al., 2006). Therefore, the narrative synthesis was identified to be the most suitable method for this systematic review. We used the narrative synthesis procedures outlined by Popay et al. (2006). This entails including the following elements: (1) theory development, (2) development of a preliminary synthesis, (3) exploration of relationships in the data, and (4) assessment of robustness of the synthesis. Furthermore, this review was presented following the PRISMA 2020 guidelines (Page et al., 2021).

The aims of Element 1: Theory development were to inform the research questions and the type of studies to include, support the interpretation of the findings, and assess the potential generalizability of the findings (Popay et al.,

2006). One of the key elements of peer support is social support (Barak et al., 2008; Keyes et al., 2014). Research demonstrates that supportive social relationships can promote health and overall wellbeing. Receiving social support and believing social support is available when needed can improve coping skills, which can reduce the impact of stressful life events, such as living with a chronic health condition (Cohen et al., 2000). This also relates back to the social health framework (Dröes et al., 2017; Huber et al., 2011).

The aim of Element 2: Development of a preliminary synthesis was to provide an initial description of the findings of the included studies. The findings in this review were presented through textual descriptions, grouping and clustering, and tabulation (Popay et al., 2006). In Element 3: Exploration of relationships in the data, the preliminary synthesis was used to get more insight into patterns between the different studies. Exploring the relationships within the data helps to develop an understanding of how and why an intervention or a practice works. The methods that were used for this review are translation (way to explore relationships across studies) and qualitative case descriptions (Popay et al., 2006). Finally, Element 4 aimed to assess the robustness and trustworthiness of the synthesis. Where the robustness included an interpretation of the methodological quality of the included studies, the trustworthiness also included an assessment of the methods that were used for the synthesis. For this review, the robustness was addressed with two quality assessment tools to assess the quality of the included studies. The trustworthiness was addressed by assessing the strengths and limitations of this review (Popay et al., 2006).

3.2.2 Search strategy

A systematic database search was conducted in April 2020. The search strategy was developed with help of two librarians and Professor Neil Coulson who is an academic expert on online peer support. Six databases were searched: CINAHL, Cochrane Library, Embase Medline, PsycINFO, Scopus, and Web of Science. The keywords used for the searches are presented in Appendix 3. One search filter regarding year of publication: 1989 – 2020 was applied. This was because the World Wide Web was introduced in 1989. No filters on the study design

were applied. Finally, the reference lists of the included papers were searched manually. This did not result in any new papers being added.

3.2.3   Inclusion and exclusion criteria

Papers were included if they met the following criteria:

- The study population included people living with PD or a blend of people living with the condition and caregivers.
- The intervention included online peer support. For this review, online peer support was regarded as communication via the Internet between peers in an online environment that is designed to facilitate social contact (e.g. social media platforms, forums, or chat rooms).
- Publication between 1989 and 2020 (the World Wide Web was introduced in 1989).
- Publication in peer reviewed journals.

Papers were excluded if:

- The study focussed solely on caregiver perspectives;
- The intervention did not include online peer support or included online peer support that was part of a programme that also included in-person or telephone-based peer support;
- The study did not report on peer-to-peer interactions (This exclusion criterion was added after the initial screening. See '3.2.4 Study selection' for more details);
- Literature reviews, opinion pieces, editorials, protocols, conference abstracts;
- Studies written in a language other than English if a translation was not available;

3.2.4 Study selection

The search results were imported into Endnote, after which all duplicates were removed. The primary reviewer (EVG) reviewed each title and abstract against the eligibility criteria. The primary reviewer consulted a second reviewer (ARL) on the titles and abstracts that she was unsure about. The title and abstract screening was followed by a full-text analysis of the potentially relevant papers. The initial full-text analysis was conducted by EVG. The same procedures as with the title and abstract screening were followed. At this stage the main reason for labelling a paper as unsure was that while the paper met the eligibility criteria, it mainly focussed on other outcomes other than peer-to-peer interactions (e.g. quality of life). Following the discussion with a third reviewer (OM) it was decided to refine the exclusion criteria and add the criterion that papers could be excluded if they did not report on peer-to-peer interactions. The papers that were included up until that point were reassessed against the newly added exclusion criterion.

3.2.5 Data extraction

Following the study selection, EVG extracted the data using standardized data extraction forms. Data were extracted on (1) study information, (2) study characteristics, (3) population characteristics, (4) characteristics of the online platform, (5) outcomes, and (6) implications for future research. ARL provided a second independent review of the completed data extraction forms.

3.2.6 Quality assessment

Two quality assessment tools were used to assess the risk of bias in individual studies. For the assessment of the risk of bias in qualitative studies, the Critical Appraisal Skills Programme (CASP) checklist was used (Critical Appraisal Skills Programme, 2018). This checklist consists of 10 questions related to "rigour, credibility and relevance" (Centre for Reviews and Dissemination, 2009). For studies that could not be assessed by the CASP checklist, the Downs and Black Quality Checklist will be used. This tool consists of 27 items and is suitable for both randomised and non-randomised studies (Downs et al., 1998).

Both the CASP checklist and the Downs and Black Quality Checklist were chosen because they are recommended in the Centre for Reviews and Dissemination guidance for undertaking reviews in health care (Centre for Reviews and Dissemination, 2009) and have successfully been used in previous narrative synthesis systematic reviews (Cavalcanti Barroso et al., 2020; Lee et al., 2021; Rai et al., 2020).

For the CASP checklist, studies were graded 'high' if they met or partially met 8-10 items, 'medium' if they met or partially met 5-7 items, and 'low' if they met or partially met 0-4 items (Bayliss et al., 2016). For the Downs and Black Quality Checklist some of the items were left out of consideration as they were not applicable to the studies assessed (McDermott et al., 2013). Therefore, the new maximum score was 25. Papers were labelled 'excellent' if they had 22-25 points, 'good' if they had 17-21 points, 'fair' with 13-16 points, and 'poor' when they had less than 13 points. A detailed explanation of the new scores and according labels are presented in Appendix 3.

3.3 Results

The results section covers element 2 of a narrative synthesis: developing a preliminary synthesis. The online database search returned 10,987 unique titles and abstracts. After screening of the titles, abstracts and full-text, 8 papers met the inclusion criteria for this review. An overview of the online database search and screening process can be found in Figure 3.1.

3.3.1 Study characteristics

An overview of the study characteristics is presented in Table 3.1. This review includes a variety of methods. Three papers used a qualitative content analysis of posts on a discussion forum (Attard et al., 2012; Bakke, 2018; Stewart Loane et al., 2014), three papers reported the findings of a pilot study (Lieberman, 2007; Lieberman et al., 2006; Lieberman et al., 2005), one paper did an ethnographic study in a virtual world (Davis et al., 2016), and one paper conducted a survey and interviews (Martínez-Pérez et al., 2014).

3.3.2   Summary of interventions

For all studies the mode of communication between participants was text-based. In four studies the communication was asynchronous (Attard et al., 2012; Bakke, 2018; Martínez-Pérez et al., 2014; Stewart Loane et al., 2014), meaning that participants did not necessarily communicate with each other in real time. This is one of the characteristics of discussion forums, where people can post a message and others can respond at a time that is convenient for them. Davis et al. (2016), Lieberman (2007), Lieberman et al. (2006), and Lieberman et al. (2005) used communication in real time (synchronous). Besides Martínez-Pérez et al. (2014) all online peer support communities analysed in this review were moderated. This means that one or multiple people either guided the discussion and/ or monitored the posts. While six studies only included people living with a PD diagnosis (Attard et al., 2012; Davis et al., 2016; Lieberman, 2007; Lieberman et al., 2006; Lieberman et al., 2005; Stewart Loane et al., 2014), two studies also included caregivers (Bakke, 2018; Martínez-Pérez et al., 2014).

3.3.1   Quality assessment

Five papers were assessed with the CASP checklist. Of these, three were labelled as high quality (Attard et al., 2012; Bakke, 2018; Stewart Loane et al., 2014), one as medium (Davis et al., 2016), and one was assessed to be of low quality (Martínez-Pérez et al., 2014). Three papers were assessed with the Downs and Black Quality Checklist which were all labelled as fair (Lieberman, 2007; Lieberman et al., 2006; Lieberman et al., 2005). An overview of the CASP Checklist and the Downs and Black Quality Checklist and the scores for each study can be found in Appendix 4.

Figure 3.1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) diagram of the search and review process

Table 3.1 Study characteristics and summary of interventions

Study (author, year)	Aim(s)	Design (methods)	Intervention	Setting (country)	Study population	Eligibility criteria	Sample	Quality assessment score
Attard & Coulson (2012)	Experiences of Parkinson's disease (PD) forum users	Qualitative content analysis of posts on 4 discussion forums	Online, public, asynchronous discussion forum	Study conducted in UK. Data collected from United States of America (USA), Canada, Australia	People living with PD	PD online support groups with a discussion forum	4 online communities 1000-10.000 members per group. Approx. 100 active members per group • Age unknown, only what members decided to share • More females than males 1013 messages (approx. 250/ group)	CASP 9 (high)

Bakke et al. (2019)	Interaction between professional and personal expertise in online PD community	Qualitative content analysis of posts on discussion forum	Online, public, asynchronous discussion forum	Unknown	People living with PD and caregivers	Physician moderated forum for PD	1 online community 107 threads 409 individual comments Age and gender unknown, only what members decided to share	CASP 8 (high)
Stewart Loane et al. (2015)	Social support and consumer value in online health communities	Qualitative content analysis of posts on discussion forum	Online asynchronous discussion forum	Unknown	People with PD	Not reported	PD community: 35 members, 30 threads, 137 posts Age and gender not reported	CASP 8 (high)
Davis & Boellstorf (2016)	Creativity of people with PD in a virtual world	Qualitative ethnographic online study in virtual world	Second Life, a virtual world	Study conducted in USA (based on ethical approval)	People living with PD	Members of a PD community in Virtual World (recruited through prior fieldwork in 2004)	2 people living with PD (1 male, 1 female) Female with Young Onset PD, male unknown	CASP 7 (medium)

Lieberman et al. (2005)	Impact of group composition and utility of computer-based text analysis in developing online groups	Pre-post measurement study comparing homo- and heterogenous groups	6 online PD support groups delivered by professionals. Weekly meetings during 20 weeks. • 3 homogenous groups (2 Young Onset, age below 60; 1 newly diagnosed in the last 2 years) • 3 heterogenous groups (mix of age and time since diagnosis)	Study conducted in USA	People living with PD	People living with PD in California and attending online PD support groups, described in Lieberman et al. (2005a)	66 participants • 12 were unable to attend • 12 drop outs from homogenous groups • 9 drop outs from heterogenous groups Homogenous groups • Mean age 55.6 (SD 6.4) • 77.8% female Heterogenous groups • Mean age 63.9 (SD 8.5) • 46.2% female	Downs & Black 16 (fair)
Lieberman et al. (2006)	(1) Willingness to participate in professionally	Pilot study of effectiveness of	See above for Lieberman et al. (2005)	Study conducted in USA	People living with PD	People living with PD in California	66 participants	Downs & Black 16 (fair)

(Same population as Lieberman et al. (2005))	led online groups, (2) characteristics of participants (3) outcomes, (4) group composition	professionally led online PD support groups					32 completed pre- and post-measurements • Mean age 60.2 (SD 9.2) • 68% male	
Lieberman (2007) (Same population as Lieberman et al. (2005))	Characteristics of people with PD in online support groups and impact of fear on dropout rates	Pilot study	See above for Lieberman et al. (2005) Weekly meetings, 90 mins per meeting, 25 weeks Premature termination: attending <10 meetings	Study conducted in USA	People living with PD	People living with PD	66 participants • 26 premature terminators • 40 continuers	Downs & Black 15 (fair)
Martínez-Pérez et al. (2015)	Characteristics of Facebook groups and Twitter and their purposes and functions	Mixed-methods survey and interviews with users	Facebook and Twitter groups for PD	Unknown	People affected by PD	Facebook and Twitter focussed on prevention, treatment, fund raising, cures, or general information	257 Facebook groups 100 Twitter groups No demographic information about group members was presented	CASP 4 (low)

3.3.2 Key findings

An overview of the online platform characteristics and study outcomes is presented in Table 3.2.

Social support

One of the main characteristics of (online) peer support is social support (Barak et al., 2008; Keyes et al., 2014). This also came forward in this review and studies reported on different elements of social support. Through their content analysis of discussion forums, Attard et al. (2012), Bakke (2018), and Stewart Loane et al. (2014) observed mutual understanding and empathy among the members of the forum and an exchange of different types of support. This was observed through members sharing personal experiences and both providing and receiving support. The most frequently observed types of support were emotional and informational support.

Examples of emotional support and expressions of understanding and empathy from the work of Bakke (2018) were:

> "Hi, I feel your fear and confusion". (Bakke, 2018)
> "[…] I am responding to you mainly because I wanted to tell you that you are NOT alone with your medication problems". (Bakke, 2018)

An example of informational support was provided in the work of Stewart Loane et al. (2014). One person asked:

> "Does anyone ever experience freezing that lasts for hours on end? Please reply urgently". (Stewart Loane et al., 2014)

Another member responded quickly, and the person who asked the question replied:

> " […] I tried several of the methods that you suggested and I have found one that works for me. I'm telling you it WORKS. I'm so excited! I have been so worried about what would happen if I were alone and I froze, and now I have new freedom. Thank you". (Stewart Loane et al., 2014)

Table 3.2 Key findings

Study	Platform	Communication	Moderation	Reported outcomes	Successful elements	Implications
Attard & Coulson (2012)	Discussion forums	Text-based (asynchronous)	Yes	Positives: • Social support, mutual understanding and empathy • Sharing experiences and advice • Being part of a community, feeling less alone, friendship • Encouragement, positive thinking, resilience Negatives: • Lack of replies • Symptoms restricting ability to use computer • Lack of personal information • Absence of non-verbal communication • Members leaving could be distressing for other members	• Variety in experience, opinions, and advice • Tailored advice to individual members in simple, non-medical language • Writing may help people to reflect on their situation, and share things that are difficult to express face-to-face • Anonymous nature may help members to discuss taboo topics more openly	• Explore the use of voice tools for people with PD who have difficulties typing due to their symptoms • Ask users directly about experiences Evaluate • accuracy of shared information • impact of public nature of forum on members' experience and concerns about privacy • impact of presence of professional moderators

Bakke et al. (2019)	WebMD (discussion forum)	Text-based (asynchronous)	Physician	Role of professional expertise:
				• Trust in physician's opinion
				• Acknowledging value of lived experience
				
				Role of lay expertise:
				• Value and trust peer's experiences. Mutual understanding and empathy
				• Sharing personal experiences
				• Reciprocity in answering questions and info sharing
				• Referring to physician for advice
				Trust increased over time as members shared more
					• Having a physician moderator
					  o Opportunity to directly ask questions to physician
					  o Physician using understanding and supportive tone
					• Peer interaction, getting advice from others going through something similar
					• Forum design: clearly labelling posts and profiles of physicians may play a role in building trust
						For designing future forums:
						• Include badges and ratings to add validity to forum users' contributions
						• Clear norms and values pinned to home page
						Moderation (professional or non-professional)

Stewart Loane et al. (2015)	Discussion forum	Text-based (asynchronous)	Unknown	Information support most frequent, emotional support second. • Initial posts often request information. Responses include answers, and network and emotional support	• People with PD developed value through discussion without needing healthcare professionals to be present. This is helpful for healthcare professionals and managers. • Online discussion forums can remove barriers of	• Using different methods to directly explore members' experiences • Further explore what features of an online community promote a sense of

				• When sharing info, the posters receive positive feedback • Spiritual support (expression of gratitude and feelings of connectedness) • Ethics/ morality: participants refusing to provide a diagnosis or medical advice • Sharing poems and photos, humour, banter. Sense of community	information asymmetry and they create value and support for people with PD.	community among members • Explore variety of online communities to identify whether specific features lead to greater value for members
Davis & Boellstorff (2016)	Virtual World	Verbal (synchronous)	Researchers	Users • discovered new ways of creativity • continued creative parts of previous jobs which gave sense of purpose • created art works in the platform to express what it feels like to have PD • felt part of a community beyond PD • learned new online skills	• The Second Life platform was used for offline work purposes • Art works created in Second Life to express how it feels to have PD can be used for educational purposes • It can be difficult to find age-appropriate in-person support groups for younger people with PD. Online platforms are accessible to people from different areas	• Explore the influence of factors such as gender, age, young-onset or late-onset PD on creativity • Explore to what extend creativity is experienced as a community or an individual phenomenon

Lieberman et al. (2005)	Online support group in chat room	Text-based (synchronous)	Professional	• Quality of life of all groups improved Homogenous groups • were more committed to their group • had higher levels of commitment and attraction, and positive feelings in initial 5 meetings • had significantly greater positive changes compared to heterogenous groups	• Homogenous groups based on age or time since diagnosis • The internet makes it easier to create homogenous groups, with access to a larger group of patients • Lurking (reading posts but not creating own posts) can help with learning more about the group and finding similarities with other members	Explore • the impact of writing in online peer support groups • the impact of the absence of visual and auditory cues Internet support groups could target a more specific audience to enhance similarity between members • Option for subgroups
Lieberman et al. (2006)	Online support group in chat room	Text-based (synchronous)	Professional	Members of online groups • had lower average age • were living with diagnosis for fewer years • had better scores for depression and QoL pre- and post-intervention • felt freer to talk about certain topics compared to in-person groups Only homogenous groups continued to stay in touch after intervention	Homogenous groups based on age or time since diagnosis	• Explore why people drop out of online support groups • Explore opportunities of using voice recognition software

				Most participants heard about the online support groups through the Internet, only a small percentage through their physician.		
Lieberman (2007)	Online support group in chat room	Text-based (synchronous)	Professional	Participants who dropped out • had higher levels of anxiety • did not score differently on depression, quality of life, and intensity of PD symptoms measurements	• Homogenous groups showed significantly greater improvement compared to heterogenous groups	Explore what effective strategies are to prevent people dropping out (e.g. group structure, group composition, preparation)
Martínez-Pérez et al. (2015)	Facebook and Twitter	Text-based (asynchronous)	Unknown	• On Facebook the majority was self-help groups • On Twitter the goals of people were to share information and create awareness • There is a need for dedicated networking sites for peer support	N/A	Directly explore the experiences of users

Stewart Loane et al. (2014) observed that new posts on the forum often started with a request for information and that in their responses other members shared information, personal experiences, and emotional support. Overall, the authors of all three papers observed a real sense of community, belonging, and friendship on each of the platforms, which can be described as network support (Stewart Loane et al., 2014). An example that illustrates this type of support was seen in the work of Attard et al. (2012):

> "I am glad I found this forum, makes me feel like I am not alone". (Attard et al., 2012)

In Lieberman et al. (2005) the authors researched the impact of group composition. Participants were divided into homogenous (based on age or time since diagnosis) and heterogenous groups. Where all groups improved on quality of life scores, participants in the homogenous groups showed significant improvement on depression and PD symptoms compared to heterogeneous groups. These findings suggest that having similarity between the group members can improve the outcomes of peer support (Lieberman et al., 2005).

Benefits of online peer support

Davis et al. (2016) observed how two people with PD used the Second Life online platform. Through their ethnographic study they found that both participants were able to express themselves creatively on the platform. Through their online artworks and creative expressions both people with PD were able to continue with creative parts of their previous jobs, and they also used art to express what it feels like to have PD. The sense of community was also observed here. Furthermore, one of the participants was living in a rural area where it was difficult to find in-person support groups. In this case, the online platform provided a way to connect with other people with PD (Davis et al., 2016). The work of Lieberman et al. (2006) showed that people with PD who participated in online groups felt freer to talk about certain topics compared to in-person groups. One participant shared:

> "In an Internet group, you are much freer to talk about things that you probably wouldn't in a F2F [face-to-face]. We got into discussion of sex [meds affecting sexual desire]. I know I wouldn't have discussed in a F2F" (Lieberman et al., 2006).

Challenges of online peer support

Only one study reported on the challenges related to online peer support communities for people with PD, which was a qualitative content analysis of a PD discussion forum (Attard et al., 2012). Challenges were related to online peer support as well as the use of technology in general. Some were related to behaviour of group members, such as a lack of replies to posts and group members leaving without warning. This could be distressing for other members. An example that illustrates this is:

> "If you are out there please respond. I have searched the net for you dear friend and I would like to talk to you again" (Attard et al., 2012).

Other challenges were more related to the nature of discussion forums and online support in general, such as the absence of non-verbal communication, which at times could lead to misunderstandings, and the lack of personal information. Finally, some posts showed that at times it was difficult for people with PD to use a computer or other types of technology due to their symptoms.

> "Sometimes my PD prevents my fingers from being able to type. At other times they work fine, but my brain is a blob!" (Attard et al., 2012).

Successful elements of online peer support

Several successful elements of online peer support for people with PD have been identified in this review. First, writing may help people reflect on their own situation and share things that may be difficult to express face-to-face (Attard et al., 2012). Second, having homogenous groups based on age or time since diagnosis lead to increased benefits to its members (Lieberman, 2007;

Lieberman et al., 2006; Lieberman et al., 2005). Findings of Lieberman et al. (2005) show that people who participated in the homogenous groups felt more committed to their group and had more positive feelings about the group during the first five meetings. Furthermore, only members from the homogenous groups continued to stay in touch after the intervention ended (Lieberman et al., 2006). Finally, while most studies included in this review looked into moderated platforms, Bakke (2018) specifically looked at a physician-moderated platform. The authors observed that members appreciated the opportunity to ask questions directly to a professional. A helpful feature in the forum design was clearly labelling the physician's comments (Bakke, 2018).

3.4 Discussion

3.4.1 Principal findings

This section presents the summary and interpretation of the findings, covering narrative synthesis element 3: exploring relationships within and between studies. To the best of our knowledge this is the first review to systematically synthesise the literature on online peer support for people with PD. This review shows that online peer support can be a way for people with PD to stay socially connected, share experiences, and exchange support about managing daily life with PD. Furthermore, this review identified successful elements of online peer support.

Benefits and successful elements of online peer support

The main positive elements related to peer support are reciprocity and social support (Barak et al., 2008; Keyes et al., 2014). This has also been identified in this review, indicating that the benefits of peer support are not limited to in-person settings. Despite not knowing each other in person and not being physically close, this review shows that people with PD can find emotional support, mutual understanding and empathy through online communities. Moreover, people with PD can build new friendships and expand their social networks. People can share their personal experiences and provide and receive informational support and advice from others in a similar situation. For example,

people can share experiences with medication or how they manage PD symptoms in daily life. This is based on experiential knowledge, unique knowledge and expertise that people have because of their own personal experiences of living with PD (Dennis, 2003). Sharing knowledge and learning from other people's experience can contribute to developing coping skills of living with PD. This in turn can contribute support people in living meaningful and satisfying lives despite having PD (Huber et al., 2011). Similar findings have been published on online peer support groups for other conditions, including people with chronic illnesses (Kingod et al., 2016) and Huntington's disease (Coulson et al., 2007; Smedley et al., 2019). This review supports previous research in that benefits of peer support are not limited to a physical, in-person setting but can also be transferred online. Elements that can make online peer support successful include having homogenous groups (Lieberman, 2007; Lieberman et al., 2006; Lieberman et al., 2005), and having the option for participants to directly ask questions to a physician (Bakke, 2018). However, different people have different needs and preferences. Some who engage in online support may still miss in-person human interactions such as having a cup of tea together or being able to give someone a hug when they are upset (Giebel et al., 2021a).

There are also additional benefits that come with peer support in an online setting. First, online peer support groups are available to a wide range of people, including those who live in rural or remote areas. For those it might be especially difficult to find in-person peer support groups in their local area. PD symptoms might also impose additional challenges for people to travel to in-person peer support groups. Finally, the internet provides a form of anonymity. The anonymous nature of online peer support groups can make it easier for people to discuss taboo topics that would be difficult to talk about in an in-person setting (Gatos et al., 2021; Lieberman et al., 2006).

Challenges of online peer support

Only a few papers in this review provided information on the users' age and/or gender (Davis et al., 2016; Lieberman, 2007; Lieberman et al., 2005), whereas for the other papers it was unknown. Information on group composition and personal information, such as age, gender, or time since diagnosis, is often unknown. A lack of this kind of information can make it difficult to determine the extent to which members have things in common. This also highlights the challenge for people with PD in finding more specific peer support groups, for example Young Onset PD groups, or groups for people who are newly diagnosed. The importance of similarity between group members was presented in the work of (Lieberman et al., 2005). These findings highlight a key element of peer support and something that defines whether someone is a peer: sharing similarities (Keyes et al., 2014). A lack of personal information was mostly the case for papers analysing a discussion forum, which could be due to the anonymous nature of such forums. The papers including discussion forums in this review all used a publicly accessible platform. Reasons to use publicly accessible forums include ethical issues around informed consent, and to respect the members' privacy (Attard et al., 2012). It could be that due to the public nature, either members did not have the option to share more personal information or members chose not to share that information (Moorhead et al., 2013).

Methodological limitations of included studies

Three of the eight papers included in this review conducted a qualitative content analysis. While this method provides insights into what is happening and being shared on the platform, it does not provide information about members' personal experiences. There are a number of aspects that remain unknown with this methodology. First, the findings highly depend on the researchers' interpretation. While researchers can interpret the intention or the underlying meaning of a post, it is often not possible to directly contact the author of the post and ask if this was indeed how they intended their message. Similarly, it is often also not possible to directly contact the intended receiver of the post to confirm if they indeed perceived the message in the way that the researcher

interprets it. These challenges can be addressed by using qualitative research methods to directly explore users' experiences, as was done by Davis et al. (2016) and Martínez-Pérez et al. (2014), or setting up an online peer support intervention and doing pre-and post-measurements, as was done by Lieberman et al. (2005). Second, on discussion forums and social media pages, often all members of the group can read all posts (besides private messages). This means that not only the intended receiver but also other members can read the posts. Many people can read it but not everyone will respond or participate in the discussion. When using a content analysis method, it remains unknown how people who only read the posts but not interact, also called 'lurkers', interpret the message and experience it (Gatos et al., 2021). Steadman et al. (2014) explored the impact of a Facebook group for people with Multiple Sclerosis on non-active members. During individual interviews people expressed that they still experience social support despite not being actively involved in the discussions (Steadman et al., 2014).

Third, research into online peer support presented in this review might show an overly positive image of the online peer support group, as people who are active on the platform and post messages are often the ones that enjoy being part of the community. In many online communities people can come and go when they want, and those who have a negative experience can leave the group without giving a reason why. This means that negative experiences and potential harmful aspects of online peer support groups remain under researched. One of the potential negative experiences that has been identified in this review is the lack of responses to messages (Attard et al., 2012). This was also identified in the systematic review of Gatos et al. (2021). The authors state that especially new members of an online peer support group are at risk of withdrawing after not receiving a response to their messages. The reason for this could be that new members may be more psychologically vulnerable and have certain expectations when joining the online peer support group (Gatos et al., 2021). When selecting a specific platform for research into online peer support, there is a risk of presenting an overly positive view of the platform and the experiences of its users. An alternative could be exploring the experiences with and opinions on online peer support in the wider PD community, for example through a survey.

3.4.2   Limitations

This section covers Narrative Synthesis element 4: assessing the robustness of the synthesis. This systematic review only included studies on written communication between people with PD on publicly available platforms. Through the searching of databases it did not identify any papers which include other platforms that can potentially be used for online peer support, such as video conferencing platforms or social media platforms such as WhatsApp or Instagram. Therefore, the findings of this review are limited to the platforms that are covered in this review (discussion forums and Facebook groups) and cannot be generalized beyond these. Second, only one study included findings on the potential challenges of online peer support (Attard et al., 2012). As a result, this review may overrepresent the positive and beneficial aspects of online peer support and not provide an accurate picture of the real-world experiences of people with PD who are part of online peer support communities. In addition, within the studies it was sometimes difficult to identify the contributions of the technological, social, and individual elements to how people experienced online peer support. Third, different people have different preferences and needs, and online peer support may not be suitable for everyone living with PD. Additionally, physical symptoms of PD may be a barrier for people to use technology and thus access online peer support communities. The views and experiences of people who are unable or do not want to engage in online peer support are not represented in this review.

3.4.3   Recommendations for future research

For this review no papers were identified that cover video conferencing platforms that can be used for peer support, for example Zoom, Skype, or MS Teams. As these platforms became more widely used since the Covid-19 pandemic, future research could explore how widely used these platforms are among people with PD, and if and how they are used for peer support. Furthermore, research could focus on how people experience this form of online peer support and how it impacts their life, as it is different in nature than what has been discussed in this review. More specifically, video conferencing platforms include synchronous, verbal communication, often where you see the

other members. This reduces the anonymity and adds a face-to-face element to it in which non-verbal communication can be more prevalent.

Future research could also focus on using different methodologies for analysing online peer support for people with PD. Directly assessing users' personal experiences was also recommended by some of the studies included in this review (Attard et al., 2012; Martínez-Pérez et al., 2014; Stewart Loane et al., 2014). Examples of methods could be individual interviews, focus groups, or surveys. This is necessary to learn how people with PD truly experience being part of an online peer support community and what the impact is on their daily life. Furthermore, future research is needed to explore potential negative experiences people may have with online peer support, as these are currently under researched. Qualitative methods such as individual interviews and open question surveys could be used for this. Additionally, there is a group of people who are unable to access online peer support or use technology, for example because of their PD symptoms. It is important to explore in more detail what the barriers are that people face, and how these may be overcome. Some of the studies included in this review recommend investigating the use of voice assistive tools for people with PD (Attard et al., 2012; Lieberman et al., 2006). Research into the use of such assistive tools for online peer support has already been conducted for people with ALS, for example in the work of Caron et al. (2015).

3.5 Conclusion

Peer support can be an extremely valuable source of social support for people with PD. More specifically, peer support can improve social health and support people with PD in living meaningful and satisfying lives despite their condition. Sharing experiences with peers can improve feelings of empowerment and social connectedness, and help people with PD in developing new coping skills. Peer support is unique and cannot be replaced by family members, friends, or healthcare professionals who do not live with PD themselves. Benefits of peer support are not limited to physical, in-person support groups but can be transferred online. Online peer support is accessible to a wide range of people

and is not limited by geographical barriers. This could make online peer support particularly suitable for those who do not have an in-person peer support group in their local area, or who's PD symptoms hinder them to travel. However, research into the personal experiences of those who engage in online peer support and potential barriers in accessing online peer support remains limited. Future research could use qualitative methods such as individual interviews, focus groups, and open-question surveys to explore these fields further.

4. Online peer support for people with Multiple Sclerosis: a narrative synthesis systematic review

4.1 Aims and methods

This narrative synthesis systematic review aimed to (1) explore the benefits and challenges of online peer support for people with MS, and (2) identify successful elements of online peer support. Elements of online peer support were deemed successful if studies identified positive outcomes for the people engaging in online peer support. This narrative synthesis review followed the same methodology as described in chapter 3, pages 35-39. For this review, the database search was rerun in May 2022. When rerunning the search the filter for year of publication (i.e. 1989-2020) was adjusted to the years 2020-2022.

4.2 Results

The following sections developed a preliminary synthesis (narrative synthesis element 2). An overview of the online database search, screening, and selection process is presented in Figure 4.1. The online database search returned 10,987 unique titles and abstracts. After screening the titles, abstracts, and texts, 8 studies met the inclusion criteria. The main reason studies were excluded in the first round of screening was that their focus was not online platforms being used for peer-to-peer interactions. The second database search resulted in 3 additional studies being included. Hand searching the reference lists of the included papers did not result in additional papers being included.

Figure 4.1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) diagram of the search and review process

20,018 records identified through online database searches

(CINAHL, n=2,464; Cochrane Library, n=822; Embase, n=5,302; Medline, n=2,445; PsycINFO, n=942; Scopus, n=3,946; Web of Science, n=4,097)

10,852 studies excluded

9,031 duplicates removed

21 studies excluded

33 studies labelled 'unsure' discussed for second review

10,987 titles/abstracts screened

12 studies included

109 full-text papers excluded:

10 not incl. or enough focus on target population
23 intervention incl. offline and/or telephone-based peer support
22 no reporting or emphasis on online peer-to-peer interactions
6 no full text available
44 publication type
4 text not in English

134 full-text studies assessed for eligibility

5 studies excluded

9 studies labelled 'unsure' discussed for second review

4 studies included

25 studies included from systematic database search

8 studies on MS

3 additional studies (rerun database search)

11 studies included

62

4.2.1 Study characteristics

Five studies used a qualitative content analysis. Della Rosa et al. (2019) and Rath et al. (2017) analysed posts in a Facebook group, Giunti et al. (2020) on Twitter, and Shavazi et al. (2016) and O'Donnell et al. (2020) on a discussion forum. Other methods include a case study (Kantor et al., 2018a, 2018b), interviews (Steadman et al., 2014), cross-sectional survey (Lavorgna et al., 2017), Randomised Controlled Trial (Dorstyn et al., 2022) and a pilot study (Leavitt et al., 2019). The study characteristics are described in Table 4.1.

4.2.1 Summary of interventions

All but one study included text-based, asynchronous (not in real time) communication. In the study by Leavitt et al. (2019) participants communicated verbally in real time. The online peer support communities analysed by Della Rosa et al. (2019), Rath et al. (2017), Dorstyn et al. (2022), O'Donnell et al. (2020), Steadman et al. (2014), Lavorgna et al. (2017), and Leavitt et al. (2019) were moderated, meaning that the use of the group was monitored or the discussion was guided. In Kantor et al. (2018a) and Kantor et al. (2018b) participants spoke about online peer support in general rather than a specific platform and thus moderation was not discussed. Whether the platform was moderated in the study by Shavazi et al. (2016) is unknown. Shavazi et al. (2016) included family members and friends whereas other studies only included people with MS. A fuller description of the interventions is provided in Table 4.1.

4.2.1 Quality assessment

An overview of the scores for CASP and Downs and Black Quality Checklist are presented in Appendix 5. Eight papers were assessed with the CASP checklist. Four were of high quality (O'Donnell et al., 2020; Rath et al., 2017; Shavazi et al., 2016; Steadman et al., 2014), two of medium quality (Della Rosa et al., 2019; Giunti et al., 2020), and two of poor quality (Kantor et al., 2018a, 2018b). Three papers were assessed with the Downs & Black checklist. One was labelled as good (Dorstyn et al., 2022), one as fair (Leavitt et al., 2019), and one as poor (Lavorgna et al., 2017).

Table 4.1 Study characteristics and summary of interventions

Study (author, year)	Aim(s)	Design (methods)	Intervention	Setting (country)	Study population	Eligibility criteria	Sample size / participants	Quality assessment score
Della Rosa & Sen (2019)	Analysis of posts on MS Facebook pages	Qualitative (content analysis)	Online, public, asynchronous Facebook group	Unknown	People living with MS	Public MS Facebook groups	2 Facebook groups 16,376 and 8,539 members 1,070 and 7,029 posts	CASP 7 (medium)
Rath et al. (2017)	Patients' concerns about alemtuzumab for MS treatment in a Facebook group	Qualitative (content analysis)	Online, closed, asynchronous Facebook group	Unknown	People with MS	Facebook group for people with MS specifically for alemtuzumab	458 posts	CASP 9 (high)
Giunti et al. (2020)	Identify MS-related topics on Twitter to analyse the sentiment	Qualitative (content analysis)	Twitter analysis	Unknown	People posting about MS on Twitter	Tweets with #ms OR #multiplesclerosis OR "multiple sclerosis" posted between February 9th and June 26th 2019	74,076 original tweets	CASP 7 (medium)
Shavazi et al. (2016)	Explore dimensions of an online community for people living with MS	Qualitative (content analysis)	Online discussion forum	Iran	People living with MS, friends/ family members or other patients	Final platform (out of 2 options) was selected because of the longer history, larger number of members, and more messages	35 threads, 548 messages purposively selected	CASP 8 (high)

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O'Donnell et al. (2020)	Meditation-related information exchange on a discussion forum for people with MS	Qualitative and quantitative content analyses	Discussion forum	Multiple countries	People living with MS	• The website Overcoming Multiple Sclerosis (OMS) was specifically selected for this study	1725 posts	CASP 9 (high)
Dorstyn et al. (2022)	Test peer support forum on employment options in job-seekers with long-term MS	Phase 1 Randomized Controlled Trial	Discussion forum	Australia	People living with MS	• Aged 18-64 • Relapsing-remitting or progressive form of MS • Fluent in English • Access to a desktop, tablet, or smartphone with an Internet connection • Computer literacy	5 peer mentors 29 forum participants	Downs & Black 19 (good)
Kantor et al. (2018 a+b)	Use of the internet and social media by people with MS and the impact on patient (a) education and (b) empowerment	Qualitative (case study)	Internet in general, blog, social media	North America	Person living with MS	Person living with MS	1 person as a case study	CASP 4 (low)
Steadman & Pretorius (2014)	Experiences of non-active members of a	Exploratory qualitative design	Individual interviews about	South Africa	People living with MS	• Non-active members (post occasionally or never)	10	CASP 8 (high)

	MS Facebook group	(individual interviews)	Facebook group			• Read the group's posts regularly		
Lavorgna et al. (2017)	Impact of discussion forum on coping and social interaction for people with MS	Cross-sectional survey	Discussion forum	Italy	People living with MS	SMsocialnetwork.com was specifically selected for this study	130 (202 surveys were collected, but 72 excluded due to incomplete answers)	Downs & Black 12 (poor)
Leavitt et al. (2019)	Feasibility trial of eSupport, online support groups for people with MS aiming to reduce loneliness	Single-blind pilot study	eSupport online support group	USA	People living with MS	• MS diagnosis • 18 years or older	28 (30 were enrolled, 6 did not complete baseline surveys and 4 participated in both conditions)	Downs & Black 15 (fair)

4.2.2   Key findings

An overview of the key findings is presented in Table 4.2. Social support was the most evident benefit and successful element of online peer support. Within social support, it was possible to distinguish different types of social support, namely informational, network, and emotional support.

Benefits and successful elements of online peer support

Informational support

The most frequently addressed benefit of online peer support in this review was informational support (Della Rosa et al., 2019; Dorstyn et al., 2022; Kantor et al., 2018a, 2018b; Lavorgna et al., 2017; O'Donnell et al., 2020; Rath et al., 2017; Shavazi et al., 2016; Steadman et al., 2014). Through the online platforms, people with MS shared information on and experiences with medication and treatments, and coping strategies for challenges faced in daily life. Online peer support provided an opportunity to learn from peers while also sharing information and helping others, which can increase feelings of empowerment. This included factual or medical as well as experiential information, for example about certain medications or treatments.

> "I posted that I was about to start taking it [antidepressant] and wondered about things like dependency and mood changes. Almost instantly others from around the world were commenting and sharing their experiences, giving me the feedback I needed to make my own decision." (Kantor et al., 2018b)

Steadman et al. (2014) analysed the experiences of non-active members of a MS Facebook group. They found that despite not being actively involved in the discussions, these members still received informational support because they could read the messages of others.

> "There are lot of people that have been having MS for ten, twenty years, and I've just had it for six years now, so my knowledge of this is not that good, so I prefer the older members to actually give that kind of answers." (Steadman et al., 2014)

Table 4.2 Key findings

Study	Platform	Communication	Moderation	Reported outcomes	Successful elements	Implications
Della Rosa & Sen (2019)	Facebook	Text-based and visual, asynchronous	Yes	• Frequently discussed topics: patient support (topic with most engagement), information and awareness (mostly shared topic), drug discussion, and fundraising. • Within drug discussions, people shared experiences and advice. • Less frequently discussed topics: advertisement and research	• Engagement (comments, shares, and reactions) is high for wall posts, and posts including photos. • Facebook is a useful platform to disseminate health-related information.	• The methodology and identified categories of the study can be reproduced in other populations and platforms • Pharmaceutical companies could use the info shared on drug treatments and side effects • Policy makers should encourage pharmaceutical companies to set up online MS communities
Rath et al. (2017)	Facebook	Text-based, asynchronous	Peer moderators	• Group was mostly used to seek information and share experiences • Posts on experiences received more likes, most experiences were positive • Information seeking was mainly on complications of medication • Mainly peer-to-peer interaction, and less peer-to-healthcare professional	• Guidelines (on the home page) for the use of the group and administrators following up on this • Pinned section where frequently asked questions and documents were saved	Healthcare professionals can learn from online patient communities to better understand patients' needs and match their concerns in services and education

Giunti et al. (2020)	Twitter	Text-based, asynchronous	No	• 74,076 original tweets • 4 main topics discussed: related chronic conditions, condition burden, disease modifying drugs, awareness raising • More negative sentiment for related chronic conditions and condition burden • More positive sentiment for awareness raising	N/A	The negative sentiment for topics such as disease burden and other chronic conditions could represent a higher emotional burden, indicating that these are topics people with MS may need extra support with
Shavazi et al. (2016)	Discussio n forum	Text-based, asynchronous	Unknown	• Informational support: sharing advice based on personal experience and scientific knowledge • Referral to resources on the platform • Emotional support: friendship, mutual understanding and empathy, shared experiences • Expressing affection through emoticons and text • Esteem support: compliments • Network support: invites to discussions, companionship ('Hi dear friend')	• Resources available within online platform.	• Explore (health) outcomes of joining online support groups and compare with non-users • Use of other qualitative methods to directly assess the experience of the members

				• Tangible support: direct actions ('leave me a message')		
Dorstyn et al. (2022)	Discussion forum	Text-based, asynchronous	Peer moderators	• Engagement varied but those who used the forum reported positive experiences with peer support. • Majority indicated that they would continue accessing the forum in the future. • Half of the participants had at least read one of the information modules.	The moderator played a key role encouraging discussion and replies to posts.	• For long-term maintenance of online peer support, it can be beneficial to have a combination of media tools and intervention features (e.g. phone, email, video meetings combined with structured activities). • Interviews with peer moderators and participants to assess acceptability.
O'Donnell et al. (2020)	Discussion forum	Text-based, asynchronous	Yes	• Sharing resources and information • Providing words of encouragement and positivity, enabling other members to continue with their meditation practices • Sharing hints and tips	• A forum can be a helpful platform to share and store resources and information. • A forum can be a helpful platform to share audio-visual resources. • Forums can be used for emotional and social support.	The methods and findings of this study could also be applied to other aspects of lifestyle management.

Kantor et al. (2018a + b)	Internet in general, blog, social media	Text-based	Unknown	• Opportunities to connect with others and learn about and be involved in research • Learning from peers • Online connection with peers online gave life a purpose and hope for the future • Online connection with peers and sharing information increased feelings of empowerment towards own condition • Understanding privacy on social media can be difficult (e.g. who can see your posts) • Not always certainty that everyone in the group is really a patient • Verifying trustworthiness of information can be difficult	• Writing about MS can help online research skills and finding trustworthy information.	
Steadman & Pretorius (2014)	Facebook	Text-based, asynchronous	MS Society of the Western Cape	Facilitators • Sense of belonging, companionship • Seeing others struggle (more) increased feelings of gratitude	• Constant source of support • Large body of information and research constantly available and updated	• Compare active and non-active members • Longitudinal methods to explore experiences and benefits over time • Investigate the extent to which people identify with

				Source of information, perceived as good quality Barriers • Difficult to express emotions online • Symptoms limiting ability to use computer • Exposure to negative aspects of the condition leading to negative feelings • Amount of information could be overwhelming • Posts unrelated to MS	• Professionals providing the information increases trustworthiness	the group and the implications for their wellbeing
Lavorgna et al. (2017)	Discussion forum	Text-based, asynchronous	Healthcare professionals	• Gathering and sharing information, • Getting practical tips and advice, helping with coping strategies • Feeling connected to other members • Through the forum members looked up other sources of information	Way to reach a wide variety of other patients and healthcare professionals	• Explore combing patients and healthcare professional networks • Evaluate how members experience input of healthcare professionals
Leavitt et al. (2019)	eSupport : online group intervention	Verbal, synchronous	Yes	Feasibility • Completion: 27/28 completed baseline and follow-up instruments	• Own home provides safe environment to join the group • Online support allows people from	Future studies should consider: • a waitlist control group instead of an active one • whether participants take anti-depressants and/or

					• Adherence (eSupport): 14 /18 participants completed 9/12 sessions Loneliness and mood • Both groups showed decrease in loneliness and depressive symptoms • No significant difference between groups Participant feedback: positive changes in participants' life, improved social connection	different geographical areas to participate • The eSupport platform was inexpensive to host and easily accessible to people with MS	other psychotherapeutic treatments • longer study periods

A successful component of online peer support platforms is making information easy to find. For example, the platforms analysed by Rath et al. (2017) and Shavazi et al. (2016) had dedicated sections where frequently asked questions and resources were saved. Dorstyn et al. (2022) and O'Donnell et al. (2020) found that discussion forums can be a useful platform to share and store a variety of resources, allowing to also share audio-visual resources. Steadman et al. (2014) show that participants appreciated the information being shared in the Facebook group and that they perceived it as reliable and good quality. They mentioned that the advantage of it being online was that there is a large body of information that is always available and updated.

Network support

The second most frequently mentioned benefit of online peer support is having a network to exchange support (Kantor et al., 2018a, 2018b; Lavorgna et al., 2017; Leavitt et al., 2019; Shavazi et al., 2016; Steadman et al., 2014). Despite not being physically close, people with MS who participated in online peer support communities reported feeling connected with the other members, experienced a sense of community, and build friendships. Steadman et al. (2014) showed that this was also true for some non-active members.

> "I will always go on there and read the messages, it is like my family; it's like real close friends even though I'm not an a personal way close to them." (Steadman et al., 2014)

What made online peer support particularly beneficial was that support can be readily available when needed. Furthermore, Leavitt et al. (2019) showed that online peer support can be a safe and convenient way to be involved in peer support because participants do not need to travel, allowing people from remote areas to take part as well.

> "Of the support groups I've been in, this one feels most intimate. Joining from my home makes me feel very safe." (Leavitt et al., 2019)

Emotional support

Kantor et al. (2018a), Kantor et al. (2018b), Leavitt et al. (2019), O'Donnell et al. (2020), Shavazi et al. (2016), and Steadman et al. (2014) reported on emotional support with online platforms as a place for bonding and sharing mutual understanding and empathy, despite members not being physically close. On text-based platforms such as social media and discussion forums, emoticons can be a way to express emotions and affections online (Shavazi et al., 2016). By sharing personal experiences, members shared words of encouragement, hope, and reassurance. Moreover, being able to share this connection with others can give people hope and purpose in their lives (Kantor et al., 2018a).

> "Don't worry, my problems also began with pain in my eyes, blurred vision […]. I also was very worried about losing my eyesight forever … Don't stress yourself, and don't think about it. I regained my eyesight and I don't have any problems now, but it takes some time." (Shavazi et al., 2016)

Challenges of online peer support

Although access to a wide range of information can be a benefit of online peer support, at the same time the amount of information can feel overwhelming and people may share posts that are not in line with the purpose of the group (Steadman et al., 2014). Furthermore, it is not always possible to verify the trustworthiness of information online (Kantor et al., 2018a, 2018b). These issues can be solved by having clear guidelines on the purpose and use of the group and group moderators monitoring the posts (Rath et al., 2017). Additionally, having professionals provide information could improve the trustworthiness (Steadman et al., 2014).

Furthermore, the lack of non-verbal communication such as body language and facial expressions can be a limitation of online peer support in text-based platforms. As a result, people may experience a lack of emotional connection and may not always feel comfortable sharing their experiences with the group (Steadman et al., 2014). While Leavitt et al. (2019) reported findings of an online peer support intervention using video meetings, they did not report on the

particular benefits or challenges of using video meetings as the mode of communication.

Finally, MS symptoms can limit one's ability to use the computer, and thus be a barrier to access online peer support. Steadman et al. (2014) found that members with a non-active status at times experienced difficulties socialising, as due to their non-active status other members of the group did not always reach out or keep in contact. Furthermore, understanding privacy on social media can be a challenge, for example knowing who can and cannot see your posts (Kantor et al., 2018a).

4.3 Discussion

4.3.1   Principal Results

The following sections explore the relationship between studies (narrative synthesis element 3). To the best of our knowledge this is the first systematic review that synthesises the literature on online peer support for people living with MS. The findings show that through online peer support people with MS can exchange information and ways of coping with MS symptoms in daily life, as well as emotional support. This can improve all dimensions of the social health framework for people with MS.

Benefits and successful elements of online peer support

This review demonstrates that benefits of peer support can go beyond in-person settings and can be present in online communities as well. People with MS frequently use online peer support communities for informational support. People can gather information through online resources and personal experiences of others. For example, people could hear from others how they experienced taking certain medications. These findings are supported by Loane et al. (2013) who researched an online peer support community for people with Amyotrophic Lateral sclerosis. They found that people often started a conversation on the platform by asking for information, and that often lead to others sharing personal experiences and exchanging emotional support (Loane

et al., 2013). An advantage of online peer support is that threads, discussion topics, or information can be archived or saved. The asynchronous (not in real time) and text-based nature allow people to revisit different threads or topics when they want to access the information. Another benefit of text-based online peer support communities, such as discussion forums, is that these are typically much larger in size (e.g. several 100 or 1000 members) compared to in-person peer support groups. This offers a much wider and heterogeneous pool of people to exchange support with and experiences to learn from (Rath et al., 2017; Shavazi et al., 2016; Steadman et al., 2014). Learning from others can help in developing and improving coping skills to live well with MS. This relates to the first and second dimensions of the social health framework; ability to fulfil potential and obligations and to manage life with some level of independence (Huber et al., 2011). Finally, the anonymous nature of some platforms may make it easier for people to discuss certain topics that they would not feel comfortable discussing in person, such as relationships and sexuality (Gatos et al., 2021; Lieberman et al., 2005).

This review also shows that people with MS can experience social connection, mutual understanding, and friendship in online peer support communities, fulfilling the third dimension of the Social Health Framework: the ability to participate in social activities and work (Huber et al., 2011). While not being physically close, people were able to express emotions, including through emoticons. This is similar to findings on online peer support for people with Parkinson's Disease (Gerritzen et al., 2022b). Steadman et al. (2014) found that even nonactive members of a Facebook group felt connected, and Leavitt et al. (2019) demonstrate that being able to join a peer support group from home can make people feel safe and more comfortable. This was also identified by Davis et al. (2016), who also found that online peer support could be particularly helpful for people who live in rural areas. The opportunity to join from the comfort of one's own home without the need to travel is unique to online peer support and cannot be transferred into more traditional in-person settings. Furthermore, in the UK, 92% of the adult population uses the internet (Office for National Statistics, 2021). During the COVID-19 pandemic when videoconferencing platforms, such as Zoom and MS Teams, became more

popular. Such platforms allowed people to still access health and social care services.

Challenges of online peer support

First, although internet use and access are common, this differs, with some people having reduced or no access to the Internet, particularly in rural areas (Internet World Stats, 2021). Even with internet access, people need modern digital devices and a strong stable internet connection. Because these are not accessible to everyone, some miss out on the benefit of online peer support services (Watts, 2020). Second, the amount of information can at times feel overwhelming (Steadman et al., 2014), and it can be difficult to assess the trustworthiness of online resources (Kantor et al., 2018a, 2018b). Research shows that especially social media platforms can be a source of misinformation (Wang et al., 2019). In addition, learning about the progression of MS and the severity of symptoms from informational resources or the experiences of others can be distressing. Moderators can monitor the platform for misinformation and remove harmful or misleading posts, keeping the community a safe space for everyone (Gatos et al., 2021; Perry et al., 2021). Without moderators there is not a dedicated person to provide resources and to check in on members should there be a concern for or risk of significant emotional distress or self-harm. Moderators can also remind people to always consult with their physician regarding treatment or medication. Having professionals share information or review the resources that are being shared may reduce concerns around trustworthiness (Steadman et al., 2014).

Third, people may have concerns regarding privacy and security when interacting with others in an online setting, because there is often a lack of personal information due to the open nature of such platforms. This makes it difficult for people to identify the level of similarity with other group members, for example in age or time since diagnosis, which is one of the key aspects of peer support (Keyes et al., 2014). When researching online peer support communities, researchers tend to select open groups that are freely accessible without having to create an account or become a member. This is often driven

by ethical concerns. It could be that due to the open nature of such platforms participants decide not to share personal information, and that this might be different in closed groups (Gerritzen et al., 2022b). The importance of similarity was also identified by Garabedian et al. (2019), who found that for people who are newly diagnosed as having MS, a support group with people who are in a more advanced stage of the disease can be a negative experience. Unwanted exposure to negative aspects of a condition is a common problem of online peer support (Coulson, 2013; Holbrey et al., 2013).

Finally, the anonymous nature of some online forums may also result in people feeling a lack of connection with other group members, or feeling unsure if they can trust others (Kantor et al., 2018a), and leaving the group for these or other reasons. Even with moderators, follow-up with those who leave may be difficult. Leavitt et al. (2019) focussed on peer support through video meetings, which could potentially reduce the anonymity, however, they did not report on particular benefits or challenges of video meetings as the mode of communication.

4.3.2 Limitations

This section assesses the robustness of the synthesis (narrative synthesis element 4). Online peer support can be provided in a variety of online platforms, including both text-based and verbal communication; however, the systematic database search identified only one study [38] focussing on verbal communication. In addition, only two studies discussed potential barriers and challenges (Kantor et al., 2018a, 2018b; Steadman et al., 2014). Therefore, this review may over represent the positives of online peer support and not provide enough insights into potential negatives. This is a common limitation of research into online peer support (Gerritzen et al., 2022b). Finally, physical symptoms associated with MS may hinder some people to use technology and limit their options to access online peer support. Although one study mentioned this issue (Steadman et al., 2014), this review does not include the perspectives of those who cannot or do not want to use online peer support.

4.3.3   Recommendations for future research

During the COVID-19 pandemic videoconferencing platforms such as Zoom and MS Teams became more popular, but the update of the database searches in May 2022 did not identify any studies including peer support through videoconferencing platforms. Peer support through video meetings differs from text-based platforms, as it is verbal communication in real time, and can include a face-to-face element. Although this review included one study on peer support through video meetings (Leavitt et al., 2019), it does not provide detail on how people experienced the video element. Future research could explore whether people with MS are using videoconferencing platforms for peer support, and if so, what their experiences are. Additionally, such exploratory research could include outcome measurements related to mental health, linking to previous research on impact of social support on mental health outcomes such as depression and anxiety [11].

Because MS symptoms may make it difficult for some people to use digital devices (Steadman et al., 2014), future research could explore whether certain platforms are easier to use or whether other technology might help, such as assistive tools similar to those used by people with amyotrophic lateral sclerosis (Caron et al., 2015). Another research avenue would be to explore the experiences and views of those with MS who cannot or do not want to use online peer support, what barriers they face, and how they might be overcome. Qualitative or mixed-methods research using for example interviews or surveys could explore people's experiences and needs.

4.4 Conclusion

Peer support can be a way for people with MS to stay socially connected and reduce the risk for loneliness and social isolation by sharing their experiences and learning from others, including developing coping strategies. Online peer support offers many benefits, including improved access to peer support. Moreover, even simply reading about others' experiences can already make people feel supported and help with developing coping skills. Through online platforms, information can be archived as well as constantly updated. On the

other hand, online peer support also has challenges that should be addressed or understood. People should be cautious when interpreting information that they find online and should always consult with their doctor regarding medication and symptoms. Physical symptoms of MS may hinder some people from using the technology needed to access online peer support. Future research is needed to further explore the barriers to online peer support for people with MS and how to overcome them.

5. Online peer support for people with Amyotrophic Lateral Sclerosis: a narrative synthesis systematic review

The findings presented in this chapter were submitted as a journal article: Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Amyotrophic Lateral Sclerosis (ALS): a narrative synthesis systematic review. *Frontiers in Digital Health (submitted)*

5.1 Aims and methods

This narrative synthesis systematic review aimed to (1) explore the benefits and challenges of online peer support for people with ALS, and (2) identify successful elements of online peer support. Elements of online peer support were deemed successful if studies identified positive outcomes for the people engaging in online peer support. This narrative synthesis review followed the same methodology as described in chapter 3, pages 24-27. For this review, the database search was rerun in June 2022. When rerunning the search, the filter for year of publication (i.e. 1989-2020) was adjusted to the years 2020-2022.

5.2 Results

The online database search returned 10,987 unique titles and abstracts, of which nine were included (Figure 5.1). The updated search in June 2022 did not result in new studies being included.

Figure 5.1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) diagram of the search and review process

20,018 records identified through online database searches

(CINAHL, n=2,464; Cochrane Library, n=822; Embase, n=5,302; Medline, n=2,445; PsycINFO, n=942; Scopus, n=3,946; Web of Science, n=4,097)

9,031 duplicates removed

10,987 titles/abstracts screened

134 full-text studies assessed for eligibility

25 studies included from systematic database search

10,852 studies excluded

21 studies excluded

33 studies labelled 'unsure' discussed for second review

12 studies included

5 studies excluded

9 studies labelled 'unsure' discussed for second review

4 studies included

109 full-text papers excluded:

10 not incl. or enough focus on target population
23 intervention incl. offline and/or telephone-based peer support
22 no reporting or emphasis on online peer-to-peer interactions
6 no full text available
44 publication type
4 text not in English

9 studies on ALS

5.2.1 Study characteristics

All studies had a qualitative design. The most frequently used method was content analysis (Frost et al., 2009; Frost et al., 2008; Hargreaves et al., 2018; Hemsley et al., 2016; Stewart Loane et al., 2013; Stewart Loane et al., 2014; Versteeg et al., 2019). Other methods include an asynchronous online focus group (Caron et al., 2015), interviews (Hargreaves et al., 2018), and a case study (Hemsley et al., 2016). Stewart Loane et al. (2013) included people with ALS and carers, whereas the other studies only included people living with ALS. An overview of the study characteristics can be found in Table 5.1.

5.2.1 Summary of interventions

All studies focused on text-based, asynchronous (not in real time) communication and covered a variety of platforms. The most frequently analysed platforms were discussion forums (Hargreaves et al., 2018; Stewart Loane et al., 2013; Stewart Loane et al., 2014; Versteeg et al., 2019), followed by the PatientsLikeMe platform (Frost et al., 2009; Frost et al., 2008; Kazmer et al., 2014). Finally, Hemsley et al. (2016) used Twitter, and Caron et al. (2015) used a Wikispace for their online focus group.

Most studies analysed a moderated platform, meaning that someone monitored posts or facilitated the discussion (Caron et al., 2015; Frost et al., 2009; Frost et al., 2008; Hargreaves et al., 2018; Kazmer et al., 2014), whereas others were unmoderated (Hemsley et al., 2016) or it was unknown (Stewart Loane et al., 2013; Stewart Loane et al., 2014; Versteeg et al., 2019). A fuller description of the interventions is presented in Table 5.2.

Table 5.1 Study characteristics and summary of interventions

Study (author, year)	Aim(s)	Design (methods)	Intervention	Setting (country)	Study population	Eligibility criteria	Sample size / participants	Quality assessment score
Stewart Loane and D'Alessandro (2013)	Communication in an online ALS community (carers and patients)	Qualitative (content analysis)	Discussion forum	Unknown	People living with ALS and carers	Members from the ALS community selected for this study and their posts	133 members 61 threads 499 posts	CASP 9 (high)
Stewart Loane et al. (2014)	Social support and consumer value in online health communities	Qualitative (content analysis)	Discussion forum	Unknown	People with ALS	2 online health communities, one for PD and one for ALS	PD community: 35 members, 30 threads, 137 posts ALS community: 133 members, 61 threads, 499 posts.	CASP 10 (high)
Versteeg and te Molder (2019)	Balance between expert advice and patient experiences	Qualitative (content analysis)	Discussion forum	Netherlands	People with ALS	Dutch online forums	1 patient support forum for ALS 20 threads	CASP 5 (medium)
Hargreaves et al. (2018)	Empathy in discussion forums	Qualitative (interviews and content analysis)	Discussion forum	UK	People living with MND (ALS)	Open access forums for MND that allowed the data to be used for research	52 threads 5 interviews	CASP 8 (high)

Frost and Massagli (2008)	Use of visual displays of health communication and conversations by people with ALS	Qualitative (content analysis)	PatientsLikeMe platform	Unknown	People living with ALS	ALS community on PatientsLikeMe	95 users with ALS 123 postings	CASP 9 (high)
Frost and Massagli (2009)	Use of PatientsLikeMe by people with ALS in pulmonary health decision making	Qualitative (content analysis)	PatientsLikeMe platform	Unknown	People living with ALS	Posts and comments on the PatientsLikeMe ALS community including the words 'trach' and 'bipap'	• 395 members reporting non-invasive ventilation, 61 reporting tracheotomy and ventilation • Bipap: 583 forum posts, 26 comments, 907 private messages • Trach: 829 forum posts, 46 comments, 815 private messages	CASP 5 (medium)
Kazmer et al. (2014)	Knowledge-building processes in online ALS community	Qualitative (content analysis)	PatientsLike Me platform	Unknown	People affected by ALS	Random selection of posts in ALS community of PatientsLikeMe	241 individuals 1,000 messages	CASP 8 (high)

Hemsley and Palmer (2016)	Feasibility and utility of Twitter data from adults with ALS and identify patterns in Twitter use	Qualitative (single case study and content analysis)	Twitter	Australia (based on ethical approval)	People living with ALS	Inclusion Tweets including #ALS and #MND Exclusion Tweets that were: duplicates; fundraising; tagged #ALSIceBucketCh allenge or #StrikeOutALS	1 Twitter user with ALS for the case study 4,625 tweets for content analysis	CASP 6 (medium)
Caron and Light (2015)	Use and advantages of social media and barriers and facilitators to independent use for people with ALS,	Qualitative (asynchron ous online focus group)	Social media / Wikispace	USA	People living with ALS	• ALS diagnosis • use of AAC for speech • independent use of at least one social media platform	11 people with ALS 2 drop-outs □ final sample size: 9 Age: 35-76 Male: n=5 Female: n=4	CASP 9 (high)

Table 5.2 Key findings

Study	Platform	Communication	Moderation	Reported outcomes	Successful elements	Implications
Stewart Loane and D'Alessandro (2013)	Discussion forum	Text-based (asynchronous)	Unknown	• Majority of users was a patient, female, and reached out to the forum short after their diagnosis Social support: • Informational: most frequent • Network: second most frequent • Other: emotional, esteem, and instrumental • People initially join community to seek information, and are offered network and emotional support in addition	• Being part of an online peer community allows members to provide support to others as well. • This can be empowering, particularly for people who are highly dependent on others due to their condition	• Observation over a longer period • Specific attention to new vs long-term members • Combination studies including observations, surveys, and participant interviews
Stewart Loane et al. (2014)	Discussion forum	Text-based (asynchronous)	Unknown	Information support most frequent, followed by emotional support • Initial posts are often to request information, responses provide answers, and network and emotional support	• Patiens with ALS are highly dependent on others, but in an online community they can provide support to others, which can increase feelings of empowerment	• Using different methods to directly explore members' experiences • Further explore what features of an online community promote a sense of community among members

				• When sharing info, the posters receive positive feedback • Spiritual support (expression of gratitude and feelings of connectedness) • Ethics/ morality: participants refusing to provide a diagnosis or medical advice, but merely sharing personal experiences • Sharing poems and photos, humour, banter • Sense of community	• ALS symptoms can limit a person's ability to fully participate in society in-person. Online communities overcome these barriers	• Explore variety of online communities to identify whether specific features lead to greater value for members
Versteeg and te Molder (2019)	Discussion forum	Text-based (asynchronous)	Unknown	• Members shared experiences and empathy • Members motivated each other to stay positive, be hopeful, and trust the medical / research community • Staying informed was seen as a moral duty	N/A	Exploring and understanding the patients' needs can help to improve the relationship between patients and healthcare professionals

Hargreaves et al. (2018)	Discussion forum	Text-based (asynchronous)	Charity staff	Themes:
				• Empathy through shared experiences
				  o Reciprocity
				  o Building friendships
					• Introductory posts to share story, starting point for conversation
					• Anonymous nature helped to be more open
						Explore:
						• barriers to expressing empathy online

					- Expression of feelings: language of empathy and cue for others to provide support - Empathy through connections (sense of belonging) - Space to share experiences and emotions - Feeling understood and less alone - Connection through similarity (symptoms, personal lives)	- Most found forum through own research (only 1 person was referred by a healthcare professional) - Members could create new spaces within forum	- impact of conflicts users and levels of sharing and empathy - relation of empathy on other aspects, e.g. self-disclosure or trust - role of privacy and trust in forum development Practice: - Raise awareness among healthcare professionals about online health communities - Make it easy for users to find specific info on forum - Allow different levels of communication (forum, one-to-one messages) - Interaction with other platforms (e.g. Facebook)

Frost and Massagli (2008)	Patients LikeMe	Text-based (asynchronous)	Yes	Comment categories: • Questions to others with relevant experience • Advice and recommendations • Relationship building • Comments lead to further conversations on discussion forum or private messages.	Technological features: • Graphical display of Gantt charts and images indicates length of illness, symptoms and treatments • Allow members to find others with relevant experience easily and to retrieve and provide tailored advice • Option to indicate geographical location: allowed members to connect and share info about local support	Explore the personal experiences of users through interviews and surveys
Frost and Massagli (2009)	Patients LikeMe	Text-based (asynchronous)	Yes	Members shared: • Advice on palliative care and assistive technologies for respiratory support • How they came to their palliative care decision • Views on end-of-life care and ALS progression	Technological features of forum: see Frost & Massagli (2008) above.	Study the prevalence of each type of interaction and how it affects health outcomes
Kazmer et al. (2014)	Patients LikeMe	Text-based (asynchronous)	Yes	Distribution of knowledge:	• Online, knowledge is distributed across	• Role of technological design

				in single thread: multiple users answer one question from another member • across threads: users referring to other relevant threads • across participants Creating knowledge: • Co-creating undiscovered public knowledge based on lived experiences • Co-creation of authoritative knowledge: combining medical literature with lived experience ○ Preference for lived experience • Other sources if no one has an answer	geographical areas and time • When new members join, previously shared knowledge gets refreshed and they bring new knowledge. They can also identify new knowledge gaps • Technological feature: option to search for and link previous posts	in distributing knowledge • Tools to streamline knowledge to support patients better • Use findings to design effective online platforms and encourage experts to join
Hemsley and Palmer (2016)	Twitter	Text-based (asynchronous)	No	Study 1: • Most tweets were directed to individual Twitter users, including @ • Only 26% of the tweets included # and were directed to wider Twitter community • Content: ALS info, aspects of daily life, gratitude and	• Majority of tweets would not come up when selecting data based on # only • Twitter is useful for people with ALS/MND and communication dissabilities	• Greater use of Twitter in future research for people with ALS and other conditions with communication disabilities • Explore lived experience of Twitter users with

				emotions, social engagement and support. Study 2: • Main purpose of #s was to share Internet content (85%) • Conversational tweets (8%) included support, sympathy, concern, and encouragement • Status broadcast tweets, including hashtags such as #ALSsucks, #NeverGiveUp, related to raising awareness, creating one voice		ALS or other conditions • Use study methods with larger groups
Caron and Light (2015)	Wiki space	Text-based (asynchronous)	Researchers	Social connections: • Maintaining existing relationships • Reconnecting with people • Developing new connections Support network: • Reciprocal support • Raising awareness about ALS • Retrieving and sharing research-related info Communication opportunities: • Wider network to communicate with, reduced	Social media • allows for communication beyond speech-based interaction • increases communication opportunities and access to support networks, and expanded social networks • overcomes challenges related to synchronous	Recommendations from participants: • technology developers: allow flexible use AAC technology (indoors vs outdoors, different websites) • policy makers: better support access to AAC technology • people with ALS: join social media and ALS groups

				social isolation and loneliness Barriers: • Physical symptoms • Technological difficulties with AAC device	communication, for example through phone or video calls. The asynchronous nature allows people to communicate at their own pace	Recommendations from authors: • Provide access to information about range of social media options • Provide access to appropriate supportive technologies • Provide people with knowledge and skills to use social media

5.2.2 Quality assessment

All studies were assessed with the CASP checklist. Six studies were of high quality (Caron et al., 2015; Frost et al., 2008; Hargreaves et al., 2018; Kazmer et al., 2014; Stewart Loane et al., 2013; Stewart Loane et al., 2014), and three were of medium quality (Frost et al., 2009; Hemsley et al., 2016; Versteeg et al., 2019). An overview of the scores for each study is presented in Appendix 6.

5.2.1 Key findings

An overview of the key findings is presented in Table 5.2. Different types of social support were identified: informational, network, and emotional support.

Benefits and challenges

Online peer support can be a convenient way of staying in contact with others. People with ALS can experience difficulties in getting out of the house and meeting people. The Internet could be a suitable alternative (Caron et al., 2015). Furthermore, the Internet offers different modes of communication, addressing different needs and abilities. Being part of an online network can also create opportunities to get involved in advocacy for those who want to, and to raise awareness about ALS (Caron et al., 2015).

> "One of the first abilities I began to lose was speech. Social events became more uncomfortable the worse my speech became. In many ways my world became more closed in and isolated. Even with the help of speech assistance [AAC support with speech output], group interaction is difficult. Facebook is a better communication tool for me. On Facebook we all are on the same level of communication ability." (Caron et al., 2015)

Only one study reported on challenges and potential barriers of online peer support (Caron et al., 2015). Some of the physical symptoms of ALS can cause difficulties using a computer and typing. A potential solution could be eye-gaze technology. Furthermore, people may feel that online, text-based communication cannot replace real-life communication which includes emotion as well as body-language (Caron et al., 2015).

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Informational support

The Internet can offer a large amount of information on treatments, medication, and research opportunities (Caron et al., 2015). Frost et al. (2008), Frost et al. (2009), and Kazmer et al. (2014) analysed the PatientsLikeMe platform. On PatientsLikeMe users can share symptoms, medications, and assistive tools that they use through symbols on their profile page. This helps to identify others in a similar situation or with relevant experience. Frost et al. (2008) found that when sharing advice and recommendations, people often shared their personal experiences based on what others added to their profiles. People also asked targeted questions, for example:

> "I notice you have had a tube for about 8 months. I'm having difficulty eating so the neurologist suggested I look into getting one. It would help me if you would send me a message about your experience, pro and con." (Frost et al., 2008)

People used PatientsLikeMe to get advice on assistive technologies and discuss advance care planning and palliative care. They shared their experiences in deciding which type of assistive technology to use, as well as practical hints and tips (Frost et al., 2009). For example, one person shared how they remain mobile while using a bipap machine:

> "We put it on a small shelf behind the wheelchair and set the bipap on top of the battery […]. You plug your bipap in an inverter and plug the inverter into the battery. Very portable." (Frost et al., 2009)

Kazmer et al. (2014) identified that different people answered questions that were posted, and signposted to other relevant threads on the platform. Threads had subject headings, for example 'Loss of appetite from taking scopolamine', making it easier to identify relevant topics. The option to search for information and previous discussion topics on the platform was experienced as helpful (Kazmer et al., 2014). Another benefit of asynchronous (not in real time) platforms is that people can ask for support or information when needed (Caron et al., 2015).

Network support

Through individual interviews, Hargreaves et al. (2018) found that members of an ALS forum perceived a real sense of community and support. People emphasized the importance of connecting with others who understand. This helped people talk about things that they would not necessarily feel comfortable speaking about with their family or friends (Caron et al., 2015; Hargreaves et al., 2018).

> "I have emotional lability […]. For those who understand, no explanation is necessary, for those who don't, no explanation is possible. Social media allows those emotional outbursts with no external discomfort. We can share in a place of understanding, in our own time and own pace without expectation or interruption." (Caron et al., 2015)

Being part of a network and being able to provide support to others can increase feelings of empowerment (Caron et al., 2015; Stewart Loane et al., 2013). This is incredibly important, as people with ALS become increasingly reliant on others. Online peer support provides an opportunity to offer support to others and create value by sharing their experiences and advice (Stewart Loane et al., 2013).

> "I am so glad to find this site because I see there are many of us with slower progression than stereotypical. The support groups locally really focus on immediate need patients […]. It has been so great to see how long timers cope with losing our function slowly." (Frost et al., 2008)

Emotional support

Through online platforms people shared expressions of empathy and compassion. For example:

> "I'm so sorry to hear you are both going through this" and "Your mother is very lucky that she has such a caring daughter" (Stewart Loane et al., 2013).

Versteeg et al. (2019) observed that people with ALS and their families try to have a positive outlook on things. People share this attitude by expressing empathy and support to others going through something difficult. Hargreaves et al. (2018) discussed how it was for forum members when others dropped out because their ALS had progressed too much or they passed away. Sharing the grief over losing other members of the forum, and losing the person someone once was created an emotional bond.

> "There is a tremendous empathetic bond between the forumites. We share a life sentence. It cannot be more powerful than that. The feeling between us all on the forum has been strengthened through all these deaths. It is tangible." (Hargreaves et al., 2018)

5.3 Discussion

5.3.1 Principal findings

This review suggests that online peer support could be a valuable source of post-diagnostic support. Moreover, it has the potential to improve every domain of the Social Health Framework (Huber et al., 2011).

Benefits and successful elements

People with ALS use online peer support to exchange experiences and information. Learning from others with ALS can help people to develop and improve coping skills. Online health communities, such as discussion forums, allow for a much larger membership compared to in-person peer support groups, often with several 100 or 1000 members, providing the opportunity to learn from a wide range of experiences. This relates to two dimension of the Social Health Framework: 1) ability to fulfil potential and obligations, and 2) manage life with some level of independence (Huber et al., 2011).

Websites such as PatientsLikeMe allow people to share information related to medication, symptoms, and assistive technologies on their profile, making it easier to identify others in a similar situation or with relevant experience (Frost et al., 2009; Frost et al., 2008; Kazmer et al., 2014). Sharing similarities can

stimulate conversation and make people feel more connected (Hargreaves et al., 2018). This supports earlier work by Lieberman et al. (2005) on online peer support for people with Parkinson's Disease. People who had either a similar age or time since diagnosis, felt more connected to their group and were less likely to drop out (Lieberman et al., 2005). Additionally, online text-based platforms, such as discussion forums or social media groups, can save information or discussion topics, allowing people to revisit what they find relevant (Rath et al., 2017; Shavazi et al., 2016).

People with ALS can build meaningful connections and exchange support in an online setting, supporting findings on online peer support for people with Parkinson's Disease (Gerritzen et al., 2022b) (chapter 3), Multiple Sclerosis (Gerritzen et al., 2022a) (chapter 4), and other chronic conditions (Kingod et al., 2016). Online peer support can be a convenient way to connect with others as ALS symptoms can make it more difficult to travel. This supports previous work by Leavitt et al. (2019) who found that people with Multiple Sclerosis felt safe and more comfortable joining an online peer support network compared to in-person support groups. Additionally, difficulties with speech and experiencing emotional lability can make in-person events more challenging for people with ALS (Caron et al., 2015). Online peer support offers different forms of communication, tailoring towards different needs, abilities, and preferences. Asynchronous text-based platforms allow people to communicate at their own pace and in their own time, without the need for verbal communication or the use of voice-assisted technologies. This relates to the last dimension of the Social Health Framework: being able to participate in social activities and work (Huber et al., 2011).

Challenges

Physical symptoms of ALS can make it more challenging to use technological devices. Eye-gazing technology or AAC support could help. However, verbal and group interaction can remain challenging as it takes time to type on an AAC device, slowing down the communication, particularly when with others who do not need assistive technology (Caron et al., 2015). Asynchronous text-based

platforms could offer a solution. Additionally, sometimes it can be difficult to judge the trustworthiness of online information (Steadman et al., 2014). People must also be aware that their peers are not medical experts. Facilitators and moderators have an important role to remind people to always consult with their physician regarding medication, treatments, or symptoms (Gerritzen et al., 2022a) (chapter 4).

5.3.2 Limitations

Seven out of nine studies conducted a qualitative content analysis. This methodology includes a number of limitations, for example, the findings of the analysis highly depend on the researchers' interpretation of the posts, and that it remains unknown how the readers interpret the post (see Gerritzen et al. (2022b) (chapter 3) for more detail). Moreover, due to the large amount of studies that used a qualitative content analysis methodology, this review mainly represents the views and experiences of people with ALS who are active on the online peer support platform, meaning that they either create posts or respond to others. However, research shows that non-active members of online peer support networks can still benefit (Steadman et al., 2014).

Additionally, this review may overrepresent positive aspects of online peer support for different reasons. 1) People who are active on an online platform tend to be the ones who enjoy it. 2) Only one study reported on the negatives and potential challenges of online peer support for people with ALS (Caron et al., 2015). 3) This review does not represent the views and experiences of those who are unable to use or stopped using online peer support.

5.3.3 Recommendations

The systematic database search did not identify studies that assessed verbal communication, for example through videoconferencing platforms. During the COVID-19 pandemic communication through videoconferencing platforms became increasingly popular. Nevertheless, after rerunning the database search no studies on using videoconferencing platforms for peer support for people with

ALS were identified. Despite the potential challenges with verbal communication, future research could explore whether such platforms could be useful for people with ALS and if they would be helpful for online peer support. Furthermore, given the popularity of text-based platforms such as discussion forums and social media, it can be assumed that there might be a large group of people who are not active on the platform, but do follow what is being shared (Steadman et al., 2014). Future research could explore the experiences of this group, for example through surveys or interviews. Finally, knowledge on the barriers for people with ALS to engage with technology or online communication remains limited. Due to the progressive nature of ALS it is important to gain more insights in the barriers that people face and how to overcome them, so that people with ALS can use online resources for longer.

5.3.4 Conclusion

Peer support can provide a non-judgemental and supportive environment people with ALS in which they can connect and share experiences with others in a similar situation. People can learn from experiences of others with certain treatments or assistive technologies, and develop adaptive coping skills. Online platforms can accommodate towards various needs, abilities, and preferences, as it offers different modes of communication. Particularly text-based, asynchronous (not in real time) platforms allow for people to engage at their own pace and in their own time, from the comfort of their own home. Such platforms can be especially useful for those who experience difficulties with verbal communication. However, ALS symptoms may make it more difficult for people to use technological devices and engage in online peer support. More research is needed to identify what kind of barriers people with ALS experience, and how these could be overcome.

6. Experiences with peer support through video meetings: focus groups with people with YOD

The findings presented in chapter were published journal article: Gerritzen, E.V., Kohl, G., Orrell, M., & McDermott, O. (2023). Peer support through video meetings: experiences of people with Young Onset Dementia. *Dementia, 22*(1). https://doi.org/10.1177/14713012221140468

6.1 Introduction

The systematic reviews (chapters 3-5) provided insights into successful elements of online peer support for people with a chronic, neurodegenerative condition. All three reviews found that the benefits of peer support were also present in online platforms, and that people with these chronic, neurodegenerative conditions experienced social support, mutual understanding and empathy through online platforms. Online platforms were also rich sources of information and hints and tips. However, all three reviews also found that the different symptoms associated with these conditions can make it more difficult to use technology and engage in online communication. Both the reviews on Parkinson's disease and Multiple Sclerosis also found that people also can miss in-person interaction and miss the lack of non-verbal communication in asynchronous platforms.

The review on online peer support for people with Parkinson's disease (chapter 3) highlighted the importance of similarity between peers, for example in age or time since diagnosis (Lieberman, 2007; Lieberman et al., 2006; Lieberman et al., 2005). One of the benefits of online platforms that was identified was that it can make it easier for people to discuss certain topics that they would not feel comfortable speaking about in-person (Lieberman et al., 2005). Furthermore, while peer support is about support between people with lived experience, people may also appreciate it if they can ask some of their questions directly to a professional (Bakke, 2018).

The review on online peer support for people with Multiple Sclerosis (chapter 4) showed that even simply reading about the experiences of others can already

provide people with social support (Steadman et al., 2014). Moreover, the asynchronous nature of some platforms means that discussion topics can be saved and archived, so that people can find relevant information at any time (Rath et al., 2017; Shavazi et al., 2016).

Finally, the review on Amyotrophic Lateral Sclerosis (ALS) highlighted the physical challenges people with ALS face due to their condition, making it difficult to physically get to in-person peer support groups. Additionally, people with ALS often experience language difficulties, making verbal conversations more challenging. Online platforms made peer support accessible as it overcame those challenges. The review found that finding others with similar experiences, for example people with similar symptoms or treatments was very important. Similarly, online platforms provided opportunities to find others with relevant experiences. For example, if people had certain symptoms or were considering a specific treatment, they could search for others who already had experience with that treatment (Frost et al., 2009; Frost et al., 2008).

The current research builds on these findings and shifts focus towards online peer support for people with YOD. Previous studies into online peer support for people with (Young Onset) dementia (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2023; Talbot et al., 2020) all focus on text-based and asynchronous (not in real time) communication. During the COVID-19 pandemic and national lockdowns videoconferencing platforms such as Zoom and MS Teams became more popular. During this time many in-person (peer) support services for people with dementia were disrupted, and some adapted to online platforms (Giebel et al., 2021a). Videoconferencing platforms include verbal, synchronous (real time) and often face-to-face communication, making it a different type of online peer support than previously researched. Research has been conducted into using videoconferencing platforms for (peer) support for informal carers of people with dementia (Banbury et al., 2019), yet, no research has been conducted into how people with a YOD diagnosis use online videoconferencing platforms for peer support.

The method selected for this study is focus groups. Focus groups allow us to explore how members of peer support groups for people with YOD experience meeting with their group online. Additionally, focus groups can provide us with insights into the dynamics within a group. This study aimed to (1) explore the personal experiences of people with YOD with peer support meetings through online videoconferencing platforms, and (2) identify barriers and facilitators of participating in online peer support through videoconferencing platforms.

6.2 Methods

For this qualitative study, focus group discussions were conducted to explore how people with YOD experience participating in an online peer support group through videoconferencing software. The focus groups were held with existing peer support groups, which were all based in the UK. The findings are reported following the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

6.2.1   Recruitment

In May and June 2021 existing peer support groups were recruited using a combination of convenience and purposeful sampling. For the convenience sampling method, the study was advertised through (1) an online Patient and Public Involvement event, and (2) the Dementia Engagement and Empowerment Project (DEEP), which is a UK-based network of support groups for people with dementia. People who were interested in taking part could contact the first author (EG). For the purposeful sampling method, EVG contacted peer support facilitators in her professional network. This included facilitators from (1) the Young Dementia Network, which is a collaborative network consisting of people living with YOD, their supporters, and professionals, and (2) the Rare Dementia Support (RDS) service.

Initial contact with the peer support group was made through the group facilitator. Before each focus group EVG had a meeting with the group facilitator to learn a bit more about the group, explain the purpose of the study, and assess

the eligibility of the group members. Next, the facilitator shared the study with the group and gathered interest among the members. EVG also offered to present the study during one of the group's meetings. This was done for two of the four focus groups. In both instances no issues or concerns were raised, and members expressed interest in taking part in the focus group.

6.2.2   Eligibility criteria

People were eligible for the study if they (1) were living with a dementia diagnosis, (2) received their diagnosis before the age of 65, and (3) were part of an existing peer support group that met online. People did not have to be younger than 65 at the time they took part in the study, as long as they had received their diagnosis before the age of 65. For support groups that included both people living with dementia and family members, EVG and the facilitator came to an agreement that, while the emphasis of the focus groups would be on the experiences of those living with dementia, family members could join if they wanted to. This was to not exclude some of the group members.

6.2.3   Consent procedures

Each participant received a Participant Information Sheet (Appendix 7) and an Informed Consent form (Appendix 8) via email or per post, depending on their preference. Due to the COVID-19 pandemic and UK-wide lockdowns as well as the wide variety in geographical locations of the participants, informed consent was taken remotely. The informed consent process was offered in different formats to accommodate to the different needs and preferences of each individual participant. Participants could provide written or verbal consent. Written consent could be done by either signing the consent form on paper or digitally and sending it back to EVG. For verbal consent EVG went through the study information and consent form over a videocall on MS Teams or over the phone, which was recorded (after the participant gave permission). All options were presented to the group facilitator, who would advise on the most suitable option for each participant.

6.2.4 Focus group procedures

The focus groups were conducted online through the group's usual meeting platform at a time and day that was convenient for the group. The aim was to conduct 4-6 focus groups, as data saturation tends to occur after 4-6 focus groups have been conducted (Hennink et al., 2019). Each focus group was facilitated by EG, who has a background in health sciences. A co-facilitator, GK, with a background in psychology was present to take field notes, monitor the chat, and ask additional questions. Both facilitators were early-career researchers. The group's usual facilitator was present at the beginning of the meeting to welcome everyone, but was not there during the focus group itself. This was to ensure that people could speak freely about their experiences. EVG discussed this with the facilitators beforehand, who all agreed.

The focus groups were semi-structured using a pre-defined topic guide. Informal consultations with people with YOD and professionals working with people with YOD, literature research, and discussions within the research team informed the topic guide. The informal consultations were held before developing the topic guide, to get an understanding of the challenges that people with YOD face, in particular with finding peer support and using technology. During the informal consultations people shared the challenges they faced while adapting to a live with YOD, such as stigma and difficulties in finding age-appropriate support and information that met their needs and wishes. Furthermore, they spoke about some of their experiences with (online) peer support and how it helps them in adapting to and living a life with dementia, but that this is not accessible for everyone. The topic guide covered (1) finding a peer support group, (2) general peer support experiences, (3) online peer support experiences and use of technology, and (4) hints and tips on coping with YOD, finding support, and provision of information and support for people with YOD. The reason why the first two items were included in the topic guide is that some of the barriers of accessing a peer support group can be due to a lack of in-person services, stigma, and negative experiences with dementia and peer support services. The step towards online peer support might then be smaller compared to in-person groups.

6.2.5 Data collection

The focus groups were screen- and audio-recorded using the recording function of the videoconferencing platform and an external recorder. The recording from the videoconferencing platform was saved on EVG's computer. Immediately afterwards the recording was uploaded onto a password secured online storage space of the University of Nottingham and deleted from EVG's computer. The field notes from the co-facilitator were also saved on the password secured online storage space of the University of Nottingham. All focus groups were transcribed verbatim by Dictate2Us[1].

6.2.6 Data analysis

The data were analysed through thematic analysis using an inductive approach. The thematic analysis was conducted using the procedures outlined by Braun et al. (2021a) and consisted of six phases: (1) familiarising with the data, (2) coding the data, (3) developing initial themes, (4) developing and reviewing themes, (5) refining, defining and naming the themes, and (6) writing up.

Phase 1 and 2: familiarising with and coding the data

During the first phase, EVG and GK independently read the transcripts multiple times and wrote down and discussed their insights. For the second phase one transcript was selected to look at in more detail. Due to the amount of data it was decided to select a sample rather than using the full dataset. EG, GK, and OM, a senior member of the research team with a background in music therapy, familiarised themselves with this transcript. During this phase the initial thoughts and ideas were refined and each author identified codes. In this context codes can be described as specific and detailed segments of the transcript that are potentially interesting and relevant (Braun et al., 2021a). This process was followed by a discussion between EVG, GK and OM.

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[1] Dictate2Us is a transcribing company that is approved by and has an agreement with the University of Nottingham.

Phase 3, 4 and 5: developing initial themes, reviewing themes, refining themes, and writing up

During the third phase EVG and GK went back to the selected transcript and generated initial themes. Themes are different than codes as themes describe a broader meaning rather than something very specific, as is the case for codes (Braun et al., 2021a). The initial themes were discussed among EVG and GK who developed an initial coding framework. Some examples of the initial themes are 'time right after diagnosis', 'facilitators to joining a peer support group', and 'negatives of peer support in an online platform'. For the fourth phase the initial coding framework was applied to the selected transcript. EVG and GK independently coded the transcript to see whether the initial coding framework captured the important elements of the data and whether it showed relationships between the different themes. After discussing this process, EVG and GK refined the coding framework during the fifth phase. The main reason that refinement was needed was that there were too many themes and that at times it was difficult to know where a certain section of the data would fit best. During this phase the refined coding framework was applied to all transcripts and EVG and GK independently coded each transcript. Afterwards EVG and GK compared and discussed the results of the coding. Finally, during the sixth phase EG took the lead in writing the manuscript, and the other authors provided detailed feedback.

6.2.7 Trustworthiness of data

Triangulation was applied to ensure trustworthiness of the data. Multiple methods of data collection were used to achieve method triangulation. These included audio- and screen recording of the focus groups and field notes (Carter et al., 2014). The audio of what was spoken matched the body language observed in the screen recordings. The field notes gave an insight into which particular topics were important during each focus group, which was helpful during the first phase of the analysis process. Furthermore, the research team consisted of researchers in different stages of their career and with different professional backgrounds, ensuring investigator triangulation (Carter et al., 2014). Finally, member checking was used to ensure the analysis accurately reflected the participants' experiences. The initial findings of the study were written up in a

report and shared with the participants. All participants were given the option to provide feedback and additional insights (Braun et al., 2021a). Nine participants expressed interest in receiving the initial findings of the study, of whom four provided feedback. All four agreed with the provisional findings, so there was no need for the research team to make changes. The information letter that participants received for providing feedback is presented in Appendix 9.

6.2.8 Participants

The groups

Three groups were mixed groups for people living with YOD and family carers and one was for people with a YOD diagnosis only. Three groups were facilitated by a (healthcare) professional, whereas one was facilitated by a former family carer of someone with dementia. At the time of the focus groups, all groups were meeting once a month through a videoconferencing platform. Two groups existed before the COVID-19 pandemic and used to meet in person before lockdown measures came into place. Two groups were formed during lockdown, one with the intention to move to in-person meetings when restrictions allowed, and one was founded as an online-only group with the intention to include people from a wide geographical range. For one participant in group 4 the focus group was their first time joining the group's meeting. The person attended the meeting with the intention of becoming a member of the group, and not merely to participate in the focus group.

Every participant took part from a place of their preference. Three focus groups were held on Zoom and one on GoToMeeting. The focus groups lasted between 73 and 120 minutes. One focus group lasted longer than the others because of technical problems and a longer break. In total 23 people expressed interest in taking part, including two family members. The family members were part of the group and were also there to supported the person with dementia to attend the meeting. Three people, including both family members, dropped out after signing the Informed Consent form. All three were not present at the start of their scheduled focus group. The group facilitator tried to contact them, but it is unknown to the research team why those members did not attend the focus

group. This resulted in 20 people with YOD taking part in the study. Of these, one person was based outside the UK. An overview of the focus groups is presented in Table 6.1.

Table 6.1 Focus group characteristics

Group	Participants	Drop-outs	Platform used	Location and membership
1	2	1	Zoom	North England (local and regional members)
2	4	2	Zoom	Scotland (local and regional members)
3	6	0	GoToMeeting	South England (UK and international members)
4	8	0	Zoom	Central England (local and regional members)

6.2.8.1 Individual participants

All participants were members of the support group. In one focus group, one participant joined the group for the first time during the focus group, with the intention of becoming a member of the group. The participants represented a wide geographical area, from the south of England up to Scotland, and one international participant. Of the 20 participants, 11 were male and 9 were female, aged between 48 and 68. One participant received his formal diagnosis at the age of 68, however, the dementia symptoms started years before that. The most prevalent type of dementia among the participants was Alzheimer's disease, followed by frontotemporal dementia. More information on the participant characteristics is presented in Table 6.2.

Table 6.2 Participant characteristics

Male (%)	11 (55%)
Female (%)	9 (45%)
Age Mean (min-max)	59.6 (48-68)
Dementia diagnosis	
Alzheimer's Disease (%)	7 (35%)
Frontotemporal Dementia (%)	4 (20%)
Posterior Cortical Atrophy (%)	3 (15%)
Primary Progressive Aphasia (%)	3 (15%)
Lewy Body Dementia (%)	2 (10%)
Semantic Dementia (%)	1 (5%)
Time since diagnosis	
< 1 year (%)	7 (35%)
1-2 years (%)	2 (10%)
2-3 years (%)	4 (20%)
> 3 years (%)	6 (30%)
Unknown (%)	1 (5%)
Living situation	
Living with partner (%)	9 (45%)
Living with partner and other family members (e.g. children) (%)	6 (30%)
Living alone (%)	3 (15%)
Other (%)	2 (10%)
Paid employment Yes (%)	4 (20%)

6.3 Results

In Phase 1 of the analysis process EVG, GK and OM discussed which elements of the data stood out to them. These included the difficulties during the post-diagnostic period and the losses that people faced, the positives of peer support in general, and missing not being together in person for some people. For the second phase EVG and GK developed codes that would then inform the overarching themes and subthemes. Codes that informed theme 1: 'Inconsistent signposting and ambivalence to peer support' included 'feelings of loss, low mood, no hope', and 'those groups are for old people'. For theme 2: 'Staying socially connected' some examples of codes that were used to develop this theme include 'they laugh with me, not at me', 'different people bring different things' and 'Zoom has given us a purpose'. 'There's always someone there', 'kept us as

a group in contact with each other' are examples of codes that informed theme 3: 'Overcoming physical isolation'. Finally, codes that informed theme 4: 'Navigating technological limitations' included 'it's not the same as meeting in-person', 'different providers can be confusing' and 'people missing out because they cannot use technology'. The four overarching themes and nine subthemes that were developed which are presented in Table 6.3 and Figure 6.1.

Table 6.3 Overarching themes and subthemes

Overarching theme	Subthemes
1. Inconsistent signposting and ambivalence to peer support	• Lack of awareness of local support and misconceptions about peer support • Losing self-confidence
2. Staying socially connected	• Mutual understanding and empathy • Friendship and social support • Finding a new purpose
3. Overcoming physical isolation	• Staying connected during COVID-19 pandemic • Overcoming geographical barriers
4. Navigating technological limitations	• Difficulties when using technology • Digital exclusion

6.3.1 Theme 1: Inconsistent signposting and ambivalence to peer support

People frequently spoke about the challenges they faced in identifying (age-appropriate) support services and the lack of signposting. Across the groups there was a variety in available support groups and resources, with some areas having excellent services, and some having hardly any at all, or support was difficult to find.

> "People promise you things and then sometimes they don't come through with the promise […] It's unfortunate we have to be so proactive, particularly given the fact that sometimes we find it hard to be proactive and we wish people would come and knock on our door and say 'Look. Hello. Come and play with us today'." (P10, group 3)

Figure 6.1 Overarching themes and subthemes

Inconsistent signposting and ambivalence to peer support

- Lack of awareness of local support and misconceptions about peer support
- Losing self-confidence

Barriers to access and use in-person peer support services

Increased risk of becoming socially and physically isolated

Potential solution

Navigating technological limitations

- Difficulties when using technology
- Digital exclusion

Online peer support

Staying socially connected

- Mutual understanding and empathy
- Friendship
- Social support
- Finding a new purpose

Overcoming physical isolation

- Staying connected during COVID-19 pandemic
- Overcoming geographical barriers

Lack of awareness of local support and misconceptions about peer support

People mentioned that before they joined their group, they were often unaware that there were groups specifically for younger people. This relates to some of the misconceptions that exist around peer support. For example, some people felt that peer support groups were only for older people and were about 'singing songs about the war'. Some had previous negative experiences with support groups that were not age-appropriate, or experiences with an older parent with dementia.

> "There was a lot of trepidation because I didn't realise that there was a group that was very similar age, similar diagnosis etcetera […] I expected it would just be a lot of old people in their 70s and 80s." (P1, group 1)

> "I didn't want to join a group because my mum's experience was going away in a mini bus and disappearing for the day […] I had no idea what she did, I had no idea how she got on other than what she told me." (P5, group 2)

Losing self-confidence

Receiving the diagnosis was a life-changing experience and was accompanied by uncertainty about the future and where to find support. People also experienced many losses, such as losing their jobs, having to give up driving, and losing contact with friends. For many, these losses resulted in losing their self-confidence as well.

> "As soon as I was made to give up my job it felt like all the doors that were open to me before had shut […] People say 'Oh, you know, you'd better not do that and you can't do this. It's unrealistic'. Expectations of yourself and from other people go right down." (P7, group 3)

> "[…] you lose your independence" (P5, group 2), "you lose your self-worth" (P6, group 2) "… The thought of joining a group of people when really, all you've had is your confidence kicked down, it's really pretty hard." (P5, group 2)

6.3.2 Theme 2: Staying socially connected

While some people said they had doubts before joining a group, they all agreed that joining the group was the right decision for them because it had a positive impact on their lives. People who participated in this study recommend to those who are reluctant to join a peer support group to just give it a try. They highlighted that there is a wide variety of topics and activities to take part in, that there is no need to say or do anything if you do not want to, and that there is no pressure to join every single meeting.

> "I was silent for quite a long time when we started because A. I didn't know what to say, and B. I didn't really want to be there, [I was] kind of in denial with everything. But gradually I thought 'actually this is alright'. It's like with any sort of introduction to anybody, it takes a little while to get in there, but it's definitely worth it." (P14, group 4)

Mutual understanding and empathy

One of the most important aspects of peer support was the mutual understanding and acceptance within the group.

> "There's lots of things we don't have to say to each other because we live in the same fog" (P4, group 2).

> "You feel like you are losing yourself and you have things that you can't necessarily discuss with other people, or feel awkward or uncomfortable about. But here you don't feel uncomfortable because people understand. You are on the same level." (P7, group 3)

People explained that others, whether it is family members, friends, or healthcare professionals, do not always understand what it is like to have YOD.

> "You might have your partner living with you, but you still feel alone to a certain extent because your partner cannot understand what you're going through." (P1, group 1)

Friendship and social support

People shared that their group was a great source of friendship and support and that it helped them to manage daily life with dementia. Through peer support people could share hints and tips for the challenges they face in their daily lives.

> "We have had the privilege of being in each other's company, meeting lifelong friendships, and that's what gets you through the days and the months and hopefully the years [...] it's much more than that, it's about enjoying them and making the most of them." (P5, group 2)

> "When you hear what people do with their lives, how they go about everyday living with this diagnosis, that they can achieve lots of things, it gives each one of us hope that you can keep going and do lots of things." (P7, group 3)

Finding a new purpose

Peer support also offered people new opportunities for meaningful activities, involving research and advocacy, but also creative and arts-based activities that people might not have considered if it were not for the support group. The same is true for the opportunity to meet new people.

> "We are going to have a dance group going on. I have a Zoom dance for different groups in [location] and we are going to start one for this group." (P9, group 3)

> "We've done so many things, we've been part of groups that have created training schedules [...] Zoom has given us a purpose [...] You think 'I've made a difference. I've helped, I did something that's really worthwhile'." (P5, group 2)

People mentioned that a structure and an agenda for the meeting with specific topics can be helpful, but it can also be nice to have no structure and to use the meeting to just socialise and have a good time. Whether to have an agenda or not and what to discuss during the meeting was mostly a collaboration between the facilitator and the group. Moreover, people emphasized that the group was

there for them, to meet their needs and wishes. The role of the facilitator was mainly described as providing the platform and connecting people, and to not talk too much. One group had two different meetings. One was reserved for more serious and dementia-related topics, and one was more of a social meeting. About the social meeting someone said:

> "It is kind of a break from dementia. We focus on our interests, our opinions, how things are going for us in our personal lives, it's a very rich experience […]. It's an open slot for us to contribute in any way that we want to share." (P20, group 4)

6.3.3   Theme 3: Overcoming physical isolation

Online peer support can overcome some of the limitations of in-person peer support. Not everyone may be able or feel comfortable to attend an in-person peer support group. Meeting a new group of people and speaking openly about one's experiences with dementia can be daunting. One of the main positives of online peer support that people spoke about is being able to join from the comfort of their own home.

> "You can feel a bit more comfortable when you are in your own home […] I've got my dogs here and I'm quite comfortable." (P12, group 3)

> "For those of us who are nervous about public speaking, Zoom is actually better because you are in your own environment. You can mute. You can fiddle about on the desk or whatever. You don't get told off either. It has got its advantages." (P10, group 3)

Furthermore, depending on the type of online setting, support could be readily available when needed. One group also had a WhatsApp group. Here people shared information and things that were going on in their lives, but it was also a place for people to share when they were feeling low. There would always be someone from the group to talk to. Furthermore, someone said the following about the WhatsApp group:

"You don't feel obliged that you've got to respond. It just feels as if you are still in touch, that you're not in your own little silo because other things are going on and it's great to see what other people are doing." (P8, group 3)

Staying connected during COVID-19 pandemic

Videoconferencing platforms allowed people to stay connected during the COVID-19 pandemic. People shared how important their peer support group was during this difficult time.

"I felt obviously on my own [but] I know that they are there at the other end of the computer and I just feel like I was part in their day." (P3, group 2)

"I think if we didn't have Zoom, I don't know how I would be, but having the support in the group, even though it's on Zoom, it is support and you can talk to people who are in the same shoes." (P15, group 4)

Overcoming geographical barriers

Online meetings also allowed people to connect with others from different places, and provided opportunities to get involved in, for example, research projects across the country. Furthermore, it was a convenient way to stay connected.

"I've had some struggle to get out. Even if it was a local meeting I'd possibly have had problems actually physically getting there. Being able to have this, it breaks down lots of barriers because of distance, we can meet wherever we are internationally, but also if you struggle mobility wise or with anxiety about getting places, that sort of thing, it takes that away." (P7, group 3)

6.3.4 Theme 4: Navigating technological limitations

Online peer support and technology in general has its limitations. People frequently mentioned that online meetings cannot replace in-person interaction and that this was something they missed.

> "Whilst Zoom meetings are well and good, they're not the same as meeting people and having cups of tea and eating biscuits and just doing that human connection thing that's so important." (P4, group 2)

Difficulties using technology

People shared that they sometimes had difficulties with joining a video meeting and navigating different platforms could be confusing.

> "I was used to the Zoom platform and where all the buttons were […] but coming on this sometimes that's a bit of a challenge because things are in different places. […] It can be very distracting." (P8, group 3)

To overcome such challenges, people would message or call each other, and someone else would help them find the link or get in the meeting. Members of the group and their families also helped each other with setting up the technology, and for example installing Zoom. Facilitators can also play an important role in this. People agreed that it is important that the facilitator has good organisational skills to overcome these challenges, for example, by sending out timely reminders and providing clear instructions on how to join the meeting.

Digital exclusion

While all participants in this study were successfully using technology and videoconferencing platforms, digital exclusion was mentioned as an important limitation. Some of the groups used to meet in person before the COVID-19 pandemic. They noticed that some members of their group did not manage to take part in the online meetings, and therefore lost contact with the group. People felt that the main reason why other group members were unable to take part was that their dementia symptoms made it too difficult.

"The sad bit is that several members of the group can't access Zoom […].
I really feel a loss for some of the folk who just not have had the same
connection or same continuity that some of us have had and that's quite
sad because they're very important members of the group." (P5, group 2)

6.4 Discussion

6.4.1 Key findings

This study shows that beneficial elements of peer support, such as emotional and
social support, friendship building, and sharing experiences and information
(Keyes et al., 2014), are not limited to in-person settings. This supports findings
from our systematic literature reviews (Gerritzen et al., 2022a, 2022b) (chapters
3-5). It adds to findings of previous research on text-based platforms for online
peer support (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et
al., 2023; Talbot et al., 2020). This study shows that the benefits of online
platforms for peer support can go beyond text-based platforms, and are also
present in video meetings. During the COVID-19 pandemic, for some the video
meetings were better than having no support at all. However, this study also
shows that peer support through video meetings is more than just a replacement
of in-person peer support in times of worldwide disruption and crisis, and has its
own unique benefits.

Benefits of online peer support using videoconferencing platforms

Peer support can be very valuable for people with YOD as it can make the post-
diagnostic experience more positive (Rabanal et al., 2018; Stamou et al., 2021b)
and reduce the risk of social isolation (Pierse et al., 2022). These findings suggest
that every person with YOD should have access to peer support. However,
people often experience difficulties in accessing age-appropriate, local (peer)
support services (Cations et al., 2017; Mayrhofer et al., 2018). Negative
experiences with peer support groups that are not age-appropriate can have a
negative impact on someone with YOD, and result in reluctance to use formal
dementia services.

Dementia symptoms can make it more difficult to travel to in-person peer support groups. Our systematic review on online peer support for people with ALS (chapter 5) showed that in-person support groups can be particularly difficult to access for people who experience physical challenges that make it difficult for them to travel. Moreover, research shows that geographical and logistical challenges, such as time and money spend on travelling, are barriers to accessing (peer) support services (Cations et al., 2017; Matthias et al., 2016). Therefore, online platforms can make peer support more widely accessible. Online peer support can also be a good option for those who may not feel comfortable meeting new people in person and speak openly about their experiences with dementia. In video meetings people can still see and hear the others and feel connected. At the same time, there is the option to turn off their cameras or mute themselves, step away from the meeting for a moment, or leave the meeting at any point while being in a comfortable and safe environment.

Limitations and challenges of online peer support using videoconferencing platforms

This study identified that missing being together in person is one of the main limitations of online peer support. This was also identified in our systematic reviews on online peer support for people with Parkinson's disease (Gerritzen et al., 2022b) (chapter 3) and MS (Gerritzen et al., 2022a) (chapter 4). In the current study, the focus groups that met in person or were founded with the intention of being an in-person group expressed the wish to meet in person (again) when once COVID-19 restrictions were lifted. The feeling of online support being better than no support at all was present in these groups. These findings add to previous research on the experiences of people with dementia and their families during the COVID-19 pandemic (Giebel et al., 2021a). On the other hand, the online-only group whose members were from different parts of the UK and the world expressed themselves about the benefits of meeting online. Other challenges included difficulties to join a meeting, having to navigate different platforms, and digital exclusion. Clear guidelines on how the platform works, having someone to help set up the necessary software, and timely reminders for the meeting can help mitigate such challenges.

6.4.2   Limitations

First, this study only included people who were able to use technology and participate in video meetings. Therefore, it did not represent the views and experiences of those who are unable to use these. Second, besides one group speaking about their WhatsApp group, this study mainly focussed on real-time contact in video meetings, and did not represent how people with YOD may use other platforms for online peer support, such as social media or discussion forums.

6.4.3   Recommendations for future research and practice

This study identified two main reasons why people with YOD may experience difficulties in accessing peer support. First, there is inconsistent availability of specialised (peer) support services across the UK. Moreover, there is a lack of clear signposting to such services by healthcare professionals. This echoes previous findings by Cations et al. (2017) and Mayrhofer et al. (2018). As a result, people are often unaware that specific YOD peer support exists. Second, there is still the misconception that peer support groups are mainly for older people. Better signposting to specialised YOD (peer) support services is needed.

One of the challenges identified in this study is digital exclusion. Participants found that not all group members were able to take part in their online meetings. Reasons could be different levels of tech savviness and progressing dementia symptoms making it difficult to use technology. More and more of our communication is taking place online, and more and more health and social care services are being digitalised, a process that accelerated during the COVID-19 pandemic. Therefore, it is important to get more insight into the views and experiences of people with YOD who do not or cannot use online (peer) support services, identify the barriers, and how to overcome these. This is important to make peer support and other services accessible to anyone living with YOD who needs it.

Finally, there are many different forms of online peer support and using video meetings is only one of them. While previous research explored how people with dementia used other platforms, such as social media and discussion forums

(Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2020), it remains unknown how people experience being part of such online support communities and how it affects their daily lives. Future research could focus on exploring how people with YOD experience using different online platforms for peer support, by using qualitative methods such as interviews or surveys.

6.5 Conclusion

Peer support is a valuable and important source of post-diagnostic support for people with YOD. However, not everyone with YOD has access to age-appropriate peer support due to dementia services and support groups often being tailored towards older adults. Online platforms can make peer support more accessible for people with YOD as it overcomes geographical barriers as well as barriers for those who feel uncomfortable attending an in-person peer support group. Through video meetings people can join from the comfort of their own homes and mute themselves or turn off their cameras at any point while still having the option to see and hear the other participants and feel part of a group. This study recommends that researchers and policy makers further explore how to implement and overcome barriers to online peer support, so that peer support is more widely accessible and signposted to people with YOD.

7. Views on and experiences with online peer support: an online survey for people with YOD

The findings presented in this chapter are published as a journal article: Gerritzen, E.V., McDermott, O., & Orrell, M. (2023). Online peer support: views and experiences of people with Young Onset Dementia (YOD). *Aging & Mental Health.* https://doi.org/10.1080/13607863.2023.2205833

7.1 Introduction

Research into online peer support for people with dementia (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2023; Talbot et al., 2020) suggests that there is a need for more research into the direct experiences and perspectives of both users and non-users. This could be done through surveys or interviews. We aimed to address this gap in research by conducting focus groups with existing peer support groups to explore how people with YOD experience peer support through videoconferencing platforms (chapter 6) (Gerritzen et al., 2023a).

The findings of the focus groups showed that the benefits of peer support that were previously identified in in-person groups and asynchronous online platforms can also be present in videoconferencing platforms. People shared that through the video meetings with their support group they experienced social support, friendship, and felt a real connection with the group. The additional benefit of the online platform was that it allowed people to get involved in for example research projects across the country, outside of their local area. Furthermore, because of the audio-visual format people could see and hear the others and speak with them in real-time, creating a sense of being together. However, as was also identified in the systematic reviews on Parkinson's disease (Gerritzen et al., 2022b) (chapter 3) and Multiple Sclerosis (Gerritzen et al., 2022a) (chapter 4), some still missed being together in-person. This was mainly true for the groups that used to meet in-person but then had to move to online meetings because of the COVID-19 pandemic and restrictions on in-person gatherings. For the group that was intended as an online-only group, people

expressed themselves more about the benefits that the online format offered them.

Furthermore, some gaps in research remain because the focus group study does not represent the views and experiences of people with YOD who cannot or do not want to engage with online peer support, as well as the experiences of those who stop engaging with online peer support. Additionally, the focus groups only explored people's experiences with one specific type of platform, namely online videoconferencing platforms. Therefore, the findings cannot be generalised to other platforms that can be used for online peer support, such as social media platforms or discussion forums. Online surveys allow for a larger sample size and have the potential to reach a wider population, meaning that it could also reach people who have never engaged with online peer support or those who have in the past but stopped. It can also reach people who use a wider variety of online platforms rather than focussing on videoconferencing platforms only. Finally, a benefit of online surveys compared to focus groups is that it is less time consuming for people to take part, they can answer the questions at their own pace and in their own time, and they can remain anonymous if they want to.

This study aimed 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.

7.2 Methods

This was 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., 2021b; Braun et al., 2017). As the personal views and experiences of people with YOD regarding online peer support is an under-researched area, a mixed-methods survey was identified as a suitable method. This chapter followed 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).

7.2.1 Survey development

The survey content was informed by informal consultations with people with YOD and health and social care professionals, literature research (chapters 3-5), and the focus groups (chapter 6). First, the informal consultations with people with YOD and health and social care professionals provided more insights into potential benefits and challenges of online peer support. For example, question 12 'How did you find out about ways to meet with / talk to other people with Young Onset Dementia online?' was included because through the informal consultations we learned that people often have to find out about support services on their own with limited signposting from healthcare professionals. Question 20 'Why do you not meet with / talk to other people with Young Onset Dementia online?' was included because one of the people in the informal consultations had very positive experiences with (online) peer support but kept hearing from others that they felt that it was not something that suited them. He wondered why that is, and how peer support can 'not be for someone'. For question 20, the answer options 'I never heard about this' and 'I do not know where to look for support' were included because through the informal consultations we learned that people often had to find out about post-diagnostic support on their own with limited signposting by healthcare professionals. Finally, a peer support facilitator shared that some people experienced significant challenges when the in-person meetings moved online during the pandemic. This informed one answer options for question 20: 'I am not able to use a computer/ phone/ tablet'.

Second, the systematic literature reviews on online peer support for people with chronic, neurodegenerative conditions (Parkinson's disease, Multiple Sclerosis and Amyotrophic Lateral Sclerosis), provided insights on successful elements of online peer support (Gerritzen et al., 2022a, 2022b). This informed the list of answer options for question 10: 'What platform do or did you use to meet with / talk to other people with Young Onset Dementia?' ('Facebook', 'Twitter', 'discussion forum'). It also informed the answer options for question 14 'What

do / did you like about meeting with / talking to other people with Young Onset Dementia online?' ('building friendships', 'sharing experiences, tips and tricks', 'learning about dementia') and question 15 'Is there anything that you do not like about meeting with / talking to other people with Young Onset Dementia online?' ('sometimes I do not get a reply to my message', 'I miss not being together in-person').

Third, this survey was informed by the findings of the focus group study, which explored how people, who were part of an existing peer support group, experienced using videoconferencing platforms for their meetings during the COVID-19 pandemic (Gerritzen et al., 2023a). These findings informed the list of answer options for question 14 'What do / did you like about meeting with / talking to people with Young Onset Dementia online?' ('meeting new people', 'doing activities together', 'learning about research') and question 15 'Is there anything that you do not like about meeting with / talking to other people with Young Onset Dementia online?' (e.g., 'I find it difficult to keep up with the conversation', 'I find it difficult to keep up with the conversation', 'I miss not being together in-person'). It also informed question 12 'How did you find out about ways to meet with / talk to other people with Young Onset Dementia online?', question 13 'How often do / did you meet with / talk to other people with Young Onset Dementia online?', question 16 'Did you ever have a negative experience when meeting with / talking to other people with Young Onset Dementia online?' and question 17 'Is there anything about online peer platforms that could be improved'.

The online survey was built in the Jisc Online Surveys platform (Jisc Online Surveys). The research team developed the first draft of the survey. Three Patient and Public Involvement (PPI) members were consulted before the survey got published. The PPI team included two people living with YOD and one family carer of someone with YOD. All three PPI members 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 feedback from the PPI members, fixed-choice options were added to most of the open questions, with the option to leave a free-text response

as well. The PPI members also provided input on the content for both the type of questions and the answer options.

The survey had tailored questions for current, past, and non-users of online peer support. The beginning of the survey was the same for everyone and included demographic questions on gender, age, time since diagnosis, living situation, employment status, ethnicity, and experience with online peer support. Based on their answer to that last question (current, past, or non-user), participants were send to specific questions in the survey. 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, positive and negative, any 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 final version of the survey (Appendix 10). 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) (NIHR, 2022).

7.2.2 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 (Appendix 11) 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.

7.2.3   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 minutes), 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 could leave their name and contact details to receive updates about this study or future opportunities to be involved. Survey data were stored in a password secured account on Jisc Surveys, under the license agreement with the University of Nottingham. After the survey closed, the data were 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.

7.2.4   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 et al. (2021a) 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 et al., 2021a).

7.3 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 7.1.

Table 7.1 Participant characteristics

Male (%)	43 (62.3%)
Female (%)	26 (37.7%)
Age Mean (min-max)	60.6 (42-69)
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	
No – never used	47 (68.1%)
No - used before, but not currently	6 (8.7%)
Yes – current user	16 (23.2%)

7.3.1 Quantitative results

No significant association could be 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 of the 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 for people to stop 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 itself was too difficult to use (n=2/6, 33.33%), or that 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%) were the most popular, followed by 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 sometimes be difficult to understand people (n=7/22, 31.8%) or to 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 engage in online peer support because they do not like to talk to other people with dementia (n=7/47, 14.9%), or more generally they 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, other people said that 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[2]) 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.

7.3.2 Qualitative results

During the first phase of the analysis process, elements that stood out to EVG and in the discussions with OM about the data 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. In the second phase EVG developed codes. For theme 1: 'The importance of peer support after a diagnosis', some examples of codes included 'peer support as a lifeline', 'being with people who understand' and 'sense of purpose'. Some of the codes that for example informed theme 2: 'Overcoming the physical limitations of in-person peer support' included 'living in rural area', 'can be a good way to get to know people before meeting them in-person' and 'makes it easier to check out different groups'. For theme 3: 'Navigating the limitations and challenges of online peer support', some of the codes included 'background noise on Zoom', 'it can be difficult to keep a conversation going online', 'lack of body language and facial expressions' and

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[2] 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.

'limited input from people with dementia'. Finally, theme 4: 'Navigating the barriers of online peer support' was informed by codes such as 'unsure of the benefits online', 'there is no support available', and 'no need for peer support because of having enough support from friends and family'. An overview of the four overarching themes and eight subthemes that were developed are presented in Table 7.2.

Table 7.2 Overarching themes and subthemes

Overarching theme	Subtheme
1. The importance of peer support after a diagnosis	• Experiencing social connectedness, empathy, and mutual understanding
2. Overcoming the physical limitations of in-person peer support	• Convenience of joining from home • Overcoming geographical barriers
3. Navigating the limitations and challenges of online peer support	• Navigating challenges of using technology and online communication • Exploring ways to make online peer support work better • Previous negative experiences with (online peer support) services
4. Navigating the barriers to 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

Theme 1: The importance of peer support after a diagnosis

Many people described their positive experiences of online peer support and how it 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.

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"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
People mentioned that their online peer support group made them feel less alone and isolated. People felt that they did not have to explain everything, because they could tell that the others really understand. They experienced a great amount of support, acceptance and understanding from their online peer support network. 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)

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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, 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 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 was 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)

7.4 Discussion

7.4.1 Key findings

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., 2014; Pierse et al., 2022; Stamou et al., 2021b). 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. This supports the findings of the focus group study presented in chapter 6. This study provides new insights in the experiences of people with YOD who do not engage with online peer support and what barriers and challenges they face, as well as the experiences of people who had engaged with online peer support in the past and stopped.

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 (chapter 6), in which people with YOD shared that they were unaware that there were peer support groups specifically for younger people (Gerritzen et al., 2023a). This also adds to earlier research by Giebel et al. (2021b) 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 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 et al., 2023a; Gerritzen 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., 2019). 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 et al., 2023a), for others it can be simply reading about or listening to other people's experiences and getting information (Steadman et al., 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 et al., 2023a; Kingod et al., 2016). 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., 2014; 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., 2021a). 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., 2022b).

7.4.2 Limitations

When interpreting the findings of this study it is important to consider the time when the data were collected. The data were 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 et al., 2021a). During this period, some in-person peer support groups adapted and moved their meetings online (Gerritzen et al., 2023a). 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., 2021a).

When advertising the survey online through social media channels such as Twitter and LinkedIn, very little is known about the population that is reached and who could have filled in the survey (Andrade, 2020). To mitigate the impact of potential sampling bias, the survey was also advertised among more targeted

populations through the NHS services, newsletters of dementia organisations, and through Join Dementia Research. Similarly, it remains unclear for how many participants someone else filled in the survey on their behalf. People were reminded that if they were filling in the survey on behalf of a person with dementia, they should answer the questions from the perspective of the person with dementia. 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; van Vliet et al., 2013). Therefore, we may have missed people who received their diagnosis after the age of 65, but whose symptoms started before that (Carter et al., 2022).

7.4.3   Methodological reflections

Based on the PPI input it was decided to have a combination of 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 ones thoughts and experiences in more detail. However, a limitation of online surveys is that it is not possible to ask the participants to elaborate on their answers, or to ask participants for clarification.

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 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. 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. (2021a) (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. (2021) and Stamou et al. (2021b)).

Members of the research team had no direct contact with participants. While the participants had the option to contact the research team and go through the survey together with a member of the team, no participants made use of this offer. However, the survey was advertised on the professional social media channels of the research team (Twitter and LinkedIn) which could potentially have influenced participants.

7.4.4 Recommendations for research and practice

Many people with YOD lack access to age-appropriate (peer) support (Cations et al., 2017; Mayrhofer et al., 2018). Reasons identified in the current 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 et al., 2023a; Gerritzen et al., 2022a, 2022b) showed 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 training and support for facilitators and moderators. Future research could further explore what specific elements make online peer support work well, for example in terms of group size

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and duration of the meeting. The group size depends on the type of platform. For example, for discussion forums research shows that 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 et al., 2023a). 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.

7.5 Conclusion

This study confirms some of our findings from chapter 6 that peer support is a valuable source of post-diagnostic support for people with YOD. The known benefits of peer support, 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. This study adds to our previous work that the main reason why people did not engage with online peer support was because they were unaware that online peer support exists or did not know where to look for more information. Furthermore, online peer support did 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.

8. Views on and experiences with online peer support: Interviews with people with YOD

8.1 Introduction

There are many positive aspects about online peer support, but we need to know more about why some people are hesitant to engage. Furthermore, we need to get a better understanding of how people use a variety of platforms for peer support, for example social media as well as Zoom meetings. The online survey (chapter 7) addresses these gaps in knowledge and shows that the main reasons why people do not engage in online peer support is because they did not know that this existed or where to look for support. A smaller group also answered that privacy concerns or not wanting to talk about dementia were reasons for not engaging in online peer support. However, the nature of online surveys meant that people could not provide as in-depth answers as they would be able in a conversation and the researcher cannot ask follow-up questions for more detail or clarification. Therefore, the online survey provided limited insights into what people's considerations were for engaging or not engaging in online peer support, and what specific aspects of online platforms or what underlying reasoning stopped them from engaging in online peer support. This is important to explore, as the majority of non-users of online peer support indicated that they would be curious to try online peer support. Furthermore, in the survey people emphasised that having a good facilitator is important. Similarly, the survey does not provide in-depth information about what people believe a good facilitator looks like and what specific skills or qualities a facilitator should have. Interviews allow to develop a deeper understanding of this.

This study aims to (1) develop an in-depth understanding of why some people are hesitant to engage in online peer support and what they would need to get involved, (2) what could be done to get more people involved in online peer support, and (3) get a deeper understanding of what exactly makes online peer support work well for people, and how they think online peer support could be optimised.

8.2 Methods

This qualitative study uses individual interviews with people with YOD. The interviews were conducted during June – September 2022. The findings are reported following the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

8.2.1 Recruitment and eligibility criteria

Participants were recruited through the online survey. Out of 69 survey respondents, 56 people expressed interest to be involved in further parts of the study. The aim was to conduct 10-15 interviews or reach a point of data saturation, as was not possible to conduct more interviews due to limited time and resources. Therefore, a sample of 19 people was invited. The sample was selected taking into account diversity and representativeness of the total sample. People from less representative groups (e.g. ethnicity other than White British, people living alone, or people in paid employment) were prioritised. The rest of the sample was made to create a balance of gender, age, time since diagnosis, living situation, and experience with online peer support.

8.2.2 Consent procedures

For the interview, participants received a Participant Information Sheet (Appendix 12) and Informed Consent Form (same as Appendix 8), either via email or per post, depending on the participant's preferences and the contact details that they provided. Due to the wide variety in geographical locations of the participants (including one international participant), consent was taken remotely. The informed consent process was offered in different formats to accommodate to individual needs and preferences. Participants could provide written or verbal consent. Written consent could be done by either signing the consent form on paper or digitally and sending it back to EVG. For verbal consent, EVG went through the study information and consent form over a video call on MS Teams or a phone call, which would be recorded (after the participant gave permission to do so). Both options were presented to each participant, and all participants chose the option for written consent, signing digitally.

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8.2.3 Interview procedures

Participants were interviewed either via a videocall on MS Teams or a phone call. All participants chose for the videocall on MS Teams. All interviews were conducted by EVG. The interviews were semi-structured using a pre-defined interview guide (Table 8.1). The interview guide was informed by the findings from the survey. The interview guide was shared with the participants in advance, so that they could prepare if they wanted to.

Table 8.1 Interview guide

General questions:
1. Do you use technology in your daily life? What do you use it for?
2. Did you ever experience difficulties when using technology? How did you deal with this?
3. Where do you go if you need support or information?
4. Have you used online peer support before? (For example, peer support in Zoom meetings, Facebook groups, Twitter, WhatsApp, or email)
If you <u>have not</u> used online peer support before:
5. Is this something you would consider using?
If you <u>have</u> used online peer support before:
6. What are your reasons for using online peer support?
7. What platforms do you use for online peer support? (For example Zoom, Facebook, Twitter, WhatsApp, email)
8. How does online peer support work for you?
9. What would you like to say to others who are considering getting involved in online peer support?
If you stopped using online peer support:
10. What are the reasons that you stopped using it?

8.2.4 Data collection and analysis

The interviews were screen and audio-recorded using the recording function and automatically transcribed verbatim using the transcript function in MS teams. EVG checked the transcripts for accuracy and listened back to the recording to adjust the transcripts where necessary. The recordings and transcripts were automatically saved on the password-secured University of Nottingham OneDrive account of EVG. The data were analysed through thematic analysis

using an inductive approach. The thematic analysis was conducted using the procedures outlined by Braun et al. (2021a), including six phases: (1) familiarising with the data, (2) coding the data, (3) developing initial themes, (4) developing and reviewing themes, (5) refining, defining and naming the themes, and (6) writing up.

Phase 1 and 2: familiarising with the data and coding the data

During the first phase, EVG read the transcripts discussed initial thoughts and aspects that stood out with OM, an experienced qualitative researcher. For the second phase, EVG looked at the transcripts again in more detail and refined the initial thoughts and ideas, to then translate these into codes. During this phase, codes are specific and detailed parts of the transcript that are potentially interesting and relevant (Braun et al., 2021a).

Phase 3, 4 and 5: developing themes, reviewing themes and writing up

For the third phase, EVG went back to the data and generated initial themes. Themes differ from codes in that they describe a broader meaning rather than focussing on specific element from the transcript (Braun et al., 2021a). EVG discussed the initial themes with OM and adjusted where necessary. For the fourth phase, EVG applied the themes to all transcripts, to see if the themes captured the important elements and relationships within the data. After completing the application, EVG discussed the process with and refined the themes with OM and MO during Phase 5. Finally, during Phase 6, EVG took the lead in writing up the findings, with detailed feedback from OM and MO.

8.2.5 Trustworthiness of data

Triangulation can ensure trustworthiness of the data. Multiple methods of data collection were used: audio- and screen recording, and field notes (Carter et al., 2014). The audio matched the body language that was observed during the interview. The field notes highlighted the most important or striking elements that came forward during each interview, which was especially helpful in the

first two phases of the analysis process. The research team consisted of researchers with different levels of experience and different professional backgrounds, which contributed to investigator triangulation (Carter et al., 2014).

8.3 Results

Of the 19 people who were invited, five never responded to the invite, two expressed interest but did not respond again to schedule a date for the interview, and for three people their supporter responded to the email to let the research team know that due to the progression of symptoms the person with dementia was be unable to take part in an interview. This resulted in nine people taking part in an interview. After nine interviews the research team discussed whether more interviews were necessary. The conclusion was that after nine interviews participants did not introduce any new topics anymore, and the views and experiences that they shared were in line with what was shared in previous interviews. Thus, the research team concluded that a point of data saturation was reached, and therefore it was decided to not invite more people for an interview. An overview of the participant characteristics is presented in Table 8.2.

In Phase 1 of the thematic analysis process, aspects from the data that stood out were how people described peer support as their lifeline and how it brought them hope and positivity after often a very difficult time after their diagnosis. On the other hand, for those who do not use online peer support, it stood out that often people did not know where to find support that suits them. Some had experiences where the support did not meet their needs and interests. In Phase 2 we developed codes that would then inform the development of the themes and subthemes. For theme 1: 'Looking for support after the diagnosis and managing life with YOD' the codes included: 'do not know what support is out there', 'doctors do not understand why peer support is important' and 'stigma, depression, low mood'.

Table 8.2 Participant characteristics

Male (%)	4 (44.4%)
Female (%)	5 (55.6%)
Age Mean (min-max)	59.6 (50-67)
Time since diagnosis	
<1 year (%)	3 (33.3%)
1-2 years (%)	3 (33.3%)
> 3 years (%)	3 (33.3%)
Living situation	
Living with partner (%)	5 (55.6%)
Living with partner and other family members (e.g. children) (%)	3 (33.3%)
Living alone (%)	1 (11.1%)
Paid employment Yes (%)	2 (22.2%)
Ethnicity	
White – British (%)	8 (88.9%)
White – European (%)	1 (11.1%)
Experience with online peer support	
No – never used	3 (33.3%)
No - used before, but not currently	1 (11.1%)
Yes – current user	5 (55.6%)

Codes that informed theme 2: 'Barriers that may stop people from engaging with online peer support' included 'communicating on Zoom is not as natural and organic as in-person', 'not wanting to talk about dementia all the time', 'fear of seeing others in a more advanced stage' and 'dementia things are for people further along the journey'. Theme 3: 'Navigating challenges with technology and online peer support' was informed by codes such as 'knowing that technological support is there when needed', 'finding the right time in the day to do online meetings', and 'trying different groups before finding the right one'. 'A facilitator should get to know the members of the group' and 'giving everyone an opportunity to speak' were examples of codes that supported theme 4: 'The role of the facilitator in making online peer support work well'. Finally, some examples for codes that informed theme 5: 'Wider opportunities for in-the-moment support' included 'not having all the stimulation that is there in in-person meetings', 'no need to travel', and 'support can be there when you need

it'. An overview of the five overarching themes and ten subthemes are presented in Table 8.3.

Table 8.3 Overarching themes and subthemes

Overarching theme	Subtheme
1. Looking for support after the diagnosis and managing life with YOD	• Finding appropriate support can be difficult. • Low levels of understanding of and signposting to peer support services by healthcare professionals. • The impact of living with a YOD diagnosis.
2. Barriers that may stop people from engaging with online peer support	• Online peer support not meeting someone's needs, and/or abilities, and/or interests. • Unsure of what to expect.
3. Navigating challenges with technology and online peer support	• Dementia symptoms impacting someone's ability to use technology. • Coping with challenges of online interpersonal communication. • Need for technological support.
4. The role of the facilitator in making online peer support work well	• Organisational skills of the facilitator • Helping someone find the support that matches their needs and interests.
5. Wider opportunities for in-the-moment support	

8.3.1 Theme 1: Looking for support after the diagnosis and managing life with YOD

Most participants received little to no information about peer support when they got their diagnosis. Many shared that they spend a long time after their diagnosis with no support at all, while trying to find some on their own. One person shared their experience with her mum, who has dementia.

"My mum is in her 80s and she's had someone coming to her house to do testing of words and memories and stuff like that. But I've not had any of that." (Female, 54, living with partner and other family members)

Finding appropriate support can be difficult

For some who had non-Alzheimer's dementia it was difficult to find others with a similar diagnosis. Others struggled to find people of similar age, or with similar interests. People described their journey in finding the right support group for them, and some are still looking for it. One person was still working and shared she wished she could meet other people with YOD who were also still working.

"I'm testing the waters of different groups to see where I fit in. Unfortunately, I haven't found one where I fit in and I'm comfortable, but I'm sure that there might be one someday, so it's just keep on trying. Keep positive." (Female, 57, living with partner)

Low levels of understanding of and signposting by healthcare professionals

Many participants shared that they did not receive information from their physician regarding peer support, and that they had to search for this themselves. Some felt that their physician did not have an understanding of what peer support can do for people.

"I got some information from Dementia Mentors and Dementia Alliance International, and I had them send me some brochures [...] I brought them to my doctors, but they had no interest. And I'm like: 'this is basically saving my life'." (Female, 50, living alone)

The impact of living with a YOD diagnosis

For many, the diagnosis came as a shock and was followed by significant changes in their lives. Some heard how many years they would likely have left to live, and many had to give up their jobs. Participants also shared that they experienced a lack of understanding from family and friends.

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"The one thing about this shocking news in your midlife is: you don't know who to talk to. Some people might just think: 'Oh, she's got dementia, why doesn't she talk to her mum?'. Well, my mum, she's much more declined than I am, and she's an old lady and she got Alzheimer's. I think a lot of people don't realise that Alzheimer's is so different." (Female, 54, living with partner and other family members)

8.3.2 Theme 2: Barriers that may stop people from engaging with online peer support

One of the barriers that could make it either difficult or stop a person from using online peer support was difficulties with internet connection. One person who lived rurally shared that in-person support services can be far away, so that sometimes online is the only way to connect with others. However, the quality of the internet connection could be a problem.

"Online has the issue of connectivity, because we get three mega seconds and that's good for up here. People get frustrated with the speed. People start talking over you but you're still talking, due to the speed of the network." (Male, 63, living with partner)

Online peer support not meeting someone's needs, abilities, or interests
Participants in the earlier stages of dementia said they felt that services were often more tailored towards the needs of older adults. Some expressed they would like specific information, for example on continuing working. Others had tried online peer support, but it was not helpful.

"There was only two other people with dementia on the call and like five or six technical people, like doctors or nurses. We did that for probably about three months and then it just became a bit irrelevant because it was just going into a lot of technical detail about the whole thing, rather than just some sort of basic guidance as to what we should be doing." (Male, 60, living with partner and other family members)

Dementia symptoms could sometimes make it difficult to use technology, which could be a barrier for people to use online peer support. For example, one participant needed support from his wife when attending video meetings. Another person said videoconferencing platforms were difficult that they missed in-person, real human contact.

> "I'm not meeting these people. It's not like a real person. It's like talking to a screen all the time. And so I stopped doing the groups because it was affecting me mentally, I think I just needed people contact rather than a screen." (Female, 57, living with partner)

Feeling unsure what to expect

Participants were hesitant to join because of being unsure what to expect or feeling anxious about potentially seeing others in a more advanced stage of dementia. They said it was important to have similar interests and be of similar age.

> "I'm frightened of what I might see there [dementia cafes]. All the people that use those are further on than me, and I would perhaps feel like a fish out of water in a sense. That 'so what am I doing here?'. 'What can they do for me?' type of thing. Because I don't need something like that." (Female, 67, living with partner).

8.3.3   Theme 3: Navigating challenges with technology and online peer support

People experienced challenges with using technology and online peer support but found alternatives or ways to cope and did not let the challenges stop them. One person who had PPA (Primary Progressive Aphasia) and his wife explained that participating in group conversations, particularly online, was challenging due to difficulties with speech and recognising faces. They turned to YouTube videos as an alternative.

"They're [people with or caring for someone with PPA] all putting their own experiences of things that have gone wrong and ways they've solved it, and activities. Some things we've picked up on and some things we thought 'no, that's not for us'. Even if we can't attend the session in person, I've been able to follow a link later on if it's being recorded." (Male, 64, living with partner)

Another person said there are certain times where "her brain works better", which is when she tries to engage in online peer support or research activities.

"There are times where I'll forget how to turn my laptop on […]. Sometimes just nothing will make sense when I'm looking at the technology. And so, I just close the laptop and [think] 'You know what, tomorrow's gonna be better'." (Female, 50, living alone)

Online peer support can come with communication challenges, particularly for text-based communication on social media, for example Facebook and Twitter. One person shared his political opinion on Twitter:

"I literally got hundreds of horrible tweets, every day for about a week. I am really careful now what I tweet because everybody can see your tweets. I don't tweet much about my dementia, because again, you don't know what response you're going to get." (Male, 55, living with partner and other family members)

8.3.4 Theme 4: The role of the facilitator

A key aspect to make online peer support work well was having a good facilitator who gives everyone gets an opportunity to speak, allows for the conversation to flow rather than speaking too much themselves, and who ensures that the meeting is a positive experience for everyone.

"Sometimes I've been on a group and it's been one person talking an awful lot, and then I just think 'what's the point?' and I don't bother holding my card up. Or sometimes I may have forgotten what I wanted to say by the time it comes around for me to say something." (Female, 66, living with partner)

Part of the role of a facilitator included supporting people in accessing the online meeting, such as by sending timely reminders, being available to provide technological support when needed, and providing instructions on how to join the meeting.

> "I did a research project with [name university] and we spoke to the facilitator beforehand. And she was wonderful. She asked us all what would help us in a peer support group, and she made a note of everybody individually about our needs and about the things that needed to be addressed for us." (Female, 66, living with partner)

Participants who were not involved in online peer support said it would be helpful to know exactly what to expect from the group and whom it is for.

> "It would be helpful to know what to expect when you go in rather than 'oh well, we do our projects'. Ok well, so what does that mean? Do you have anybody with mild dementia? I don't even know if there is anything out there for people like me." (Female, 67, living with partner)

8.3.5   Theme 5: Wider opportunities for in-the-moment support

Most people appreciated exchanging social support, experiences, and information through online peer support. Participants felt a sense of mutual understanding and acceptance in their online peer support network, and some made new friendships.

> "Because we're all living independently, we have the same kinds of challenges. You don't have to explain how difficult things are because everybody knows. In the group you can just relax. Finding them was just one of the true highlights of my life." (Female, 50, living alone)

Potential advantages of online platforms included support available when someone needs it. One person shared about his peer support WhatsApp group:

> "Last week I had a bit of a moment. At 4am I wanted to go for a walk. I don't know where, I don't know why. I put that on my [group's name]

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WhatsApp group and it was great, because I got five or six replies 'don't worry about it, it's part of dementia'. It was nice to be able to put that on the WhatsApp group and somebody responds." (Male, 55, living with partner and other family members)

Furthermore, people can feel comfortable at home. One person shared that not everyone in her environment knew about the diagnosis yet. With the meeting being on Zoom, she could turn off her camera and just listen in, and in that way stay anonymous. Others shared they do not feel comfortable being in large groups, so that it was nice being able to join from their own home.

"We're all like in the same room together, but without all that stimulation that you have when you're in a room with nine other people. So Zoom, it's just such a blessing." (Female, 50, living alone)

8.4 Discussion

This study provides new insights into why people with YOD may be hesitant to engage in online peer support. The interview methodology allowed to generate a deeper understanding of the reasons to not engage with online peer support compared to the online survey methodology. The findings from the current study show that one of the main reasons why people were hesitant to engage in online peer support was that they were unsure of what to expect and felt anxious about potentially seeing others in a more advanced stage of dementia. Having a clear description of the group so that people can know exactly what to expect can help overcome this hesitancy. The study also adds to the findings of the focus group study (chapter 6) because it includes people with and without experience with online peer support. Furthermore, this study does not just show that a skilled facilitator is key in making online peer support work well for people with YOD, which was identified in the online survey (chapter 7), but it also provides insights into what specific skills make a facilitator successful. This is discussed further below.

8.4.1 Key findings

One of the barriers to online peer support for people with YOD was not knowing what to expect. More specifically, some said they feel anxious about potentially seeing others who are in a more advanced stage or who experience more severe symptoms. This is common in online peer support and has been identified in earlier research including a variety of health conditions (for example Multiple Sclerosis (Garabedian et al., 2019) and Polycystic Ovary Syndrome (Holbrey et al., 2013)). The current study also shows that there are some misconceptions among people with YOD about what (online) peer support entails, as some said that online peer support is only for older people or for those who are in a more advanced stages of dementia. We also identified this in our focus group study (chapter 6) (Gerritzen et al., 2023a).

To address these barriers and make online peer support more accessible, participants said that it would be helpful to have more information about the group beforehand. They explained that groups tend to have a generic description, for example that they do arts-related activities. However, to determine whether the group is suitable for them people may need more information. A good group description should include information on the age range of the people who attend, whether it includes people who are newly diagnosed or not, whether people who attend are working (in paid employment, or in roles of volunteering, research, policy, or advocacy), and what people can expect from a meeting (e.g. the kind of topics that are discussed and the way a meeting normally goes). This is in line with the one of the core principles that defines whether someone is a peer: sharing similarities (Keyes et al., 2014; Mead et al., 2001; Solomon, 2004). The importance of similarity in peer support has also been highlighted in previous research. Lieberman et al. (2005) found that people with Parkinson's disease who were in a homogenous support group (either based on time since diagnosis or age) felt more positive about their group compared to those in heterogenous groups. Similarly, in their research on online peer support for informal carers of people with dementia, Han et al. (2020) found that the similarities shared made that people felt understood and motivated to actively take part in the online group.

It is important to reduce barriers to online peer support, by developing clear descriptions of the group, and through training the facilitators on how to support people with YOD in accessing and engaging with online peer support. The current study confirms that through online peer support people can build friendships, share support, find out about new information, and find opportunities to be involved in new, meaningful activities in which they can use their skills and abilities. These findings support earlier research on the interactions between people with dementia on online platforms, which show that the benefits of peer support can also be present online (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2023; Talbot et al., 2020).

One of the key elements to make online peer support work well is having a skilled facilitator. Participants shared their views on what they think a good facilitator should do. For example, that the facilitator should get to know people beforehand, and get an understanding of their needs and wishes. In this way the person with dementia can find out if the group is something for them, and the facilitator can find out about any support the person with YOD may need. Furthermore, the facilitator should ensure everyone gets a chance to speak, and that it is a safe and confidential space. This is in line with previous research on the role of moderators in text-based online peer support communities. For example, research by Coulson et al. (2013) shows that the moderators feel that it is their responsibility to create a sense of community and ensure that it is a safe space for everyone, welcome new members, and to establish ground rules. Similarly, Huh et al. (2016) found that having a skilled moderator can help people feel safe in the online community, and that moderators can also help answering questions.

8.4.2   Limitations

This study only included people who were able to take part in a remote interview, either over a MS Teams videocall or a phone call. The reason for this was the wide geographical spread of participants, which made it not feasible to visit everyone in-person. However, even if meeting in-person would have possible in terms of distance and logistics, concerns around COVID-19 made that this was

not preferred. Even though formal lockdowns lifted and many people had their first vaccinations, as researchers working with people with dementia we were still being extra careful to not expose anyone to unnecessary risk. People who were unable to take part in a remote interview may have been discouraged to take part, and as a result the views and experiences of those who experienced significant barriers in using technology and engaging in online communication are not reflected in this study.

While we aimed for a diverse sample by giving people from less representative groups preference, the final sample was not as diverse as we had hoped (e.g. for ethnicity, employment status, or living situation). This reflects the population that we recruited from (people who took part in the online survey) which had a small proportion of non-white British participants, as well as a few people still in employment, or living alone. Potentially, we could have recruited a more diverse sample if we recruited from the general population rather than from the survey participants, but this would need a much larger study.

8.4.3 Methodological reflections

We aimed for 10-15 interviews and therefore invited a sample of 19 participants, assuming some would not be able to take part in an interview. However, just over one-third of the people who were invited to take part either never responded, or did not schedule a date for the interview, possibly because of the interviews taking place over the summer, during which people may not have had time to take part in research. Additionally, in the summer of 2022 many of the COVID-19 restrictions were lifted and people may have picked up their in-person activities again or gone on holiday, which could have influenced their interest in online peer support or taking part in online research. This resulted in fewer interviews (n=9) than we had hoped for.

8.4.4   Recommendations for future research

Future research could use the findings of this study to develop guidelines for facilitators on how to optimise online peer support for people with YOD and how to support them. Through qualitative methods such as surveys with open questions and interviews, we can explore whether peer support facilitators and moderators find the guidelines helpful and what improvements we can make. Scoping research can also explore whether implementation of the guidelines results in more online peer support groups being created, for example by doing a content analysis of dementia organisations or questionnaires among dementia organisations and NHS services for people with YOD.

8.5 Conclusion

Online peer support can be an important source of post-diagnostic support for people with YOD. However, to make it work well a trained and skilled facilitator, who gives everyone a chance to speak, ensures the group is a safe space for everyone, and gets to know the members well, is key. Additionally, some people were hesitant to get involved in online peer support because they were unsure of what to expect. This study recommends that facilitators of online peer support groups provide a detailed description of their group so that people can better assess whether the group would suit them. The insights obtained from this study will be used to develop a Best Practice Guidance on online peer support for people with YOD.

9. Development of a Best Practice Guidance on online peer support for people with YOD

9.1 Introduction

This chapter brings the evidence of the systematic literature reviews (chapters 3-5), focus groups (chapter 6), online survey (chapter 7) and interviews (chapter 8) together to develop a Best Practice Guidance on online peer support for people with YOD. Our online survey showed that there is a lack of awareness about online peer support, and a lack of knowledge on where to look for support. These findings suggest a need for clear and accessible information. The lack of awareness on (online) peer support also indicates a lack of advertisement and signposting to (online) peer support. This suggests that many people with YOD may miss out on the benefits of (online) peer support, which is in line with previous research on access to relevant information and age-appropriate support services for people with YOD (Grunberg et al., 2022; Mayrhofer et al., 2018; Mayrhofer et al., 2021b). A Best Practice Guidance on online peer support could raise awareness among people with YOD and provide tailored and evidence-based information on what online peer support entails. It could also provide opportunities for advertisement and signposting.

This chapter describes the development of the Best Practice Guidance on online peer support for people with YOD. The aims of the Best Practice Guidance are to provide:

- people with YOD with evidence-based, relevant, and accessible information about what online peer support is and how it could help them;
- providers of online peer support with guidelines on how to optimise the positive outcomes for people with YOD; and
- healthcare professionals with a concise and accessible tool for signposting.

9.2 Methods

An overview of how the Best Practice Guidance was developed is presented in Figure 9.1. The first draft of the Best Practice Guidance was informed by:

1) consultations with peer support facilitators and a systematic literature review on online peer support for people with a chronic and neurodegenerative condition;
2) a focus group study with existing peer support groups for people with YOD;
3) an expert consultation with the European Working Group for People with Dementia (EWGPWD);
4) an online survey for people with YOD;
5) individual interviews with people with YOD who took part in the online survey.

The development of the second draft and final version of the Best Practice Guidance followed a consultation process. The first draft was shared with people with YOD who took part in or were involved as Patient and Public Involvement (PPI) members in any of the studies, and professionals (PPI feedback). Based on the feedback, the second draft of the Best Practice Guidance was developed. For this draft, feedback from the research team was gathered, which then informed the final version of the Best Practice Guidance.

The Best Practice Guidance consists of two parts: one for people with YOD (part 1) and one for online peer support facilitators (part 2). The aim for the guidance for people with YOD was to give an overview of what online peer support entails, to address common questions and concerns, and to provide a list of resources where people can find more information. The aim for the guidance for facilitators was to provide clear guidelines on how to optimise online peer support for people with YOD.

Figure 9.1 Development of the Best Practice Guidance (BPG)

| PPI feedback | 8 people with YOD, 1 person with dementia (age unknown), 5 professionals Written feedback on BPGs draft 1. People received information on how the BPGs were developed and 8 guiding questions |

BPG draft 2

Feedback from research team

Final BPG

BPG draft 1

- Insights in challenges faced by facilitators
- Successful elements of online peer support
- Potential challenges and how to cope with them

- How people experience peer support in video meetings
- What makes it work well
- Potential barriers and challenges and how to cope with them

- Practicalities to consider when organising online peer support meetings
- The role of the facilitator
- Aspects that make a meeting work well

- Popular platforms for online peer support
- Likes and dislikes about different platforms
- Challenges and how to overcome them
- Reasons why people stopped using online peer support

- How to make online peer support more accessible (reducing barriers)
- What kind of information would be helpful

Consultations with peer support facilitators
- Individual consultations, 5 facilitators
- Meeting via MS Teams or Zoom

Systematic literature review
- Online peer support for people with a chronic and neurodegenerative condition
- Narrative synthesis

Focus groups
- 4 focus groups, 20 people with YOD
- Existing peer support groups that had their meetings online through a videoconferencing platform
- Focus group was online via group's usual platform (Zoom, n=3, GoToMeeting, n=1)

Consultation with EWGPWD
- 6 people with dementia and 6 informal carers
- Experts received information and questions two weeks beforehand
- Meeting via Zoom

Online survey
- 69 responses from people with YOD
- Paper version was available upon request
- Tailored questions for current users, past users, and non-users of online peer support

Individual interviews
- 9 interviews with people with YOD who took part in the survey
- Interviews via MS Teams

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9.2.1 Developing draft 1 of the Best Practice Guidance

To decide on a style and format examples from the Dementia Engagement and Empowerment Project (DEEP) were used. These were chosen as they are developed by and for people with dementia. Senior members of the research team have extensive experience in working with and developing study materials for people with dementia. This further informed the format and style, for example the font, font size, line spacing, use of coloured and bold text, and use of images.

Systematic literature research

A systematic database search was conducted on online peer support for people with a chronic, neurodegenerative condition. The systematic review generated insights into (1) successful elements of online peer support (aspects that make online peer support work well for the people engaging with it), and (2) potential risks and how to mitigate these (chapters 3-5) (Gerritzen et al., 2022a, 2022b).

Focus groups

Four focus groups (chapter 6) (Gerritzen et al., 2023a) were conducted with existing peer support groups for people with YOD. In total 20 people with YOD took part. All groups were meeting online through videoconferencing platforms at the time of the focus group. The focus groups generated insights into how people with YOD experience meeting with their peer support group through video meetings, what makes online peer support work well, the potential challenges and barriers, and how people cope with these.

Expert consultation with the EWGPWD

The Best Practice Guidance was discussed in a meeting with members of the EWGPWD to gather input on the content of the Best Practice Guidance. In total 6 people with dementia and 6 family carers provided feedback. People received a brief summary of the project and guiding questions two weeks before the

meeting, which they addressed during the meeting. They also shared their own views and experiences beyond the questions. The guiding questions were:

1) When organising online peer support meetings for people with Young Onset Dementia, what do you think we should consider when thinking about:
   a. The group size;
   b. How to support people participating in the online peer support group;
   c. The facilitation of the sessions;
   d. Any other issues.
2) In the Best Practice Guidance we want to include information about online peer support that is relevant for people with Young Onset Dementia. What kind of information would you like to have if you:
   a. Never attended a peer support meeting;
   b. Never attended an online meeting.

Online survey

An online survey (chapter 7) (Gerritzen et al., 2023b) was conducted collecting the views and experiences of people with YOD regarding online peer support. The survey had tailored questions for 3 groups: people who currently use online peer support, people who had used online peer support in the past but stopped using it, and people who never used online peer support before. All participants were people living with YOD. The online survey provided insights into which platforms people use for online peer support, what they like about it, what they dislike about it, or what challenges they face. For people who stopped using it, the survey provided insights into what made them stop engaging with online peer support. Finally, for people who had never used online peer support the survey provided insights into why this was, and how to overcome potential barriers.

Individual interviews

Individual interviews (chapter 8) were conducted with people who took part in the online survey. The interviews provided more insights into topics for which the survey did not provide a deeper understanding. For example, the survey did

not provide a deeper understanding of those barriers that stop people from using online peer support, but these were addressed in more detail in the individual interviews. The interviews were also used to ask people if they could recommend any topic or type of information that they would like to see back in the Best Practice Guidance. Those who are actively engage in online peer support were also asked if there is any advice that they would like to give to others who are hesitant to get involved in (online) peer support, or what kind of information would have been helpful for them before they got involved in online peer support.

9.2.2   Developing draft 2 and the final version

The first draft of the Best Practice Guidance was sent to 60 people with YOD who took part in one of the studies or were involved as PPI members and 14 professionals working with people with YOD. People were contacted via email, phone call or per post, depending on their preference. The professionals included the facilitators of the groups that took part in the focus groups and others who were identified through the network of the research team. Everyone received both versions of the Best Practice Guidance alongside an information letter (Appendix 13) which included how the Guidance was developed, guiding questions to help people give feedback, and contact information of the research team. Finally, after receiving the PPI feedback, both parts of the Best Practice Guidance were adjusted accordingly. These adjustments were discussed within the research team, after which the final version of the Best Practice Guidance was developed.

9.3 Results

The final versions of both parts of the Best Practice Guidance can be found in Appendix 14 and Appendix 15. An overview of the different sections, how they were developed, and what changes were made after the PPI feedback is presented in Table 9.1.

Table 9.1 Best Practice Guidance key points, resources, and changes

Best Practice Guidance part 1 for people with YOD				
Section	**Source**	**Key points draft 1**	**PPI feedback on draft 1**	**Changes for draft 2**
What different types of online peer support are there?	1. Online survey (chapter 7) (Gerritzen et al., 2023b) 2. Systematic reviews (chapters 3-5) (Gerritzen et al., 2022a, 2022b) for text-based platforms; focus groups (chapter 6) (Gerritzen et al., 2023a) for audio-visual platforms; online survey and interviews (chapter 8) for both 3. Systematic reviews	1. List of different audio-visual and text-based options used by people with YOD 2. Pros and cons for each type 3. Online safety message	From people with YOD: Bullying or conflict, impact on mental health	**PPI** In the 'Safety first!' box: *Be mindful of how online peer support affects your mental health. If you notice a negative impact, reach out to the group's facilitator or moderator. You can also take a break from it or try finding another group. You can also unfollow someone that has a negative impact.*
What can I expect from online peer support?	Focus groups; interviews	1. What can online peer support be like? 2. Common questions and concerns about online peer support	No feedback	No changes
How can online peer support help me?	1. Focus groups; online survey; interviews 2. See above (1). 3. Systematic review on MS (chapter 4) (Gerritzen et al., 2022a); interviews	1. Benefits of peer support 2. Benefits of online 3. 'Did you know? Even just listening or reading about others' experiences can be helpful'	No feedback	No changes

How can I overcome technological challenges?	Focus groups, interviews	Question and answer format of challenges people with YOD experienced, and how they coped with them.	No feedback	No changes
Where can I find more information?	1. Focus groups; online survey; interviews 2. Online survey; interviews; systematic review on MS 3. Focus groups; interviews	1. I want to find a peer support group 2. I want to learn from other people's experiences but not be part of a group 3. I want more information about YOD	No feedback	No changes
Best Practice Guidance part 2 for facilitators				
Section	**Source**	**Key points draft 1**	**PPI feedback on draft 1**	**Changes for draft 2**
Peer support in video meetings	1. Informal consultation with peer support facilitators; consultation with EWGPWD; focus groups 2. Consultation with EWGPWD; consultation with peer support facilitators; interviews 3. Consultation with EWGPWD; interviews 4. Consultation with EWGPWD	1. Important things before the meeting 2. Important things during the meeting 3. Important things after the meeting 4. Further practical things	From people with YOD: 1. How can I identify a group that matches my needs? 2. Bullying or conflict 3. Staying in contact outside the meetings	1. Under 'Further practical things': *Make sure to have a clear description of the group. This should include information on who the group is for, what generally happens during the meetings and what kind of topics are discussed, and when and on which platform the group meets*. A brief version of this point has been added to the key points in the same section. 2. Under 'What is important during the meeting': *Make sure the meeting is a safe and confidential space for everyone. Speak up against*

				inappropriate or harmful comments and bullying. Under 'What is important after the meeting': *If there were any inappropriate, disrespectful, or harmful comments or if you noticed bullying during the meeting, address this. Contact both the person who made and the person who received the comments.* 3. Under section 4 'Further practical things': *Ask the group how they feel about sharing contact details with each other so that they can stay in contact outside of the meetings if they want to. Make clear that this is optional and that no one should feel pressure to do so.*
Peer support in text-based platforms	1. Consultations with peer support facilitators; online survey 2. Systematic reviews; online survey; interviews 3. Systematic reviews; interviews	1. Different text-based platforms 2. Group description and accessibility 3. Role and expectations of the moderator	From professionals: Role of host/ moderator, welcoming people	Under 'Your role as a moderator / facilitator': *Welcome new members and explain how the group works.*

9.3.1 Developing draft 1 of the Best Practice Guidance

Part 1: Guidance for people with YOD

This guide is for people with YOD to inform them about what different types of online peer support exist, what they can expect from it, and where they can find more information. It also addresses some common questions and concerns. The guide consists of 5 sections:

1) What different types of online peer support are there?
2) What can I expect from online peer support?
3) How can online peer support help me?
4) How can I overcome technological challenges?
5) Where can I find more information?

What different types of online peer support are there?

This section was included because the findings of the online survey (chapter 7) (Gerritzen et al., 2023b) show that many people were not aware that online peer support existed. This section consists of an overview of different platforms that can be used for online peer support, and differentiates between text-based and audio-visual platforms. It lists examples for each as well as the pros and cons. Although discussion forums were not mentioned by people with YOD in any of the studies, a scoping search on online peer support for people with dementia identified Alzheimer Society Talking Point, a UK-based discussion forum for people with dementia and informal carers. Recent work by Talbot et al. (2023) shows that it can be a helpful peer support platform for people with dementia. Finally, this section contains a message stating 'Safety first!'. Safeguarding messages are common on text-based platforms, for example discussion forums or Facebook groups (Gerritzen et al., 2022a, 2022b).

What can I expect from online peer support?

This section was included because the interviews (chapter 8) showed that some people feel hesitant to join (online) peer support groups because they do not know what to expect, or they assume that it will not be helpful or suitable for them, either because of their age or because of being in the milder stages and

therefore not needing as much support. They shared that knowing what to expect and who the group was for (e.g. people of a certain age, people still working, people with a specific type of dementia) would help them feel comfortable in trying. Similarly, in the focus groups (chapter 6) (Gerritzen et al., 2023a) it also came forward that people had misconceptions about peer support and that they thought it was only for older people. However, the online survey (chapter 7) (Gerritzen et al., 2023b) and interviews (chapter 8) also showed that some people who were not currently engaging with online peer support were curious to see what it could bring them.

How can online peer support help me?

The online survey and individual interviews showed that people may not always be aware of what online peer support entails and what it could bring them. Some shared they feel they have enough support from family and friends and that therefore they do not need peer support. However, peer support is unique and could offer additional benefits. Peers may be able to provide different support or insights because they have a shared experience of living with YOD. Through peer support people can identify new and different support services, as people shared in the focus groups (Gerritzen et al., 2023a), online survey (Gerritzen et al., 2023b) and interviews. This section provides some of the benefits that can be associated with peer support in general, such as meeting new people in a similar situation and sharing experiences, but it also contains a section on specific advantages of online peer support.

How can I overcome technological challenges?

The online survey and interviews show that one of the reasons for people to not engage with online peer support is around the technological challenges, or dementia symptoms making it difficult to use technology. This section aims to address some of the challenges that people with YOD in the focus groups and the interviews experienced, and how they coped with these. This section is presented in a question and answer format, for example: 'My dementia makes it

difficult to use technology. What can I do?'. This is followed by a list with hints and tips from people with YOD who took part in one of the sub-studies.

Where can I find more information?

The online survey showed that many people are unsure where to go for more information, either regarding (online) peer support, or support in general. The focus groups and interviews also showed that for many people finding the information they needed and finding the right support was a long and difficult journey. This section is divided into three parts addressing different information needs:

- I want to find a peer support group
- I want to learn from other people's experiences but not be part of a group
- I want more information about Young Onset Dementia

The resource lists are informed by the online survey and individual interviews and include those organisations that people with YOD mentioned and found helpful. The 'Opening Doors' organisation did not come forward in either of the sub-studies but was identified through the professional network of the research team.

Part 2: Guidelines for facilitators

This guide is for online peer support facilitators to provide them with hints and tips, coming directly from people with YOD, about how to optimise online peer support and how to make it a positive experience for those involved. It was also informed by experiences and insights from peer support facilitators. This guide contains two main sections: one for peer support in video meetings, and one for peer support in text-based platforms.

Peer support in video meetings

This section is divided into four parts: (1) what is important before the meeting?, (2) what is important during the meeting?, (3) what is important after the meeting?, and (4) further practical things to keep in mind. Each part contains hints and tips that people with YOD shared in one of the sub-studies or that came forward in the consultation with the EWGPWD. It includes the kind of information that people with YOD belief facilitators should be aware of.

Peer support in text-based platforms

This section is specific for moderators of online peer support groups in text-based platforms. Because some people reading this document may not be familiar with online peer support in text-based platforms and what their role can be, this section starts with general information about what online peer support in text-based platforms is. We included the suggestion to consider offering a Q&A session with a healthcare professional. This was informed by the systematic review on Parkinson's disease (chapter 3). This review showed that people appreciate it if there are opportunities to ask their questions directly to a healthcare professional, for example regarding medication use. Although concerns specifically around medication use did not come forward during the focus groups (chapter 6), online survey (chapter 7) and interviews (chapter 8), people did mention that they have questions about how to live well with dementia after a diagnosis. While peers can give practical hints and tips, some people may like having an opportunity to ask specific questions to a professional as well. This is something that the facilitator or moderator could consider and discuss with the group.

9.3.2 Developing draft 2 and the final version of the Best Practice Guidance

Feedback from people with YOD

In total 8 people with YOD and one person with dementia whose age is unknown (contacted by one of the professionals from their own network) gave feedback. An overview and how the feedback was addressed is presented in Table 9.1.

Overall, people were positive about the Best Practice Guidance. Some shared tips on restructuring the content (e.g. putting a certain point at the top of a section). Most people shared that the guidance is clear and understandable, that the information included is relevant, and that the length is just right. One person said:

> "It is full of good info. It probably took me 12 months to find a lot of the info but with this guide it would have been a lot quicker and easier."

One person commented on the use of graphics which seemed slightly childish. In the final version the graphics have been adjusted. One person asked how they could find groups that match their needs. This highlights the importance of having a clear and detailed description of who the group is for, what is usually discussed during a meeting or what people do. This can help people in identifying groups that potentially match their needs, wishes, and expectations. This relates to findings from the interviews, chapter 8, in which two people said that they find it difficult to identify groups that they would like. They pointed out that there is often a very generic group description, which does not say much about who is attending, what the average age is, and whether the group addresses topics that are of interest to them.

Two people made a comment regarding bullying or conflict. One person said they had negative experiences with Twitter and bullying in an online peer support group. Regarding Twitter this person said that it is important to mention the potential negative impact it can have on mental health. Regarding bullying in the online peer support group, this person mentioned that the facilitator did reach out afterwards, but did not speak to the bully, making this person reluctant to engage in peer support groups for people with dementia again. The other person mentioned that particularly in text-based platforms comments and responses can be more immediate and less well thought out. People can also jump in the conversation without having to wait their turn, which can make the conversation 'messy'. Finally, one person shared that for their online peer support group they have a sheet where people can leave their contact details if they want to. This allows people to stay in touch outside of the meetings if they want to.

Feedback from professionals

In total 5 professionals gave feedback. An overview of the feedback and how this was addressed is presented in Table 9.1. They included two people from different dementia organisations, of whom one is also an academic, and three facilitators of (online) peer support groups for people with dementia and informal carers, of whom one is also a former carer of someone with YOD.

Overall, the professionals were positive about both parts of the Best Practice Guidance. While the majority felt that the guides were clear and that the information included was relevant, two mentioned that the Guidelines for facilitators may be too dense and confusing for people with dementia to read. Throughout the guidance we made the sentences shorter where needed and active instead of passive. One person was involved with an online discussion forum for people with dementia and family carers. They shared that volunteer hosts also welcome new members and help them get started on the platform, while moderators are more involved in the content (e.g. removing harmful messages) and making sure everyone follows the ground rules.

Feedback from the research team

The main point of feedback was instead of giving recommendations, remind the readers that these are things that people with YOD shared and identified as important. Further comments were related to the use of language. For example, adapting user-friendly language by saying 'we', avoiding vague terms such as 'it can be a bit more anonymous' and generally being more explicit (e.g. replace 'you can read about …' with 'this section summarises …'). Finally, it was recommended to include an acknowledgement section which explains how the Best Practice Guidance was developed and includes contact details of the research team.

9.4 Discussion

This is the first study exploring the direct experiences and views of people with YOD regarding online peer support, including both people with and without experience with online peer support, and the first study developing a Best Practice Guidance on online peer support for people with YOD. The Guidance was developed with direct input from people with YOD and the final version was developed with extensive feedback from people with YOD, professionals, and the research team. People with YOD and professionals said the Guidance was clear and understandable and contained relevant information.

9.4.1 Key findings

While the potential benefits of online peer support for people with dementia were identified in previous research (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2023; Talbot et al., 2020), there was no specific focus on people with YOD. There was also a gap in knowledge on the barriers and challenges experienced by those who do not engage in online peer support. Furthermore, there was limited research (Clare et al., 2008) into the direct experiences of people with YOD who engage with online peer support and how it impacts their life and self-management. Craig et al. (2016) proposed this as an area for future research. Through focus groups (Gerritzen et al., 2023a), an online survey (chapter 7) (Gerritzen et al., 2023b) and interviews (chapter 8) we directly explored the views and experiences of people YOD regarding online peer support. The online survey shows that the main reason why people with YOD did not engage in online peer support was because they were either unaware that this existed, or they did not know where to look for more information and support. Additionally, there were misconceptions about peer support among people with YOD, for example that it is only for older people and about 'singing songs about the war' (Gerritzen et al., 2023a). The Best Practice Guidance addresses these challenges. It includes information about different types of online peer support, what it entails, and how it can be helpful. This was all directly informed by people with YOD. By involving people with YOD throughout the different phases of the study, both as study participants and PPI

members, we ensured that the Best Practice Guidance includes information that is relevant and accessible for people with YOD.

During the COVID-19 pandemic many health and social care services for people with dementia had to move online. Research shows that this was often a difficult process, where everyone involved had to learn while doing, without specific guidance in place on how to navigate the transition from in-person to online (Giebel et al., 2021a). Consultations with peer support facilitators for this study confirmed that this was the case for peer support groups for people with YOD as well. Groups that took part in this study experienced that some of their members were unable to join the online meetings and as a result missed out on the support and benefits (Gerritzen et al., 2023a). Due to the nature of symptoms, taking part in online peer support may be particularly difficult for people with a rare form of dementia, which are more common among younger people (Harding et al., 2018; Suárez-González et al., 2020). The Best Practice Guidance includes unique hints and tips, directly from people with YOD, on how to cope with different symptoms that may make it more difficult to use technology or engage in online communication. While online peer support is not a one-size fits all, the Best Practice Guidance can offer new insights and suggestions for those who may not have considered this before.

Similarly, the Best Practice Guidance offers information and hints and tips for group facilitators or moderators on how to support people with YOD in accessing and engaging with online peer support, and how to optimise the potential benefits. The Best Practice Guidance can support organisations offering online peer support, or those that want to get started with this, with clear and accessible guidelines. It also offers a place for organisations to advertise their online peer support groups. Finally, it can be a way for healthcare professionals to signpost to online peer support. Research shows that people with YOD often experience either a lack of information at the time of diagnosis, or an information overload. When people do receive information, this is not always relevant at that time (Grunberg et al., 2022). People in this study described their peer support group as their lifeline, as something that gave them hope and a purpose again (Gerritzen et al., 2023a). Nevertheless, the focus groups, online survey, and interviews show that only a minority found out about peer support

through their doctor, while for most it was a long journey to find it themselves. The Best Practice Guidance addresses this gap by providing healthcare professionals with a concise and accessible document that they can share with people with YOD.

Finally, while the Best Practice Guidance will be aimed at people YOD, it can go beyond the dementia field. The World Health Organisation (WHO) emphasizes the importance of sharing best practices; techniques or methods that work in certain situations, contexts and groups which can support the development, adaptation, and implementation in similar contexts and populations (World Health Organization. Regional Office for Africa, 2017). For example, the current work demonstrates that best practices in related chronic and neurodegenerative conditions, such as Multiple Sclerosis, Parkinson's disease and Amyotrophic Lateral Sclerosis, can be transferred into the dementia field (Gerritzen et al., 2022a, 2022b) (chapters 3-5). Stoner et al. (2015) reviewed positive psychology outcome measures in chronic illness, traumatic brain injury, and older adults, to assess how these could be applicable to dementia. Di Lorito et al. (2017) developed a model of best practices in peer research with people with dementia, by also looking older adults (who have similar demographics as people with dementia), people using mental health services (who experience similar levels of stigma), and people with learning disabilities (as they are often also excluded from research). These examples show how knowledge from one population can be transferred to others.

9.4.2 Limitations

One of the main challenges throughout the different sub-studies and the development of the Best Practice Guidance was to include more people from underrepresented groups (e.g. people from ethnic minorities, people living alone, or people who are still in employment). While there were some people from underrepresented groups, this was only a small group. Therefore, their views and experiences may not be represented sufficiently in the Best Practice Guidance. Throughout the study the research team learned more about dementia organisations that specifically support underrepresented groups, for example the

Black Dementia Company and Open Doors (an organisation for people from the LGBTQ+ community who are over 50). For future research these organisations should be included as key stakeholders in the design of studies, as well as in advertisement of and recruitment for the study. Furthermore, through these organisations potentially a more diverse group of PPI members could be involved in dementia research.

Finally, we did not test the Best Practice Guidance in a real life setting. More specifically, we did not disseminate the Guidance in healthcare settings where people with YOD who were not involved in the study could receive them and give feedback on whether the Guidance was relevant and helpful for them. We also did not disseminate the Guidelines among facilitators and moderators, for example through dementia organisations, to see if they found the Guidelines helpful and whether there was any information missing.

9.4.3   Methodological reflections

Although the first draft of the Best Practice Guidance was shared with 60 people with YOD and 14 professionals, only a small group responded with feedback. The invitation for feedback was only send once. Potentially I could have gotten more responses if I had send a reminder email to those who had not responded yet. Furthermore, considering the limited time I had, I decided to use the style and formatting from DEEP documents as an example because these documents were developed with and for people with dementia. However, in future studies it could be helpful to involve people with (young onset) dementia more in style and visual appearance of the Guidance earlier on in the development process, to ensure it is accessible and appealing for a range of people.

9.4.4   Recommendations for future research

Future research is needed to investigate whether the Best Practice Guidance achieves its aims in practice. Through online survey methodology future research can evaluate whether dementia organisations and healthcare professionals are aware of the Best Practice Guidance, whether they find it

helpful, and whether it leads to more online peer support groups being developed. These findings could identify gaps in implementation and dissemination in healthcare practices, and signposting to online peer support.

Furthermore, future research may focus on expanding the Best Practice Guidance to in-person peer support as well, and to dementia at older age rather than focusing on YOD only. This could add more information to the current Best Practice Guidance and make it relevant for a wider group. Research methods could be similar to the ones in the current study, thus a combination of interviews or focus groups with a survey, to capture detailed views and experiences, while also targeting a bigger population. In future research participants could be older adults with dementia and should include more people from underrepresented groups. This will add to the current study and allow to further explore how to best tailor peer support to the diverse needs and preferences of people with dementia.

9.5 9.5 Conclusion

The Best practice Guidance on online peer support provides (1) people with YOD with evidence-based, relevant, and accessible information about what online peer support entails and how it could help them, (2) providers and facilitators with guidelines on how to optimise online peer support for people with YOD, and (3) healthcare professionals with a concise and accessible tool for signposting. The Guidance was fully informed by people with YOD through focus groups, an online survey, interviews, and PPI consultations, including both people with YOD and professionals. Future research is needed to implement and disseminate the Best Practice Guidance among dementia organisations and healthcare practices, and to monitor whether it is adopted in practice. This means whether providers of online peer support apply the Guidance to their existing groups and create new ones, and whether healthcare professionals share the Guidance with people with YOD.

10. Discussion

10.1 Key findings

This is the first in-depth study on online peer support for people with YOD to develop a Best Practice Guidance. Previous research explored how people with dementia engage in peer support on a variety of text-based online platforms, for example discussion forums (Clare et al., 2008; Rodriquez, 2013; Talbot et al., 2023) and social media (Cations et al., 2021; Talbot et al., 2020). The different studies conducted as part of this PhD add to the existing, and very limited, literature by showing the potential of online peer support for people with YOD specifically, on both text-based and audio-visual platforms, and by directly asking people with YOD about their views and experiences.

This study addressed online peer support for the wider population of people with YOD and not only focusses those who are involved in a specific group or platform. This provides new insights into the barriers and challenges that people with YOD face in accessing and engaging with online peer support, and how to overcome these. This is important knowledge, as more and more of our daily communication takes place online, including delivery of health and social care services. This trend accelerated during the COVID-19 pandemic. While some services returned to in-person delivery, many people and organisations learned to appreciate the convenience of online communication and hybrid approaches between in-person and online have become more common. While online communication comes with many benefits, such as not having to travel and having access to people and services that are outside one's local area, it also comes with its challenges. Particularly for people with dementia, the use of technology and online communication may not always come natural. Additionally, the disparity of specialised YOD services, including peer support, suggests that online may sometimes be the only way for people with YOD to connect with their peers.

10.1.1 The experiences of people with YOD with online peer support

A YOD diagnosis has a significant impact on a person's life. People with YOD experience many changes and losses, such as losing one's job, having to give up driving, and changes in their role within the family, their social circle, and the wider community. This has an impact on a person's sense of self and identity (Busted et al., 2020; Greenwood et al., 2016; Harris et al., 2009; Oyebode, 2022; Spreadbury et al., 2017). Similar experiences were also identified in the current research. During the focus groups people shared how the many loses they experienced as a result of the diagnosis, such as losing one's job and losing contact with friends, had a negative impact on their self-confidence and mental health (chapter 6) (Gerritzen et al., 2023a).

Peer support has the potential to address these challenges and help people cope with the impact of YOD and in adapting to a life with dementia. This relates to the Social Health Framework, which focusses on a person's ability to adapt and self-manage (Huber et al., 2011). Peer support can create an environment in which people can share similar experiences and mutual understanding and support. This can create a sense of belonging and help people feel less alone in their experiences (Söderlund et al., 2022). Furthermore, previous research suggests that peer support can help people have a more positive post-diagnostic experience and in identifying support services (Rabanal et al., 2018; Stamou et al., 2021a). The current research shows that these benefits of peer support are not limited to in-person settings but can also be present online. People shared that they build meaningful connections and friendships through online peer support, and that through the online platforms they share hobbies, experiences, and hints and tips. Specifically, in the online survey almost half of the people said that through online peer support they can learn more about dementia, what support is available to them, and opportunities to be involved in research.

Furthermore, peer support can create opportunities for people to stay socially connected (Pierse et al., 2022). This links with the Convoy Model of Social Relations, which explains how a YOD diagnosis can disrupt a person's social network and their roles within their social network, which can have a negative impact on one's health, quality of life, and wellbeing (Kahn et al., 1980). The current research demonstrates that people can also create new social networks

and build reciprocal connections through online platforms. This can have a positive impact on the structure of someone's social network, as it includes new people with similar and relevant experiences to learn from, and on the function of someone's social network, as it enables people to also provide support to others (Kahn et al., 1980). This characteristic of reciprocity is particularly important, as due to the nature of symptoms, people with YOD often become increasingly dependent on others. This can disrupt the balance of providing and receiving support in existing relationships. Being able to provide support to others through peer support can increase feelings of empowerment (Barak et al., 2008; Keyes et al., 2014; Kingod et al., 2016). In the current research people shared that hearing about how others are managing their life with dementia gives them hope that they can still live well and do the things they like.

10.1.2 Unique benefits of online platforms

Besides the finding that the known benefits of peer support can also be present in online platforms, the current research also shows that online peer support is more than just a replacement of in-person peer. Online platforms have a number of unique benefits, which can make peer support more accessible to some, and for others it can complement other in-person support services.

First, online platforms can tailor towards individual needs, as it offers a variety of options and allow people to choose one that works best for them. In the interviews people spoke about specific dementia symptoms that they have and how it impacts their daily life and ability to use technology. For example, for those who experience sensory overload or anxiety in public places or when in groups, in-person peer support groups may not be suitable. Through online platforms they can still get the benefits of peer support, but in the comfort of their own home and without the stimulation or sensory overload they may experience in in-person settings.

Second, peer support through online platforms saves people time and money on traveling (Barclay et al., 2022). Logistical challenges, such as physical distance, and time and money spend on traveling, can be barriers for people to engage in in-person peer support (Matthias et al., 2016). This particularly important to

consider for people with YOD. Many people with YOD have to give up their paid job and finding out about and applying for state benefits or financial support is often difficult. Spouses of people with YOD often find themselves having to reduce their work hours to support their partner with YOD at home, also resulting in a loss of income. Additionally, families affected by YOD are more likely to include children who are still financially dependent on their parents. This combination of factors can put families affected by YOD under significant financial pressure (Bayly et al., 2021; Kilty et al., 2022). The barrier of having to travel was also identified by participants in the current research. For example, in the interviews (chapter 8) someone mentioned it was not possible for them to always travel London for meetings of the Rare Dementia Support. Additionally, for some people with dementia traveling may be stressful and pose a barrier to attend in-person meetings, as some people shared in the focus groups (chapter 6) (Gerritzen et al., 2023a). Online platforms can also make it easier for people to get involved in a variety of activities. For example, in the focus groups and interviews people shared how they were involved in UK-wide research and policymaking projects, which would not have been possible if it was not online. For some, finding these projects brought back purpose again. It provided opportunities to use their skills and abilities and have a meaningful contribution. This relates to the Social Health Framework, particularly the dimension on 'the ability to fulfil potential and obligations' and 'the ability to participate in social activities and work' (Huber et al., 2011).

Third, online platforms can offer anonymity. For example, the anonymous nature of discussion forums can help people feel more comfortable in expressing their feelings (Hargreaves et al., 2018) and speaking openly about their experiences with dementia, which was sometimes difficult in their in-person social networks (Talbot et al., 2023). Furthermore, online people may feel more comfortable speaking about topics that are considered personal or taboo. Lieberman et al. (2006) found that online people spoke about sexuality and Parkinson medication affecting sexual desire. Participants mentioned that they would not have felt comfortable talking about that with others in-person (Lieberman et al., 2006).

Fourth, online platforms may be more accessible to those who feel anxious about joining a peer support group. In the focus groups people shared that joining a peer support group for the first time can be daunting. People may not know what to expect, feel anxious about potentially seeing others in a more advanced stage, or may think that it will only be for older people. The online survey showed that some people also do not engage in online peer support because they do not feel comfortable talking to people online that they do not know, they do not like talking about their dementia, or they are concerned about their privacy. However, the systematic review on online peer support for people with MS (chapter 4) (Gerritzen et al., 2022a) and the interviews (chapter 8) show that even reading about or listening to audio recordings from people with similar experiences can already make people feel less alone and provide them with information, hints, and tips (Steadman et al., 2014). This could be helpful for those who are unsure whether they want to get involved in (online) peer support or who feel uncomfortable talking to strangers online.

Fifth, a specific advantage of text-based platforms is that support can be readily available in the moment when someone needs it (Gerritzen et al., 2022a; Stewart Loane et al., 2014). This has also been identified in the current research, as is illustrated by a quote of someone who posted something in his peer support WhatsApp group (chapter 8, page 136), who then instantly received a response. One of the groups in the focus group study shared that through their WhatsApp group people can respond and interact if they want to, but there is no pressure to always respond either (chapter 6) (Gerritzen et al., 2023a). Furthermore, text-based platforms such as discussion forums or social media groups allow for people to read the posts without the pressure to interact with them (Gatos et al., 2021; Steadman et al., 2014). Other opportunities include reading blogs or listening to audio recordings, such as Dementia Diaries (chapter 8).

Finally, one of the limitations of text-based platforms can be that it feels too unpersonal or anonymous for people (Caron et al., 2015; Gerritzen et al., 2022b). Through audio-visual platforms such as Zoom people can still see the others and engage in real-time verbal conversation, with the opportunity to turn off their cameras or mute themselves at any point. People with YOD who took part in the focus groups shared how comfortable and convenient the online meetings were

for them because they could take a break, grab a cup of coffee or step out of the room for a moment, all while being in the comfort of their own home.

10.1.3 Barriers and challenges to online peer support

Online peer support in the context of the COVID-19 pandemic

Research on the experiences of people with dementia and their supporters during the COVID-19 pandemic and lockdowns shows that many experienced a worsening of their symptoms. People attribute this to the lack of social interactions and disruption of their routines, which kept them active and engaged (Giebel et al., 2021a; Harding et al., 2023). This can potentially make it more difficult to use technology and continue to engage in certain daily activities (Bannon et al., 2022; Harding et al., 2023). In the focus groups (chapter 6) (Gerritzen et al., 2023a) people shared that they missed meeting others in-person, and that online peer support simply was not the same. This is in line with other studies exploring the experiences of people with (young onset) dementia and their families during the COVID-19 pandemic (Bannon et al., 2022). Similarly, in the online survey (chapter 7) (Gerritzen et al., 2023b) some people shared that they would rather do activities, for example hiking or going out for a meal, than just talking online. This may have put people off to engage in online peer support. This is in line with findings of Barclay et al. (2022) on the experiences of people with spinal cord injury and online peer support during the COVID-19 pandemic. People shared that while online peer support was a good alternative during the COVID-19 pandemic, they were looking forward to going back to in-person meetings (Barclay et al., 2022). These findings suggest that online peer support is something very personal and that not every person with YOD has the same needs and wishes. Online peer support could be a 'tool' that is added to the 'support toolbox' and that can complement other forms of support, such as in-person peer support.

Dementia symptoms making it difficult to use technology

In the online survey (chapter 7) (Gerritzen et al., 2023b) and the interviews (chapter 8) people also expressed that they sometimes experience difficulties when using technology and engaging in online communication. For example, people with vision impairment shared that they find it difficult to see who is talking in a Zoom meeting or to recognise faces. Harding et al. (2018) found that for people with Posterior Cortical Atrophy (PCA) interacting with their environment and daily activities become increasingly challenging because of the vision impairments that they experience. One person with PCA who also took part in an interview (chapter 8) shared that he experiences sensory overload. The way he copes is by focussing on one sense at the time. For example, when he is in a video call, he closes his eyes so that he can concentrate on what the others are saying. When he is reading, he covers his ears so that he does not get distracted by background noises. These are the kind of hints and tips that get shared in peer support, and that people may find out about through trial and error, and because of their unique knowledge and expertise of what it is like to live with that specific type of dementia and the associated challenges.

Furthermore, several people who took part in the online survey (chapter 7) (Gerritzen et al., 2023b) expressed they had speech and language difficulties because of their PPA, which made it difficult to use technology and engage in online spoken conversations, for example via Zoom. One person with PPA took part in an interview together with his wife (chapter 8). They mentioned that because if his symptoms it is very difficult for him to follow and engage in conversations, particularly online, and that it is also becoming difficult to recognise faces. Research shows that people with PPA are interested in using technologies, for example as a support tool for speech and language therapy, but that they need support (Loizidou et al., 2022).

Challenges of online communication

In the online survey (chapter 7) (Gerritzen et al., 2023b) and interviews (chapter 8) some people shared that they find it difficult to understand others online or follow the conversation. A participant also mentioned that it can be difficult to

build a bond with people online who you have never met in-person before. A lack of or limited non-verbal communication in online peer support is a well-known challenge, for example it be challenging to interpret the meaning of a message without seeing someone's facial expressions or body language (Breuer et al., 2015; Caron et al., 2015). Due to the nature of symptoms it can be more challenging for people with dementia to pick up social cues, making the lack of or limited non-verbal communication in online platforms potentially more challenging.

Particularly in the interviews (chapter 8) people emphasized how important it is to have a facilitator with good communication and listening skills. This includes taking the time to get to know a person before they join the group to learn about their needs and expectations, to see whether the group would be something for them and to get an idea of how to support the person with YOD. During the meeting, this means listening to what the group wants to do or talk about and adjust the agenda, if there is one, and meeting structure accordingly. Both during the interviews and in the focus groups, people shared how important it is that the facilitator has good organisational skills, including sending timely reminders, and being available for support of someone has difficulties getting in the meeting, for example. Furthermore, they should also make sure it is a safe place for everyone, and address bullying or negative comments during and after the meeting. If someone appears distressed during the meeting, the facilitator should follow-up with them. For text-based platforms, this includes monitoring and deleting any harmful posts and if possible reaching out to the person writing the post.

10.2   Limitations

To make it as easy as possible for people to take part in the online survey, I decided to have an open survey, meaning that people could take part simply by clicking a link. I asked if dementia organisations could advertise the survey through their social media channels (besides their newsletters and websites), such as Twitter, Facebook and LinkedIn. I also advertised the survey through my own, professional, social media channels (Twitter and LinkedIn). This way

of recruitment introduces some bias, as anyone could click the link and take part in the survey. To balance this risk the survey was also advertised through more targeted sources, such as NHS Trusts, dementia organisations, and Join Dementia Research.

In the study information for the survey it was explained that the survey was aimed at people living with a YOD diagnosis, and that if someone was filling in the survey on behalf of a person with YOD, they should answer all the questions from the perspective of the person with YOD. In the survey I did not ask whether the person with YOD was filling it in themselves, if they received support from someone else, or if they had another person filling it in on their behalf. Therefore, I do not know in how many cases the survey was filled in my someone else, and whether this person answered the questions entirely on behalf of the person with YOD. For future studies I would consider including a question on this, as has been done by for example Stamou et al. (2021b).

Finally, in the demographic questions for the survey I did not ask participants about their dementia sub-type, because I did not think that information was necessary. However, I did ask that for the focus groups, and for consistency it would have been better if I asked the same questions for the survey as well. Additionally, it could have been interesting in the analysis to see if there were differences between people with different dementia sub-types.

10.3 Methodological reflections

10.3.1 Changes in project aims and methods

Early 2020 I changed the aims of my project towards exploring how people with YOD use existing platforms for online peer support and what the barriers are, and developing a Best Practice Guidance. This happened after a meeting I had with Professor Neil Coulson (University of Nottingham), who is an expert on online peer support. He strongly advised against developing a new platform, as it raises numerous ethical concerns. First, online text-based platforms need a very large membership to be active, as the majority of members is not active (van Mierlo, 2014). For a PhD this would be very challenging and unlikely to be achieved. In case recruitment was insufficient people would be at risk of not

actually receiving peer support, as there might have been a lack of interaction on the platform (Smedley et al., 2015). Second, a clear plan on the sustainability of the platform had to be developed. This means, deciding who would take ownership of the platform once the PhD finished. When not doing this, the risk would be that people establish valuable peer support connections over the course of the project, which they would then lose at the end. Third, research shows that people with dementia already use existing platforms for peer support, such as social media, which is already integrated in their lives (Clare et al., 2008; Craig et al., 2016; Rodriquez, 2013; Talbot et al., 2023; Talbot et al., 2020). This raised the question whether people would be willing to put time and effort into learning how to use a new platform and to integrate this into their lives. Finally, people with YOD are not a homogenous group. Rare forms of dementia are more common among people with YOD compared to late onset dementia, and as a result people with YOD are more likely to have a wide variety of symptoms, which can each impact one's ability to use technology and engage in online communication differently. Some may prefer audio-visual communication while others may give preference to text-based communication. Developing a platform covering both forms would not be possible given the time and resources available for the PhD, and deciding on one form of communication would make the platform less accessible to some. All in all, these factors combined made us decide to not develop an online platform, but rather focus on already existing platforms.

The journal publication of chapter 2 (Gerritzen et al., 2022c) includes three sub-studies that we did not conduct in the end, as it was not feasible to fit these within the scope of my doctoral time frame. Chapter 2 only covers the methods of the sub-studies that we conducted. The sub-studies we did not conduct were the grey literature review on online peer support for people with dementia, the second survey to compare users and non-users of online peer support through a number of outcome measures, and the interviews with peer support facilitators. Instead of doing a second survey, we compared the answers of the users and non-users in the online survey that we did conduct, and instead of doing formal interviews with facilitators we consulted them informally throughout the project. The aim of the grey literature review was to get an understanding of what information is

available to people with YOD about online peer support. The focus groups, online survey, and interviews provided insights into this as well. Finally, for the systematic reviews it was initially the plan to conduct one systematic review covering Parkinson's disease, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, and Huntington's disease. Considering the large number of included studies and the qualitative nature of the included studies, it was not feasible to analyse it all as one review. We therefore decided to conduct separate reviews per condition. As only two studies were on Huntington's disease, we decided to not review these.

10.3.2 Patient and Public Involvement (PPI)

I pitched my project on online peer support for the first at a consensus meeting for another YOD study in October 2019. At this time the project aims were to develop a new online peer support platform, either as a website or mobile application, and to do a feasibility study. I gathered contact details from people who were interested, however, at that time I did not gather in-depth input that shaped my project. In 2019 I also presented the same project at a PPI meeting from the Centre for Dementia at the Institute of Mental Health. Here I gathered input on using technology and online communication.

Due to the COVID-19 pandemic and national lockdowns I did not manage to pitch my new project to PPI groups. One reason was that the Centre for Dementia PPI group stopped their meetings during the pandemic. At this early stage of my project I did not develop my professional network far enough yet to know of other groups for people with YOD that would be happy to provide input on my project. At the same time, many groups were struggling to adapt to the 'new reality' and not all managed to move their activities online. However, I did have a meeting with one person with YOD who was recommended to me by Orii McDermott, and who was very active on social media and in research. With him I discussed online peer support in general and my idea to develop a Best Practice Guidance, which really helped me shape my research. While it would have been better to have had consultations with multiple people, I believe I did the best I could considering the challenges of the COVID-19 pandemic.

Another reason why I did not manage to develop a richer PPI base at the early stages of my project is because I felt time pressure. Because I decided to change the aims of my project, I had to rewrite my study protocol and other study documents, including the topic guides for the focus groups and interviews, that I already started preparing for ethical approval. This pushed back my timeline. Simultaneously, I was adapting to the 'new reality' of COVID-19 which impacted my productivity. This combination of factors made me feel that I did not have enough time to establish a more solid and diverse PPI team for the project before applying for ethical approval. In future projects I would aim to include more PPI members with different backgrounds and levels of research experience, and plan a sufficient amount of time for this at the start of the project before applying for ethical approval.

10.3.3 Recruitment

The aim was to recruit participants with various backgrounds and levels of experience with online peer support. Despite recruiting from a variety of recruitment sources, the final sample of participants taking part in this research lacks representation from ethnic backgrounds other than white. Additionally, as the vast majority of the participants was of a white British background, people whose first language is not English were underrepresented in this study. People from ethnic backgrounds other than white British may have different needs and wishes in terms of cultural appropriateness of health and social care services and language. Therefore, the Best Practice Guidance may not accurately address all these various needs and wishes. Furthermore, to take part in this study people needed to be able to understand the study information and provide written or verbal consent to take part. As a result, the study most likely mainly targeted people in the earlier stages of dementia. Thus, the Best Practice Guidance may not accurately represent the needs and wishes of people with YOD who are in a more advanced stage or who were unable to provide informed consent to take part in the study.

Central Portfolio Management System and NHS recruitment

By receiving Health Research Authority (HRA) ethical approval, the study could be advertised on the Central Portfolio Management System (CPMS), which allowed me to recruit through NHS Trusts. The main challenge for me, as a first-time user of the CPMS, was getting familiar with the system and estimating the amount of time it would take to get the study listed on the CPMS. In addition, this was all happening during lockdown, while everyone was working from home. Before the pandemic I would probably have been in the same building as the people who could help me with this, which would have made the process quicker and easier. However, while being remote it took me longer to find out who to ask for help. By the time I got everything sorted with the CPMS I already finished the focus group study, and as a result I may have missed groups offered by the NHS. Nevertheless, even without using the CPMS I still managed to recruit four online peer support groups including twenty participants with YOD by reaching out to dementia organisations and advertising my study through their networks. I also managed to find groups that covered a wide geographical range in the UK and were a mix between in-person and online-only groups.

Following the challenges described above I also opened the online survey before the advertisement on the CPMS was properly set up. Therefore, the survey recruitment through NHS sites was delayed. As a result, some of the NHS Trust only had a short recruitment window, which may have resulted in lower recruitment numbers. Additionally, only at this stage I was made aware that through the CPMS, the study could also be advertised to GP practices. However, it was too late to do this for the online survey and as a result I may have missed potential participants.

As I had never worked with NHS Trusts before it was time consuming to learn who to communicate with within the Trusts and which documents they exactly needed. At times this slowed down the communication, resulting in a Trust either not being able to commit to the study anymore, or to only do so at a later point. Potentially due to me having to learn how to navigate the CPMS and the communication with the NHS Trusts, recruitment numbers for the online survey through the NHS Trusts were relatively low compared to other recruitment sources (e.g. Join Dementia Research and dementia organisations). On the other

hand, at the time the NHS prioritised COVID-related studies which means that this study may not have gotten as much response through the CPMS.

Join Dementia Research

It was also the first time I worked with Join Dementia Research. Initially I selected the wrong route to advertise my study on the platform. Instead of going through the fast process for studies that have HRA approval, I went through the route for all other studies. As a result, it took me longer to get the study advertised on Join Dementia Research, which only happened after the survey already opened for recruitment. Recruitment through Join Dementia Research was relatively successful compared to other recruitment sources in this study. However, recruitment through Join Dementia Research was still lower than hoped for, based on previous experience in the research team where approximately 100 people took part in a survey through Join Dementia Research. A potential explanation could be that this study took place before the COVID-19 pandemic and was aimed at both people with YOD and family members. Other survey studies including only people with YOD have comparable sample sizes (Draper et al., 2016; Mayrhofer et al., 2021a). To support recruitment, we extended the survey period, and asked Join Dementia Research, dementia organisations, and NHS Trusts to send out a reminder. One reason why still the recruitment number was a bit lower than we had hoped for could be survey fatigue. Different NHS Trusts that helped with recruitment shared that they had difficulties in finding participants for a number of studies, especially online surveys. Another reason could be the topic of the survey. More than one year into the pandemic and after numerous lockdowns, many people missed in-person interaction and wanted nothing more than for things to go back to normal and being able to meet their friends, families, and peers in person. This may have reduced people's interest in the topic of online peer support.

10.4   Recommendations for future research

10.4.1 Professionals' knowledge on and attitudes towards peer support

The current research shows that only a minority of people with YOD find out about peer support through their doctor (Gerritzen et al., 2023a; Gerritzen et al., 2023b) and that only a minority would go to their doctor if they wanted more information about (online) peer support (Gerritzen et al., 2023b). However, some people from the focus groups were referred to their peer support group by their doctor, which they experienced as helpful (Gerritzen et al., 2023a). Similarly, in the interviews (chapter 8) people suggested that healthcare professionals can play an important role in signposting to (online) peer support because it can be a difficult and time consuming process having to find it all out on their own. Some who spoke to their doctor about peer support noticed a lack of understanding of the importance of peer support. These insights are related to healthcare professionals' attitudes.

On the other hand, healthcare professionals often see many different patients, and with YOD being relatively rare, many may not have many, or any, patients with YOD (Hendriks et al., 2022; Pijnenburg et al., 2022). This indicates that healthcare professionals may not always be aware of what peer support services exist for people with YOD, relating to healthcare professionals' knowledge. Future research could explore healthcare professionals' attitudes towards and knowledge on (online) peer support. This could address the following research questions: (1) what are healthcare professionals' attitudes towards peer support for people with YOD?, (2) would they recommend peer support to people with YOD?, and (3) do they know what peer support is available and where? I would propose a Delphi study using an online survey, and recruit people from GP practices and Memory Clinics. These findings could provide insights into whether it is needed to raise awareness about (online) peer support among healthcare professionals, whether there is a need for more information and training on the importance of peer support for people with YOD, and whether they would share the Best Practice Guidance with people with YOD.

10.4.2 Availability of (online) peer support

Despite many services moving online during the COVID-19 pandemic (Giebel et al., 2021a), including peer support groups (Gerritzen et al., 2023a), the online survey showed that many people were unaware that online peer support exists (Gerritzen et al., 2023b). A reason could be that many peer support groups were initially in-person groups but these moved to online platforms because of the pandemic, and therefore the groups were not widely advertised as an online group open to everyone. Research shows that people with YOD often have to look for (peer) support on their own and that it can take a very long time before they find the right support for them (Grunberg et al., 2022). In the current research people shared similar experiences (chapters 6 and 8) (Gerritzen et al., 2023a).

Online platforms have unique benefits and can make peer support accessible to a wide range of people, including those who do not have access to in-person peer support. The considerable amount of time and effort it takes for people to find (online) peer support and the findings of the survey showing that many people are unaware that online peer support exists, suggest that there is a need for a clear overview of exactly what peer support, online and in-person, is available. Future research could use grey literature review and content analysis methods to create an overview of (1) how many peer support groups exist for people with dementia (online and in-person), (2) how many groups have a specific target audience. For example groups only for people with a diagnosis or carers, or mixed groups, or groups specifically for YOD, specific diagnoses, or interests. And (3) how many of the peer support groups that went online have returned to in-person only or have adopted online or hybrid approaches. Review approaches can include a systematic search on Google (for example a similar approach as was used by Godin et al. (2015)) and a content analysis of websites of dementia organisations and NHS services, where we can also contact the organisations directly if we need more information (see for example as was done by Monnet et al. (2022)). This study could provide the needed overview of what peer support groups are available and which ones are online or YOD specific. Such an overview can be helpful for people with dementia and their families. It can also be helpful for dementia organisations and services to advertise their groups. Such

a list could be included and regularly updated in the Best Practice Guidance. This can then be shared with people with dementia, for example in healthcare practices or through dementia organisations. Finally, future research could explore ways to conduct an economic evaluation of (online) peer support groups, to support financing and implementation in the future. The Rare Dementia Support Impact Study is currently working on a Social Return on Investment study for support groups for people with rare forms of dementia and their carers (Brotherhood et al., 2020).

10.5   Recommendations for practice

10.5.1 Implementation and dissemination

The aim is to make the Best Practice Guidance freely accessible for people with YOD, their families, and professionals. Through the focus groups, online survey, and interviews we identified which are the key organisations that people with YOD consult for more information, including Alzheimer Society, Dementia UK, DEEP, the Young Dementia Network, and Dementia Alliance International. Individuals affiliated with these organisations have been involved with the project through informal consultations, and the research team has been building connections with these organisations over the course of the project. The Best Practice Guidance will be adapted into different formats. A link to download the document can be shared on websites, social media channels and in newsletters by the before mentioned organisations. The online version of the Best Practice Guidance will be downloadable from the Centre for Dementia website of the Institute of Mental Health. A paper-based flyer can be distributed as part of physical information packages, but can also be distributed in Memory Clinics, healthcare practices, dementia cafes, and community centres. Finally, the Best Practice Guidance will be disseminated internationally through the DISTINCT / INDUCT Best Practice Guidance on Human Interaction with Technology in Dementia (Dröes et al., 2022), Alzheimer Europe, and Alzheimer's Disease International. Besides making the Guidance available to inform people with YOD as well as facilitators, these organisations can also use the Guidance as a tool to support training for facilitators.

10.5.2 Supporting people with technology and online communication

Rarer types of dementia, such as PPA and PCA, are relatively more common among younger people. Therefore, people with YOD are more likely to experience a range of symptoms that can make it more challenging to use technology and engage in online communication (Harding et al., 2023; Suárez-González et al., 2020). The importance of being able to use technology and engage in online communication goes far beyond peer support. Especially since the COVID-19 pandemic, the use of technology and online platforms for delivery of health and social care services and communication have increased (Giebel et al., 2021a). This highlights that the importance of being able to use technology and engage in online communication, independently or with support, goes far beyond peer support. It shows that for people with YOD these skills are essential for self-management and access to care and support. Therefore, supporting people with YOD in using technology and engaging in online communication should be a key aspect of post-diagnostic support. Considering the wide range of symptoms and levels of tech savviness in the YOD population, this requires a tailored approach. This helps to identify the specific challenges that a person experiences and what they need to keep using technology, independently or with support, for as long as possible. I would recommend that support in using technology and engaging in online communication becomes a key aspect in post-diagnostic care and support. It should focus on identifying the needs of the person with dementia, and how their families can best support them.

There are particular challenges for implementing online peer support across the NHS and social care, partly because often the groups are set up informally by people with YOD or their carers. Therefore, there is not a specific mechanism to implement online peer support groups across current NHS services. However, practical suggestions for being able to increase the provision of peer support groups include specific funding targeted at non-governmental organisations, such as Alzheimer's Society or Dementia UK which could be used to support the setting up of (online) peer support groups. Additionally, policy initiatives could provide drivers for health and social care to find ways to promote the setting up of more peer support groups, locally and online. This could include national dementia strategies or work of international organisations such as

Alzheimer Europe or Alzheimer's Disease International. Finally, the establishment of better research may make it possible to get guidance on peer support groups and their usage into the next version of the National Institute for Health and Care Excellence (NICE) guidance on dementia care, which would be influential in both the UK and many other countries which use the NICE guidance in their policies and services.

10.5.3 Improving access to technology

However, just supporting people with YOD in using technology and engaging in online communication may not be enough. Some platforms such as Zoom require regular updates and for that people may need modern and up-to-date devices. People who do not have the financial resources to purchase such devices are at risk of falling behind and facing even more barriers in accessing health and social care, including peer support. This may be particularly important to consider in the case of YOD, as families affected by YOD are at risk of being under significant financial pressure (Bayly et al., 2021; Kilty et al., 2022). There is a joint responsibility of dementia organisations, health and social care providers, and policymakers to improve access to technology for those who have limited financial resources. For example by providing opportunities to loan technological devices such as laptops or tablets for periods of time (a bit like a technology library) or by offering quiet hours and technological support in local libraries or community centres so that people with dementia and their supporters can use the devices that are available there.

10.6   Conclusion

This is the first study exploring the views, experiences, needs and wishes of people with YOD regarding online peer support. It shows that the known benefits of peer support, such as social and emotional support, and exchanging experiences and information, can also be present in online settings. Moreover, it shows that online platforms have its own unique benefits, such as being able to engage in peer support from the comfort of one's own home and making groups and services outside one's local area more accessible. This is particularly

important for people with YOD, as availability of specialised YOD services and support groups varies widely across the UK. However, this study also shows that using technology and online communication comes with challenges. Dementia organisations, health and social care professionals, policymakers, and researchers have a joint responsibility in supporting people with YOD and their families in accessing and using technology and online communication.

The findings of this research informed the development of a Best Practice Guidance on online peer support for people with YOD and guidelines for facilitators. Feedback of people with YOD and professionals shows that the Best Practice Guidance is clear, understandable, and contains relevant information. The next steps for the Best Practice Guidance should focus on implementation and dissemination in dementia organisations and healthcare practices. Future research can evaluate the adoption of the Best Practice Guidance by dementia organisations and healthcare professionals and explore whether it improves the accessibility and delivery of online peer support for people with YOD.

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Appendices

Appendix 1 Overview of dementia sub-types

Dementia sub-type	Symptoms
Alzheimer's Disease	• Memory problems, particularly related to recent events and learning new information. • Difficulties with concentration, planning, organisation, orientation, speech, and language. • Changes in mood, e.g. increased depression and anxiety. (Alzheimer Society, 2023)
Vascular dementia	• Difficulties with concentration planning, organisation, and problem-solving. • Difficulties when performing a series of tasks (e.g. when preparing food). • Short periods of confusion. (Alzheimer Society, 2023)
Dementia with Lewy Bodies	Similar symptoms as with Alzheimer's disease, but also: • Hallucinations • Difficulties with sleep and staying alert • Difficulties with mobility and movement (Alzheimer Society, 2023)

Frontotemporal dementia	Behavioural variant:
	 • Changes in personality and behaviour
	 • Reduced motivation to do things that people used to enjoy
	 • Reduced empathy
	 • Repetitive or obsessive behaviours
	 • Reduced inhibitions and socially inappropriate behaviours as a result
	 Primary Progressive Aphasia (PPA): problems with language. Two variants:
	 • Semantic PPA:
	    o Reduced vocabulary
	    o Forgetting what objects are used for
	 • Non-fluent PPA:

	○ Changes in way of speaking, e.g. different words, grammar mistakes, speaking more slowly, or wrong order of words. ○ Using shorter sentences, leaving out words. ○ Saying the opposite of what someone intents to say (Alzheimer Society, 2023)
Posterior Cortical Atrophy	Vision impairments. Difficulties with: • Reading • Recognition • Coordination • Judging distances Sensitivity to light (Rare Dementia Support, 2023)

Appendix 2 Ethical approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Prof Martin Orrell
Institute of Mental Health, University of Nottingham
Innovation Park, Triumph Road
Nottingham
NG7 2TUN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

26 April 2021

Dear Prof Orrell

HRA and Health and Care
Research Wales (HCRW)
Approval Letter

Study title:	**An analysis of the use of online peer support by people with Young Onset Dementia**
IRAS project ID:	**291425**
Protocol number:	**291425**
REC reference:	**21/LO/0248**
Sponsor	**University of Nottingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

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Appendix 3 Search terms systematic literature research

Search term 1	Search term 2
parkinson* disease	online
parkinson*	digital
	web-based
multiple sclerosis	app-based
	internet
amyotrophic lateral sclerosis	social media
	Peer
	Peer support
	Support group
	Social support
	Online support group
	Online support commun* Discussion forum*
	Bulletin board
	Chat room*
	Computer-mediated support
	Internet support group*
	Internet support commun*
	Online self-help
	Web-based support group*
	Web-based support commun*

Appendix 4 Quality assessment of included studies in chapter 3

CASP checklist for Qualitative Studies

	Attard & Coulson (2012)	Bakke et al. (2019)	Davis & Boeschoten (2016)	Loane & D' Alessandro (2015)	Martínez-Pérez et al. (2015)
1 Clear statement of aims?	+	+	+	+	+
2 Qualitative methodology appropriate?	+	+	+	+	+
3 Research design appropriate?	+	+	+	+	+
4 Recruitment strategy appropriate? *	+	+	+	-	+
5 Data collected in a way that addressed the research issue?	+	+	+	+	-
6 Has the relationship between researcher and participant** been adequately considered?	-	-	-	-	-
7 Ethical issues been taken into consideration?	+	-	+	+	-
8 Data analysis sufficiently rigorous?	+	+	+	+	-
9 Clear statement of findings?	+	+	-	+	-
10 How valuable is this research?	+	+	-	+	-
Total score	9	8	7	8	4

+ = criterion met; − = criterion not met. *In case of qualitative content analysis this item focused on selection of platforms and messages posted. **In case of qualitative content analysis 'participants' relates to the data analysis

Downs & Black checklist for randomised and non-randomised studies

	Lieberman et al. (2005)	Lieberman et al. (2006)	Lieberman (2007)
1 Is the hypothesis/aim/ objective clearly described?	1	1	1
2 Are the main outcomes to be measured clearly described in the introduction or methods section?	1	1	1
3 Are the characteristics of the patients clearly described?	1	1	1
4 Are the interventions of interest clearly described?	1	1	1
5 Are the distributions of the principal confounders in each group of subjects to be compared clearly described?**	0	0	0
6 Are the main findings of the study clearly described?	1	1	1
7 Does the study provide estimates of the random variability in the data for the main outcomes?	1	1	1
8 Have all important adverse events that may be a consequence of the intervention been reported?	0	0	0
9 Have the characteristics of patients lost to follow-up been described?	1	1	1
10 Have actual probability values been reported for the main outcomes except where the probability value is less than 0.001?	1	1	1
11 Were the subjects asked to participate in the study representative of the entire population?	1	1	0
12 Were those who were prepared to participate representative of the entire population?	0	0	0
13 Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	0	0	1
14 Was an attempt made to blind the subjects to the intervention they have received?	N/A	N/A	N/A
15 Was an attempt made to blind those measuring the main outcomes of the intervention?	N/A	N/A	N/A

16 If any of the results of the study were based on "data dredging", was this made clear?	1	1	1
17 In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case of case-control studies, is the time period between the intervention and outcome the same for cases and controls?	1	1	1
18 Were the statistical tests used to assess the main outcomes appropriate?	1	1	1
19 Was compliance with the intervention reliable?	1	1	1
20 Were the main outcome measures used accurate (valid and reliable)?	1	1	1
21 Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	1	1	1
22 Were study subjects in different intervention groups (trials and cohort studies) or were cases and controls (case-control studies) recruited over the same period of time?	0	0	0
23 Were study subjects randomised to intervention groups?	0	0	0
24 Was the randomised intervention assignment concealed from both patients and healthcare staff until recruitment was complete and irrevocable?	0	0	0
25 Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	0	0	0
26 Were losses of patients to follow-up taken into account?	1	1	1
27 Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	N/A	N/A	N/A
Total score	16/25*** Fair	16/25 Fair	15/25 Fair

1=criterion met, 0=criterion not met, or unable to determine. *This study is a content analysis of online support groups. Therefore, for this question, 'patients' will be the online groups included in this study.

**For this question, a score of 2 indicates criterion met, a score of 1 indicates criterion partially met, and a score of 0 indicates criterion not met.

*** For this study three items from the list were excluded because they were not applicable. This brought the new maximum score to 25.

Original Downs & Black checklist		
Score	**Percentage**	**Label**
28 – 24	100 – 86	Excellent
23 – 19	83 – 69	Good
18 – 14	65 – 51	Fair
< 14	< 51	Poor
Adjusted Downs & Black checklist		
25 – 22	100 – 86	Excellent
21 – 17	83 – 69	Good
16 – 13	65 – 51	Fair
< 13	< 51	Poor

Appendix 5 Quality assessment of included studies in chapter 4

CASP checklist for Qualitative Studies

	Della Rosa & Sen (2019)	Kantor et al. (2018a)	Kantor et al. (2018b)	Rath et al. (2017)	Shavazi et al. (2016)	Steadman & Pretorius (2014)	O' Donnell et al. (2020)	Giunti et al. (2020)
1 Clear statement of aims?	+	+	+	+	+	+	+	+
2 Qualitative methodology appropriate?	+	+	+	+	+	+	+	+
3 Research design appropriate?	+	-	-	+	+	+	+	+
4 Recruitment strategy appropriate? *	-	-	-	+	+	+	+	+
5 Data collected in a way that addressed the research issue?	+	-	-	+	+	+	+	+
6 Has the relationship between researcher and participant** been adequately considered?	-	+	+	+	-	-	-	-
7 Ethical issues been taken into consideration?	-	+	+	+	-	-	+	-
8 Data analysis sufficiently rigorous?	+	-	-	-	+	+	+	+
9 Clear statement of findings?	+	-	-	+	+	+	+	-
10 How valuable is this research?	+	-	-	+	+	+	+	-
Total score	7	4	4	9	8	8	9	7

+ = criterion met; – = criterion not met. *In case of qualitative content analysis this item focussed on selection of platforms and messages posted. **In case of qualitative content analysis 'participants' relates to the data analysed

Downs & Black checklist for randomised and non-randomised studies

	Lavorgna et al. (2017)	Leavitt et al. (2019)	Dorstyn et al. (2022)
1 Is the hypothesis/aim/ objective clearly described?	1	1	1
2 Are the main outcomes to be measured clearly described in the introduction or methods section?	1	1	1
3 Are the characteristics of the patients clearly described?	1	1	1
4 Are the interventions of interest clearly described?	1	1	1
5 Are the distributions of the principal confounders in each group of subjects to be compared clearly described?**	0	1	0
6 Are the main findings of the study clearly described?	1	1	1
7 Does the study provide estimates of the random variability in the data for the main outcomes?	1	1	1
8 Have all important adverse events that may be a consequence of the intervention been reported?	0	0	1
9 Have the characteristics of patients lost to follow-up been described?	1	0	1
10 Have actual probability values been reported for the main outcomes except where the probability value is less than 0.001?	0	1	1
11 Were the subjects asked to participate in the study representative of the entire population?	1	0	1
12 Were those who were prepared to participate representative of the entire population?	0	0	0
13 Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	0	0	0
14 Was an attempt made to blind the subjects to the intervention they have received?	N/A	N/A	N/A
15 Was an attempt made to blind those measuring the main outcomes of the intervention?	N/A	N/A	N/A

16 If any of the results of the study were based on "data dredging", was this made clear?	1	1	1
17 In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case of case-control studies, is the time period between the intervention and outcome the same for cases and controls?	0	1	1
18 Were the statistical tests used to assess the main outcomes appropriate?	1	1	1
19 Was compliance with the intervention reliable?	0	0	1
20 Were the main outcome measures used accurate (valid and reliable)?	1	1	1
21 Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	0	0	0
22 Were study subjects in different intervention groups (trials and cohort studies) or were cases and controls (case-control studies) recruited over the same period of time?	0	0	1
23 Were study subjects randomised to intervention groups?	0	1	1
24 Was the randomised intervention assignment concealed from both patients and healthcare staff until recruitment was complete and irrevocable?	0	0	0
25 Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	0	1	1
26 Were losses of patients to follow-up taken into account?	1	1	1
27 Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	N/A	N/A	0
Total score	12/25*** Poor	15/25 Fair	19/26 Good

1=criterion met, 0=criterion not met, or unable to determine. *This study is a content analysis of online support groups. Therefore, for this question, 'patients' will be the online groups included in this study.

**For this question, a score of 2 indicates criterion met, a score of 1 indicates criterion partially met, and a score of 0 indicates criterion not met.

*** For this study three items from the list were excluded because they were not applicable. This brought the new maximum score to 25 or 26.

Original Downs & Black checklist		
Score	**Percentage**	**Label**
28 – 24	100 – 86	Excellent
23 – 19	83 – 69	Good
18 – 14	65 – 51	Fair
< 14	< 51	Poor
Adjusted Downs & Black checklist 1		
25 – 22	100 – 86	Excellent
21 – 17	83 – 69	Good
16 – 13	65 – 51	Fair
< 13	< 51	Poor
Adjusted Downs & Black checklist 2		
26 – 22	100 – 86	Excellent
21 – 18	83 – 69	Good
17 – 13	65 – 51	Fair
< 13	< 51	Poor

CASP checklist for Qualitative Studies

	Stewart Loane and D'Alessandro (2013)	Stewart Loane, Webster & D' Alessandro (2015)	Versteeg and te Molder (2019)	Hargreaves et al. (2018)	Frost & Massagli (2008)	Frost & Massagli (2009)	Kazmer et al. (2014)	Hemsley and Palmer (2016)	Caron and Light (2015)
1 Clear statement of aims?	+	+	+	+	+	+	+	+	+
2 Qualitative methodology appropriate?	+	+	+	+	+	+	+	+	+
3 Research design appropriate?	+	+	+	+	+	+	+	+	+
4 Recruitment strategy appropriate? *	+	+	-	+	+	-	+	+	+
5 Data collected in a way that addressed the research issue?	+	+	+	+	+	+	+	+	+
6 Has the relationship between researcher and participant** been adequately considered?	-	+	-	-	+	-	-	-	-
7 Ethical issues been taken into consideration?	+	+	-	+	-	-	-	-	+
8 Data analysis sufficiently rigorous?	+	+	+	+	+	+	+	+	+
9 Clear statement of findings?	+	+	-	-	+	-	+	-	+
10 How valuable is this research?	+	+	-	+	+	-	+	-	+
Total score	9	10	5	8	9	5	8	6	9

+ = criterion met; – = criterion not met. *In case of qualitative content analysis this item focussed on selection of platforms and messages posted. **In case of qualitative content analysis 'participants' relates to the data analysis

Participant Information Sheet – focus group with Young Onset Dementia peer support group
(Final version 2.0 Date: 01/04/2021)

IRAS Project ID: 291425

Title of Study: **Online peer support for people with Young Onset Dementia**
(Study 2(c): focus group with existing peer support group)

Name of Chief Investigator: Prof Martin Orrell
Local Researcher(s): Miss Esther Gerritzen

We would like to invite you to take part in our research study, which is undertaken as part of a PhD project. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

People with Young Onset Dementia (people diagnosed with dementia before the age of 65) often have different needs than older adults diagnosed with dementia. Dementia is often associated with older age, and because of this, young people with dementia can experience stigma. Stigma can put people at risk for being socially isolated. Being in contact with other people with Young Onset Dementia (also called 'peer support') can reduce the risk of social isolation. Peer support can happen in-person, but also online, for example through social media or Zoom calls. In this study we hope to find out more about (1) the personal experiences of young people with dementia regarding online contact with other people with Young Onset Dementia, and (2) what makes online support meaningful. We are also interested in finding out what some of the reasons can be for not

engaging in online peer support. With the findings of this study we want to develop an information tool about online peer support for people with Young Onset Dementia.

Why have I been invited?

You are being invited to take part because you have experiences of living with Young Onset Dementia and you are a member of a peer support group that meets online.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights or the care you receive.

What will happen to me if I take part?

When participating in this study you will participate in a focus group together with other members of your peer support group. 24 hours before the focus group the researcher will send you a reminder. The focus group will be facilitated by the researcher. At the start of the focus group we will discuss some ground rules. One of the main rules is to keep everything that is shared within the focus group confidential and to respect the privacy of the other participants. During the focus group the researcher will ask you questions about your personal experiences with meeting with your support group online, and about what the transition from meeting in person to meeting online was like for you. The researcher will also ask questions about other personal experiences with online peer support you may have (for example on social media). There are no right or wrong answers. Even if you feel like you do not have much experience with online peer support or social media, we are still interested in hearing your thoughts and opinions on this topic. The researcher will organise the focus group through MS Teams or attend one of the group's usual meetings. The focus group will last between 60 and 90 minutes. The focus group will be audio- and screen-recorded. The researcher will transcribe the recording and take out any personally identifiable information so that you remain anonymous. The recordings will be deleted after the transcript has been developed. There will be the option for a test session with the researcher if you are not familiar with MS Teams or would like extra support. Besides the option for a test session, support regarding participation in the study will be available before, during, and after the focus group through email, and phone and video calls.

Expenses and payments

You will receive a voucher of £20 for participating in a focus group. In case that it is possible to meet in person, travel expenses will be offered.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages and risk of taking part in this study. All the views and perspectives you provide for this study will be anonymised and confidential personal information will not be disclosed to anyone outside of the research team. Your rights and the quality of care you receive will not be affected by taking part in, or by withdrawing from the study.

There are no known adverse effects for sharing your experiences, needs, and wishes about online support and support in a survey. However, if at any point during your participation you have a negative experience, please let the research team know through the contact details provided at the end of this information sheet.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will be used to develop a guidance for people with Young Onset Dementia on online peer support. The aim is to provide young people with dementia with the right information about online peer support, so that they can make an informed decision about whether this is something for them.

What happens when the research study stops?

At the end of this study we will develop a summary report, which will be made available to all participants. Additionally, as this study is part of a PhD project, the results will be written up in a thesis, which also will become publicly available. The results of the study will also be published in open-access journals. If you would like to receive a copy from the summary report, the PhD thesis, and/or the journal articles, we will seek your consent to hold your contact details.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Patient Advice and Liaison

Service (phone: 0115 993 4542, email: complaints@nottshc.nhs.uk) if you are a participant from the Nottinghamshire Health NHS Foundation Trust. Other participants can contact Louise Sabir, contact for the Faculty of Medicine and Health Sciences ethics committee, University of Nottingham (ResearchEthics@nottingham.ac.uk).

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:
https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only

members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we are required to break the confidentiality and to report this to the appropriate persons. This is why we will ask you to provide the contact details of a family member, friend, or supporter.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

After completion of the study, we will produce a summary study report and send this (either a hard copy or electronically) to study participants, unless you tell us you do not wish to receive the report. We plan to present the study outcomes at dementia conferences and publish journal articles in due course. Furthermore, the results of this study will be included in a PhD thesis. For the journal publications and the PhD thesis we will include quotes from the interview data to support the results. We will make sure to take out any names of people or places, and any other information that could potentially identify you, so that you remain anonymous. If you would like to receive a copy of the article, please let us know.

Who is organising and funding the research?

This study is being organised by the University of Nottingham and is funded by the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie Actions – Innovative Training Networks, H2020-MSCA-ITN-2018. Grant agreement No 813196.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Bromley Research Ethics Committee.

Further information and contact details

If you would like further information on this study, please contact:
Miss Esther Gerritzen, PhD student
Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham, Institute of Mental Health, Triumph Road, Nottingham, NG7 2TU
Tel: 07472286987
Email: Esther.Gerritzen@nottingham.ac.uk

Appendix 8 Informed Consent Form focus groups

CONSENT FORM

(Final version 2.0 Date: 29/03/2021)

Title of Study: Online peer support for people with Young Onset Dementia

(Study 2: individual interviews/ focus groups with people with Young Onset Dementia)

IRAS Project ID: 291425

Name of Researcher: Esther Gerritzen

Name of Participant: [Please type your name here]   **Please tick box**

Section A: About this study

1. I confirm that I have read and understand the information sheet Final Version 2.0 dated 01/04/2021 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐

3. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

4. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

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5. I understand that the interview/focus group will be audio- and screen recorded and that anonymous direct quotes from the interview/focus group may be used in the study reports, conference presentations, academic articles, and the PhD thesis of the researcher. ☐

6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

Section B: About further parts of this study

9. I am interested in taking part in further parts of the 'Online peer support for people with Young Onset Dementia' study. I give permission to contact me in the next 12 months to inform me of other parts of the study that I may be interested in to participate.

☐ **Yes**

☐ **No**

10. If answered YES to item 9, please complete this section:

I understand that obtaining information about further parts of the 'Online peer support for people with Young Onset Dementia' study does not mean I am obliged to participate. ☐

Name of Participant	**Date**	**Signature**
[Please type your name here]	[Please type today's date here]	[Please insert your signature here or type your initials]

[Below is to be filled in by the researcher]

_____   _____   _____

Name of Person taking consent   Date   Signature

2 copies: 1 for participant, 1 for the project notes

Preliminary findings of the focus groups about online peer support

Dear [name],

Thank you very much for participating in the focus group about online peer support in July 2021! Your help is greatly appreciated, and everything you shared has been really helpful. Since the focus group I made a transcript of the conversation that we had. My supervisors and I read through the transcript and we wrote down all the things that we thought are important. These are the preliminary findings.

This document includes the preliminary findings of 4 focus groups. The findings are not published anywhere yet. I'm sharing this with you to (1) keep you informed about the progress of the study, and (2) kindly ask whether you could check if what we've done so far is ok. Giving feedback is optional and you don't have to if you don't want to.

How can you give feedback?
If you would like to give feedback, could you bear the following points in mind?
• Are the findings written in a way that is understandable?
• Do you feel that the findings reflect your experiences?
• Is there anything that we forgot to include in the findings?
• Is there anything in the findings that you think should not be in there?

Please feel free to share anything else that you think is important. If you find that this document is too long to read, please feel free to get in touch, and we can go through it together.

Important information

If you would like to give feedback, please get back to me by **20 February 2022**. If you would like more time, please get in touch. You can share your feedback via:

- Email: Esther.Gerritzen@nottingham.ac.uk
- Phone call or MS Teams video call: 07472286987 or send me an email to schedule a call on MS Teams
- Post: please send it to the address below:
  Esther Gerritzen (PhD room)
  Institute of Mental Health
  University of Nottingham Innovation Park
  Jubilee Campus
  Triumph Road
  Nottingham
  NG7 2TU

Survey: Online peer support for people with Young Onset Dementia

We would like to invite you to take part in our research study, which is undertaken as part of a PhD project. Before you decide we would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?
People with Young Onset Dementia are diagnosed before the age of 65. It can be difficult for younger people with dementia to find age-appropriate support in their local area, and to meet other younger people with dementia. Meeting with other people with Young Onset Dementia is called 'peer support'. Peer support can happen in-person, but also online, for example through social media or Zoom calls. In this study we hope to find out more about (1) any experiences you may have with **online** peer support, and (2) why you use or do not use it, and (3) what some of the barriers to online support are.

Who can participate?
You can participate if you received your dementia diagnosis before you were 65 years old. You can fill in the survey together with a family member or a friend if you need support.

What will happen to me if I take part?
There are no right or wrong answers. It will take approximately 30 minutes to complete the survey.

What are the possible disadvantages and risks of taking part?
We do not anticipate any disadvantages and risk of taking part in this study. You can participate in the survey anonymously and any confidential personal information will not be disclosed to anyone outside of the research team. Your rights and the quality of care you

receive will not be affected by taking part in, or by withdrawing from the study.

If at any point during your participation you experience emotional distress, please let the research team know through the contact details provided at the end of this information sheet.

What are the possible benefits of taking part?
We cannot promise the study will help you directly, but the information we get from this study will be used to develop better information and online support for people with Young Onset Dementia.

What happens when the research study stops?
At the end of this study we will develop a summary report. Additionally, the results will be part of a PhD thesis, which will become publicly available. The results of the study will also be published in open-access journals. If you would like to receive a copy from the summary report, the PhD thesis, and/or the journal articles, you can provide your contact details at the end of this survey.

What if there is a problem?
If you have a concern about any aspect of this study, you can contact the researcher, Esther Gerritzen (Esther.Gerritzen@nottingham.ac.uk) who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Patient Advice and Liaison Service (phone: 0115 993 4542, email: complaints@nottshc.nhs.uk) if you are a participant from the Nottinghamshire Health NHS Foundation Trust. Other participants can contact Louise Sabir, contact for the Faculty of Medicine and Health Sciences ethics committee, University of Nottingham (ResearchEthics@nottingham.ac.uk).

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence. The study will be carried out through Online Surveys (https://www.onlinesurveys.ac.uk/). This is an online research tool designed for academic research, and the University of Nottingham has a license to use it. It is up to you whether you want to share any personal information with the researcher through the survey, and if so, what information you would like to share. This information will be stored in a password-secured online storage space of the University of Nottingham. This information will be stored up to 12 months.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we

need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we are required to break the confidentiality and to report this to the appropriate persons. This is why we will ask you to provide the contact details of a family member, friend, or supporter.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you want to stop participating in the survey, you can do so by closing this tab in your browser. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Who is organising and funding the research?
This research is being organised by the University of Nottingham and is funded by the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie Actions – Innovative Training Networks, H2020-MSCA-ITN-2018. Grant agreement No 813196.

Who has reviewed the study?
All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Bromley Research Ethics Committee.

Further information and contact details
If you would like further information on this study, please contact:
Miss Esther Gerritzen, PhD student
Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham, Institute of Mental Health, Triumph Road, Nottingham, NG7 2TU

Email: Esther.Gerritzen@nottingham.ac.uk

Have you read and understood the study information, and do you consent to take part? *Please tick only one answer*

☐ Yes

☐ No

If you selected 'yes', please continue to page 5

If you selected 'no': unfortunately you need to consent in order to take part in the survey. We thank you for considering taking part in this survey. We have not collected any personal information of yours. If you have any questions or comments about this study, please contact the researcher Esther Gerritzen (Esther.Gerritzen@nottingham.ac.uk).

On page 21 you can find UK-based resources for additional information and support.

Thank you for agreeing to take part in this survey

With this survey we want to reflect the experiences and perspectives of people living with a dementia diagnosis. First, we will ask you how you found out about this survey, and some questions about yourself. After that, we will ask you some questions about online peer support. You do not need to have any experience with online peer support to take part in this survey.

It will take about 30 minutes to complete the survey. You can fill in the survey together with a family member or friend if you need support, or you can contact the researcher Esther Gerritzen (Esther.Gerritzen@nottingham.ac.uk).

Note: if you are a family member or a friend and you're helping someone with dementia to fill in the survey, please make sure to answer all questions from their perspective. This includes the demographic questions.

Q1. How did you find out about this survey? *(Please tick only one box)*

☐ Dementia Matters

☐ DEEP

☐ Join Dementia Research

☐ Social media

☐ Trent Dementia

☐ Young Dementia Network / Dementia UK

☐ Cambridgeshire and Peterborough NHS Foundation Trust

☐ Cambridge University Hospital NHS Foundation Trust

☐ Coventry and Warwickshire Partnership NHS Trust

☐ Derbyshire Healthcare NHS Foundation Trust

☐ Dorset Healthcare University NHS Foundation Trust

☐ Gloucestershire Health and Care NHS Foundation Trust

☐ Herefordshire and Worcestershire Health and Care NHS Trust

☐ Kent and Medway NHS and Social Care Partnership Trust

☐ Leicestershire Partnership NHS Foundation Trust

☐ Lincolnshire Partnership NHS Foundation Trust

☐ Medway NHS Foundation Trust

☐ North Bristol NHS Trust

☐ North East London NHS Foundation Trust

☐ Northumbria Healthcare NHS Trust

☐ Nottinghamshire Healthcare NHS Foundation Trust

☐ Oxford Health NHS Foundation Trust

☐ Oxford University Hospitals NHS Foundation Trust

☐ Solent NHS Trust

☐ South West London & St George's Mental Health Trust

☐ Southern Health NHS Foundation Trust

☐ St George's University Hospitals NHS Foundation Trust

☐ University Hospital Southampton NHS Foundation Trust

☐ Other, please tell us:

_____

Demographic questions

Q2. What is your age?

_____ years old

Q3. What is your gender? *Please tick only one answer*

☐ Female

☐ Male

☐ Other

☐ Prefer not to say

Q4. When did you receive your dementia diagnosis?

_____

Q5. What is your living situation? *Please only tick one box*

☐ Living with partner

☐ Living with partner and other family members (e.g. children)

☐ Living with other family members (e.g. children, siblings)

☐ Living alone

☐ Other, please tell us:

_____

_____

_____

Q6. Are you currently in paid employment? *Please tick only one*

answer

☐ Yes

☐ No

☐ I'm not sure

Could you tell us a bit more?

_____

_____

_____

_____

Q7. What is your ethnicity? *Please tick only one answer. The answer options continue on the next page*

(Research shows that people with dementia who participate in research are often of a white ethnic background. This does not represent the whole population with dementia. It is important to include a wide variety of experiences, opinions and backgrounds. This is why this question is included.)

☐ White – British

☐ White – European

☐ White – other

☐ Mixed – White and Black Caribbean

☐ Mixed – White and Black African

☐ Mixed – White and Asian

☐ Mixed – other

☐ Asian – Indian

☐ Asian – Pakistani

☐ Asian – other

☐ Black – African

☐ Black – Caribbean

☐ Black – other

☐ Arab

☐ Other ethnic group

☐ I'm not sure

☐ I prefer not to say

Online peer support questions

Q8. Do you currently meet with / talk to other people with Young Onset Dementia online? (For example through Zoom, Skype or social media)

☐ No, not currently but I have in the past **(please go to Q9)**

☐ Yes **(please go to Q10 on page 11)**

☐ No, I've never done that **(please go to Q20 on page 17)**

Q9. Why did you stop meeting with / talking to other people with Young Onset Dementia online? *Please tick all boxes that apply to you*

☐ I didn't like it

☐ I had a negative experience

☐ The platform was too difficult to use

☐ My dementia symptoms made it too difficult for me to use

☐ I didn't have enough time

☐ Other, please tell us:

_____

_____

_____

_____

Could you tell us a bit more? *(optional)*

_____

_____

_____

_____

_____

Q10. What platform do or did you use to meet with / talk to other people with Young Onset Dementia? *Please tick all answers that apply to you*

☐ Zoom

☐ Skype

☐ Facebook

☐ Twitter

☐ Instagram

☐ Email

☐ WhatsApp

☐ Discussion forum (for example Alzheimer Society Talking Point)

☐ Other, please tell us:

_____

_____

_____

Q11. For how long have you been / did you talk to other people with Young Onset Dementia online? *Please tick only one answer*

☐ Less than 1 month

☐ 1-6 months

☐ 7 months – 1 year

☐ More than 1 year

☐ I'm not sure

Q12. How did you find out about ways to meet with / talk to other people with Young Onset Dementia online? *Please tick all answers that apply to you*

☐ Google

☐ DEEP / Dementia Voices

☐ Dementia organisations (for example Young Dementia Network, Dementia UK, Alzheimer Society)

☐ From other people with dementia

☐ From my doctor

☐ Other, please tell us:

_____

_____

_____

Q13. How often do/did you meet with / talk to other people with Young Onset Dementia online? *Please tick only one answer*

☐ Once a month

☐ 2-3 times a month

☐ Once a week

☐ 2-3 times a week

☐ More than 3 times a week

☐ I'm not sure

Q14. What do/did you like about meeting with / talking to other people with Young Onset Dementia online? *Please tick all answers that apply to you*

☐ Meeting new people

☐ Building friendships

☐ Sharing experiences, tips and tricks

☐ Being part of a group

☐ Doing activities together

☐ Learning about dementia

☐ Learning about what support is available to me

☐ Learning about research

☐ Other, please tell us:

_____

_____

_____

_____

Could you tell us a bit more? *(optional)*

_____

_____

_____

_____

Q15. Is there anything that you don't like about meeting with / talking to other people with Young Onset Dementia online?
Please tick all answers that apply to you

☐ No, there isn't anything that I don't like

☐ Sometimes I don't get a reply to my message (for example on Facebook or Twitter)

☐ I find it difficult to keep up with the conversation (for example on Zoom or skype)

☐ I sometimes find it difficult to understand people

☐ I'm not sure who I can trust online

☐ I miss not being together in person

☐ Other, please tell us:

_____

_____

_____

_____

Could you tell us a bit more? *(optional)*

_____

_____

_____

_____

Q16. Did you ever have a negative experience when meeting with / talking to other people with Young Onset dementia online? *Please tick only one answer*

☐   Yes. Could you please tell us a bit more about it? How did you cope?

_____

_____

_____

☐   No

☐   I'm not sure

Q17. Is there anything about online platforms that could be improved? *Please tick all answers that apply to you*

☐   Simpler design

☐   Make it easier to access on the phone or tablet

☐   Make it easier to access on the computer

☐   Make it easier to find

☐   I'm not sure

☐   No, there is nothing that could be improved

☐   Other, please tell us:

_____

_____

_____

_____

Could you tell us a bit more? *(optional)*

_____

_____

_____

Please continue with Q18 on the next page

Q18. Would you recommend online peer support to other people with Young Onset Dementia? *Please tick only one answer*

☐ Yes

☐ No

☐ Maybe

Please tell us why:

_____

_____

_____

_____

Q19. Could you tell us a little bit more about your experiences with online peer support?

_____

_____

_____

_____

Q20. Why do you not meet with / talk to other people with Young Onset Dementia online? *Please tick all answers that apply to you*

☐ I never heard about this

☐ I don't know where to look for support

☐ I'm not able to use a computer/ phone/ tablet

☐ I'm concerned about my privacy

☐ I don't like talking to people that I don't know online

☐ I don't want to meet or talk to other people with dementia

☐ Other, please tell us:

_____

_____

_____

_____

Could you tell us a bit more? *(optional)*

_____

_____

_____

_____

Q21. Where would you go or look if you wanted more information about online peer support? *Please tick all answers that apply to you*

☐ I don't know

☐ Google

☐ Social media (for example Twitter or Facebook)

☐ Dementia organisations (for example Alzheimer Society, Young Dementia Network / Dementia UK, DEEP)

☐ My doctor

☐ Friends / family

☐ Other people with dementia

☐ Other, please tell us:

_____

_____

Q22. Would you like to meet with / talk to other people with Young Onset Dementia online? *Please tick only one answer*

☐ Yes

☐ No

☐ I'm not sure

Please tell us why:

_____

_____

_____

_____

Q23. Is there anything else that you would like to tell us about online peer support?

_____

_____

_____

Q24. Would you like to receive updates about this study? *Please tick only one answer*

☐ Yes. *Could you please give us your name and email address? If you prefer to receive the updates per post, please give us the address that we can send it to.*

_____

_____

_____

☐ No

Q25. Can we contact you again for future research about online peer support? *Please tick only one answer*

☐ Yes. *Could you please give us your name and email address? If you prefer us to contact you over the phone, please give us a phone number that we can reach you on.*

_____

_____

_____

☐ No

This is the end of the survey. Thank you very much for your participating, we greatly appreciate your time. Your responses are very helpful to us.

Where can I find additional support?

There are several organisations in the UK that provide information and support for people with Young Onset Dementia and their supporters. Please find a few of them below:

DEEP (UK Network of Dementia Voices)
A UK-wide network for peer support groups for people with dementia.
- Website: https://www.dementiavoices.org.uk/
- Email: Rachel Niblock, UK coordinator niblock@myid.org.uk
- Phone: 07720 538851

Dementia UK
Provides specialist dementia support for families through their Admiral Nurse service.
- Website: https://www.dementiauk.org/
- Email: info@dementiauk.org OR helpline@dementiauk.org
- Phone: 020 8036 5400 OR 0800 888 6678 (dementia helpline)

Young Dementia Network
Collaborative network including people with Young Onset Dementia, their families, professionals, and researchers to improve the lives of people affected by Young Onset Dementia.
- Website: https://www.youngdementianetwork.org/
- Email: youngdementianetwork@dementiauk.org

Rare Dementia Support (RDS)
Service provided by University College London. Offers information and support for people affected by a rare dementia.
- Website: https://www.raredementiasupport.org/
- Email: contact@raredementiasupport.org (specialist support team) OR r.mckee-jackson@ucl.ac.uk (support groups)

Pathways Through Dementia
Provides legal and financial support for people with dementia and their families.
- Website: https://pathwaysthroughdementia.org/
- Email: swilcox@pathwaysthroughdementia.org
- Phone: 0203 405 5940

Appendix 11 Recruitment message online survey

Research opportunity

For a PhD project at the University of Nottingham we are looking for people to participate in a survey about **online peer support** for people with **Young Onset Dementia**.

- Peer support is any contact you have with other young people with dementia.
- **Online** peer support happens through the Internet. Examples include Facebook, Twitter, meetings on Zoom, discussion forums or chat rooms.

Are you:

- Someone with a dementia diagnosis, and did you receive your diagnosis before you were the age of 65?
- Interested in talking about online support and sharing your experiences?

Then you might be eligible for this survey! Even if you feel like you don't have much experience with social media or online support, we are still interested in hearing your opinion on this topic.

Scan the QR code or follow this link to access the survey: https://nottingham.onlinesurveys.ac.uk/online-peer-support-for-people-with-young-onset-dementia-2

The survey closes 6 February 2022!

Please contact the PhD researcher, Esther Gerritzen, if you would like more information (Esther.Gerritzen@nottingham.ac.uk)

Brief recruitment message (shared with organisations)

This recruitment message can be shared on social media pages (e.g. Twitter, Facebook, LinkedIn), in newsletters, or on websites. If the way it's written needs to be changed (for example instead of 'we' 'Esther Gerritzen needs your help!' please let me know).

Research opportunity: peer support online!

Are you living with Young Onset Dementia (diagnosis before age of 65)? Then we need your help! We want to hear what you think about online peer support. You do not need to have any experience with online peer support in order to take part. In this survey you can share any ideas that you have about online peer support. What is good about it? What can be improved? Are there any barriers for you? Did you ever have a negative experience? Everyone's contribution, big or small, is of great help! Please click here to open the survey. If you have any questions or comments, please contact Esther Gerritzen (PhD student at the University of Nottingham, UK) via Esther.Gerritzen@nottingham.ac.uk.

Participant Information Sheet – individual interviews with people with Young Onset Dementia
(Final version 2.0 Date: 01/04/2021)

IRAS Project ID: 291425

Title of Study: **Online peer support for people with Young Onset Dementia**

(Study 2(a): individual interviews with people with Young Onset Dementia)

Name of Chief Investigator: Prof Martin Orrell
Local Researcher(s): Miss Esther Gerritzen

We would like to invite you to take part in our research study, which is undertaken as part of a PhD project. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

People with Young Onset Dementia (people diagnosed with dementia before the age of 65) often have different needs than older adults diagnosed with dementia. Dementia is often associated with older age, and because of this, young people with dementia can experience stigma. Stigma can put people at risk for being socially isolated. Being in contact with other people with Young Onset Dementia (also called 'peer support') can reduce the risk of social isolation. Peer support can happen in-person, but also online, for example through social media or

Zoom calls. In this study we hope to find out more about (1) the personal experiences of young people with dementia with online contact with other people with Young Onset Dementia, and (2) what makes online support meaningful. We are also interested in finding out what some of the reasons can be for not engaging in online peer support. We want to use the findings of this study to develop an information tool about online peer support for people with Young Onset Dementia.

Why have I been invited?

You are being invited to take part because you have experiences of living with Young Onset Dementia.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights or the care you receive.

What will happen to me if I take part?

When participating in this study you will participate in an individual interview with the researcher. 24 hours before the interview the researcher will send you a reminder. During the interview the researcher will ask you questions about your personal experiences with online peer support and what makes it meaningful to you. It is important to hear about both positive and negative experiences you may have had. If you feel like you do not have (much) experience with online peer support, you can still participate in the study. It is also important to learn about the barriers are to online peer support. The interview will be conducted through MS Teams and will last between 45 and 60 minutes. The interview will be audio- and screen-recorded. The recordings will be deleted after the transcript has been developed. The researcher will transcribe the recording and take out any personally identifiable information so that you remain anonymous. If you are unfamiliar with MS Teams or would like extra support, you can do a test session with the researcher before the interview. Support related to participation in the

study will be available before and after the interview through email, or a phone or video call.

Expenses and payments

You will receive a voucher of £20 for your participation in an individual interview. In case that it is possible to meet in person, travel expenses will be offered.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages and risk of taking part in this study. All the views and perspectives you provide for this study will be anonymised and confidential personal information will not be disclosed to anyone outside of the research team. Your rights and the quality of care you receive will not be affected by taking part in, or by withdrawing from the study.

There are no known adverse effects for sharing your experiences and ideas about online support in an individual interview. However, if at any point during your participation you have a negative experience, please let the research team know through the contact details provided at the end of this information sheet.

What are the possible benefits of taking part?

We cannot promise the study will help you directly, but the information we get from this study will be used to develop an information tool for people with Young Onset Dementia on online peer support. The aim is to provide young people with dementia with the right information about online peer support, so that they can make an informed decision about whether this is something for them.

What happens when the research study stops?

At the end of this study we will develop a summary report, which will be made available to all participants. Additionally, as this study is part of a PhD project, the results will be written up in a thesis, which will become publicly available. The results of the study will also be published in open-access journals. If you would like to receive a copy from the summary report, the PhD

thesis, and/or the journal articles, we will seek your consent to hold your contact details.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Patient Advice and Liaison Service (phone: 0115 993 4542, email: complaints@nottshc.nhs.uk) if you are a participant from the Nottinghamshire Health NHS Foundation Trust. Other participants can contact Louise Sabir, contact for the Faculty of Medicine and Health Sciences ethics committee, University of Nottingham (ResearchEthics@nottingham.ac.uk).

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:
https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are

organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we are required to break the confidentiality and to report this to the appropriate persons. This is why we will ask you to provide the contact details of a family member, friend, or supporter.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

After completion of the study, we will produce a summary study report and send (either a hard copy or electronically) to study participants, unless you tell us you do not wish to receive the report. We plan to present the study outcomes at dementia conferences and publish journal articles in due course. Furthermore, the results of this study will be included in a PhD thesis. For the journal publications and the PhD thesis we will include quotes from the interview data to support the results. We will make sure to take out any names of people or places, and any other information that could potentially identify you, so that you remain anonymous. If you would like to receive a copy of the article, please let us know.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is funded by the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie Actions – Innovative Training Networks, H2020-MSCA-ITN-2018. Grant agreement No 813196.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Bromley Research Ethics Committee.

Further information and contact details

If you would like further information on this study, please contact:

Miss Esther Gerritzen, PhD student

Academic Unit 1 Mental Health and Clinical Neurosciences, School of Medicine, University of Nottingham, Institute of Mental Health, Triumph Road, Nottingham, NG7 2TU

Tel: 07472286987

Email: Esther.Gerritzen@nottingham.ac.uk

Best Practice Guidance on online peer support: opportunity to give feedback

Dear [name],

Last year you took part in a University of Nottingham study on online peer support for people with Young Onset Dementia. Your input has been very helpful and is greatly appreciated. We're now almost near the end of the project, and we developed a first version of the Best Practice Guidance on online peer support.

How did we develop this guidance?

This work is part of a PhD project. The project started in October 2019. We asked the following research questions:

(1) How do people with Young Onset Dementia experience online peer support?
(2) What are the benefits and barriers to online peer support?
(3) How can we improve online peer support?

To answer these questions, we started with a systematic literature study. Next, we collected the views of people with Young Onset Dementia in focus groups, an online survey, and interviews. We also spoke with peer support facilitators and healthcare professionals. We used all the findings to develop the Best Practice Guidance.

What is the guidance about?

This Best Practice Guidance consists of 2 parts:

(1)   A guide for people with Young Onset Dementia

This guide contains information about what online peer support is, what people can expect from it, and how it could be helpful. All the content is directly informed by people with Young Onset Dementia who took part in this project and shared their experiences and views.

(2)   A guide for facilitators

This guide is meant for facilitators (in case of video meetings) and moderators (in case of text-based platforms such as Facebook). It includes hints and tips for different types of online peer support. The guide was informed by the people with Young Onset Dementia who took part in this project. The kind of information was also informed by what facilitators and healthcare professionals said they would find helpful to know.

Do you want to give feedback?

The guidance is a draft and is not published anywhere yet. I'm sharing this with you to (1) keep you informed about the progress of this project, and (2) kindly ask whether you could check if what we've done so far is ok. You can give feedback on both parts of the guidance or choose one. Giving feedback is optional and you don't have to if you don't want to.

You can type your feedback in this document, or we can discuss it over a phone or videocall.

1. Is the Best Practice Guidance written in a way that is clear and understandable?

2. Is there anything else that we should include?

3. Is there anything that we should take out?

4. Is there anything else we could improve?

5. Should we make any changes to the format or layout? If so, what should we change?

6. What do you think of the length of the guidance? Please tick the box of your answer.

☐ Just right

☐ Too long

☐ Too short

7. Do you think the Best Practice Guidance will be useful to your peers / colleagues? Why (not)?

[ ]

8. Is there anything else that you think is important?

[ ]

What will we do with your feedback?

Your feedback can help us to improve the Best Practice Guidance. After we incorporated all feedback, we will make the Best Practice Guidance freely available for everyone.

Important information

If you want to give feedback, please get back to me by **Sunday 9 October 2022**. If you feel that the Best Practice Guidance is too long to read, we can go through it together over a phone or videocall. Also, if you need more time, please let me know.

You can share your feedback via:

- Email: Esther.Gerritzen@nottingham.ac.uk
- MS Teams call: please send me an email to schedule a call
- Phone call: 07472286987
- Post: please send it to the address below:

Esther Gerritzen (PhD room)
Institute of Mental Health
University of Nottingham Innovation Park
Jubilee Campus
Triumph Road
Nottingham
NG7 2TU

Appendix 14 Final Best Practice Guidance part 1

Guide to online peer support
For people with Young Onset Dementia

Key benefits of online peer support

- We can join from the comfort of our own home.

- We can be as much or as little involved as we want.

- There is no pressure to say or do anything if we don't want to.

This guide provides information about online peer support. It has hints and tips from people living with Young Onset Dementia. We developed this guide together with people with Young Onset Dementia, and health and social care professionals.

Contents

1. What different types of online peer support are there?

Platforms using text and writing

- Facebook
- Twitter
- WhatsApp
- Email
- Discussion forum (for example Alzheimer Society Talking Point)

➕ We can leave messages in real time.

➕ We can search for topics that are important to you.

➖ We can't see the other people.

➖ We don't always know the other people.

Platforms using spoken language

- Zoom
- MS Teams
- Skype
- FaceTime

➕ We can see the other people.

➕ We have opportunities to get to know the other group members.

➖ We need to be available (online) at a specific day and time.

We can choose an option that works best for us. If we have difficulties with holding a conversation, a platform using text can be a good option for you. If we have difficulties reading or typing, a platform using spoken language can be a good option.

<div style="border: 2px solid red; padding: 1em;">

Safety first!

⚠️

- We should always be careful with what we share online.
- We should be mindful of how online peer support affects our mental health. If we notice a negative impact, we could reach out to the group's facilitator or moderator. We can also take a break from it or try finding another group. We can also unfollow someone that has a negative impact.
- We should always speak to our doctor before changing anything about your medication or treatment.

</div>

2. What can I expect from online peer support?

Peer support participants said that joining a new group of people can be daunting. This section summarises their experiences and some of the questions and concerns they had before joining the group.

What is a peer support meeting like?

- Friendly, non-judgmental group of people who are in a similar situation.
- You don't have to explain everything. The others "live in the same fog", they understand.
- It's a time to just have a chat and a laugh together.
- People share experiences and information. You can learn from others, and others can learn from you.

What could you do during a peer support meeting?

- It can be just about meeting others and having a chat.
- You may get involved in different activities. For example: music, poetry, arts and crafts.
- You can get involved in research, policy, and advocacy.

"We meet weekly on an evening and we talk about anything and everything. We laugh together, we cry together, and most of all, it's a safe place"

What if I don't know what to say?

You don't have to say anything if you don't want to. It's ok to just listen and observe. If you are in a Zoom meeting, you can also mute your microphone or turn off your camera.

Do I have to join every meeting?

No, you don't have to join every meeting.

What if it's not for me?

- Finding the right group can take some trial and error. Don't give up if the first group doesn't suit you. Keep exploring different groups and formats.
- You may try different types of online peer support and see what you prefer. For example, Zoom meetings and Facebook groups.
- **You are not alone**. There are others out there who are going through something similar.

"I was silent for quite a long time when we started because (a) I didn't know what to say, and (b) I didn't really want to be there, I was kind of in denial with everything. But gradually I thought 'actually this is alright'. It's like with any sort of introduction to anybody, it takes a little while to get in there, but it's definitely worth it"

What does the facilitator or moderator do?

A facilitator is there in for example video meetings. This person could be a professional, someone living with dementia, or someone who supports a person with dementia. The facilitator:

- Sends out the link for the meeting;
- Supports the meeting and steps in if necessary;
- Makes sure everyone gets a chance to speak.
- Is there for you if you have any questions or concerns.

A moderator is there in for example Facebook groups or discussion forums. This person could be a professional, someone living with dementia, or someone who supports a person with dementia. This person:

- Makes sure that the group is a safe space for everyone. For example, they delete harmful or inappropriate posts.
- Could introduce a new topic or ask a question, and invite everyone to respond.
- Is there for you if you have questions.

Key points

- Peer support is friendly and non-judgmental.
- You don't have to say anything if you don't want to. It's ok to just observe.
- Different groups can have different goals. Find a group that matches your needs and wishes.

3. How can online peer support help me?

What can I get out of it?

- Meet new people who might have similar experiences.

- Learn about support and information resources.

- Learn from other people's experiences. They may have gone through things that you haven't (yet).

- Share your experiences. Other people can learn from you too!

"We're all like in the same room together, but without all that stimulation that you have when you're in a room with nine other people. Zoom is just such a blessing"

What is the advantage of <u>online</u> peer support?

- There may not be anyone else in your area who is around the same age.
- There may not be anyone else in your area with the same diagnosis.
- Online you can meet people from all over the country and the world.
- You can join from the comfort of your own home.
- If you do not feel comfortable, you can turn off your camera, mute yourself, or leave the meeting at any time.

"I've had some struggle to get out. Even if it was a local meeting I'd possibly have had problems actually physically getting there. Being able to have this, it breaks down lots of barriers because of distance, we can meet wherever we are internationally, but also if you struggle mobility wise or with anxiety about getting places, that sort of thing, it takes that away."

Did you know?

Many participants reported that even just listening to or reading about other people's experiences can be very helpful and make you feel less alone in your experiences.

4. How can I overcome technological challenges?

Everyone can have trouble with technology sometimes. Below you can read about some of the challenges that some people with Young Onset Dementia face and how they overcome these.

I can't get in the Zoom meeting. What can I do?

- Call or message someone else from the group or the group facilitator. They can send you the link again and help you to get in.
- Check the internet connection.
- Tip: try to get in 10 minutes before the meeting starts. This will give you enough time in case something goes wrong.

My dementia makes it difficult to use technology. What can I do?

- If you experience sensory overload, it can help to try to focus on one sense at the time.
  - If you are reading, cover your ears so you don't get distracted by background noise.
  - If you are in a video meeting, close your eyes so you can focus on listening to what the others are saying.
- Tell the group facilitator about your symptoms and what challenges you face. They can consider this during the meeting and make things as smooth as possible for you.

5. Where can I find more information?

I want to find a peer support group.

1. **DEEP (Dementia Engagement and Empowerment Project)**

DEEP is a UK-wide network for peer support for people with dementia. You can find online groups and groups in your local area.

- Website: www.dementiavoices.org.uk
- Email: Rachel Niblock, coordinator. niblock@myid.org.uk
- Phone: 07720 538851

2. **Rare Dementia Support**

Rare Dementia Support (RDS) is a service provided by University College London (UCL). They offer information and support for people affected by a rare type of dementia.

- Website: www.raredementiasupport.org
- Email: contact@raredementiasupport.org (for the specialist support team) OR r.mckee-jackson@ucl.ac.uk (for information about support groups)

3. **Opening Doors**

Opening Doors is a UK charity that offers activities, events, information, and support for people from the LGBTQ+ community who are over 50. They also have monthly peer support meetings via Zoom for people living with dementia.

- Website: www.openingdoors.lgbt/ (click here for peer support information)
- Email: info@openingdoors.lgbt OR click here for the contact form on the website

> #### 4. Dementia Alliance International
>
> Dementia Alliance International (DAI) provides information and connects people with dementia from all over the world. They have a Facebook group and weekly peer support meetings via Zoom. These are for people with a diagnosis only.
>
> - Website: www.dementiaallianceinternational.org (click here for peer support information)
> - Contact them by filling in the contact form on the website.

I want to learn from other people's experiences without joining an online peer support group.

> #### 1. Dementia Diaries
>
> Dementia Diaries brings together people's experiences of living with dementia through audio diaries. You can listen to the audio diaries at any time.
>
> - Website: www.dementiadiaries.org
> - Email: Steve Milton, coordinator. steve@myid.org.uk. You can also fill out the contact form on the website.
> - Phone: 07549 944795
>
> #### 2. Blogs
>
> Many people with Young Onset Dementia write about their experiences in a blog. You can find an overview of different blogs here.

I want more information about Young Onset Dementia.

1. **Young Dementia Network**

This network consists of people living with Young Onset Dementia, their families, and professionals to improve the lives of people affected with Young Onset Dementia. Here you can also find more information about research and advocacy.

- Website: www.youngdementianetwork.org
- Email: youngdementianetwork@dementiauk.org

2. **Dementia UK**

Dementia UK is a specialist dementia nurse charity. Here you can also find specialist information about Young Onset Dementia and peer support.

- Website: www.dementiauk.org/about-dementia/young-onset-dementia/
- Email: info@dementiauk.org
- Phone: 020 8036 5400

3. **Alzheimer's Society**

Alzheimer's Society provides information and support services for people affected by dementia. They also have specialised information on Young Onset Dementia and support services.

- Website: www.alzheimers.org.uk/about-dementia/types-dementia/young-onset-dementia#content-start (general website) OR www.dementiaconnect.alzheimers.org.uk (support)
- Phone: 0330 333 0804 (general questions) OR 0333 150 3456 (Dementia Connect support line)

Acknowledgements and contact information

This Best Practice Guidance is also part of the INDUCT and DISTINCT Best Practice Guidance on Human Interaction with Technology in Dementia (more information [here](#)).

The content of this Best Practice Guidance comes from:

- literature research
- focus groups with online peer support groups for people with Young Onset Dementia
- an online survey filled in by 69 people with Young Onset Dementia
- interviews with people with Young Onset Dementia

If you have any questions or want more information, please contact Esther Gerritzen (Esther.Gerritzen@nottingham.ac.uk)

Online peer support for people with Young Onset Dementia

A guide for facilitators

> **Key messages**
>
> - Get to know people's expectations, needs, and wishes before they join.
> - Timely reminders and (technological) support are important for peer support through video meetings.
> - When using text-based platforms, make sure it is for members only, and
>   have a statement on the purpose of the group.

This guide includes practical hints and tips on facilitating online peer support for people with Young Onset Dementia. It includes information on facilitating through video meetings as well as text-based platforms. We developed this guide together with people with Young Onset Dementia, facilitators, and health and social care professionals.

Contents

Peer support in video meetings

Peer support in text-based platforms

Peer support in video meetings

1. What is important before the meeting?

Get to know the person.

- Find out if the person has similarities with the other group members, for example age, time since diagnosis, dementia subtype, hobbies and interests, professional background.
- Sharing similarities can make people feel more comfortable to share things, and feel more connected.
- Find out what someone from peer support and whether this matches with the group.
- Identify someone's **(technological) support needs**.

Ground rules. Establish together with the group and revisit and revise regularly. Below are some suggestions for ground rules from people with YOD:

- Respect people's **privacy**. Things that people share in the group are confidential and should not be shared with others.
- If someone wants to take a photo or a screenshot of the meeting, ask first.
- Mute yourself when you're not speaking.
- If someone wants to say something, they should **raise their hand** or hold op the yellow **'I want to speak please' card**.

Other practical things

- Send out a **reminder for the meeting** well in advance and closer or on the day. Include the meeting link.
- Share a guide on how to use the meeting platform.
- Be available to **provide (technical) support**.
- **Open the meeting 10-15 minutes before** the official start time, to allow people to come in and have a chat.
- Remind people that it's ok if they just want to listen in and observe.
- Remind people that it is ok if they need to step out of the meeting or turn off their camera at any point.
- If it's a new group, or if new members are joining, prepare an **ice breaker activity** and allow enough time for introductions.

Key points

- Get to know the person well before they join the group. Find out what their expectations, needs, and wishes are.
- Establish some ground rules with the group and repeat and revise these regularly.
- Send out timely reminders and be available to provide support.

2. What is important during the meeting?

- Give everyone a chance to speak.

- Remember who raised their hand/card first, and make sure to **address everyone in order**.

- Make sure the meeting is a **safe and confidential space** for everyone. Speak up against inappropriate, disrespectful, or harmful comments and bullying.

- Allow the group to share what they feel is important. Even if there's an agenda for the meeting, sometimes there are more important matters that people want to discuss, for example something impactful that happened in their lives.

- If you use an agenda, **ask the group what they want** on it.

🔑 **Key points**

- Give everyone a chance to speak.
- Allow the group to discuss what is important to them (either through an agenda or on the spot).

3. What is important after the meeting?

- If someone appears to be distressed or leaves the meeting abruptly, check in with them afterwards.
- If there were any inappropriate, disrespectful, or harmful comments or if you noticed **bullying** during the meeting, address this. Contact both the person who made and the person who received the comments.
- If appropriate, share some **meeting notes**.
- Follow up on any **unanswered questions** that came up during the meeting.

🔑 **Key points**

- Check in with people afterwards if they left the meeting suddenly or appeared distressed.
- Follow up with any notes or answers to questions.

4. Further practical things to keep in mind

- Have a **clear group description** including: (1) who the group is for, (2) what you usually do during the meetings, and (3) when and on which platform the group meets.
- Group size should be **10-12 people** maximum.
- The meeting should not be longer than **1.5 hour**.
- Many people prefer **Zoom** over other platforms.
- Try to offer meetings on different days of the week and different times of the day.
- Ask the group how they feel about the **chat function**. Some may find it distracting while others find it helpful.
- Ask the group how they feel about **sharing contact details** with each other to stay in contact outside of the meetings if they want to. Make clear that this is optional and that no one should feel pressure to do so.

Support for facilitators

- Think about how your work impacts your **own mental health**.
- Consider reaching out to other facilitators for support.

Key points

- Have a clear description of the group.
- Max. 10-12 people, max 1.5 hour.
- Consider impact of being a facilitator on your own mental health and reach out to others.

Peer support in text-based platforms

There are different text-based platforms that can be used for peer support. For example:

- Facebook
- WhatsApp
- Discussion forums.

Facebook groups and discussion forums allow for a large membership. There are many different needs and expectations from the platform. Some may want to find more information, others may want to make new social connections and build friendships. It's important to tailor towards different needs and wishes within the platform.

> **Have a clear description of the group**
>
> - Give a clear **group description**. This should be **pinned at the home page**, or be send to new members before joining the group. The statement should include:
>   - **Who the group is for**;
>   - What kind of content will <u>not</u> be allowed (e.g. advertisements for drugs or offensive and inappropriate messages);
>   - Who the **moderators** are, their (professional) background, and their role;
>   - **A 'safety first' reminder**. People should always be careful with what information they share online, and they should always speak to their doctor regarding any medication or treatment.
>   - to respect other members' privacy.
> - Make sure the group is a **closed group**, and that you as a moderator need to allow someone to join.

Your role as a moderator / facilitator

- **Welcome new members** and explain how the group works.

- **Monitor the content** and remove posts that are not allowed. If someone shares inappropriate content, contact this person privately if possible.

- If someone is not receiving a response to a message, try to bring this post to the front/top of the page, invite others to respond, or provide a response yourself.

- You could start a discussion topic and **invite members to respond**. You could do a poll among members to learn which topics are important for them.

- Based on the discussion topic, you could set up **smaller 'rooms'** or groups within the platform.

- Depending on the platform and the purpose of the group, you could schedule a **Q&A session with a professional**. For example, concerns around driving and dementia, or lasting power of attorney. For such topics people might want to ask their questions directly to a professional.

Key points

- Have a clear group description.
- Make the group closed so that you as a moderator need to give permission for people to join.
- Monitor content, remove inappropriate content, and if possible contact the author of inappropriate content.
- If possible, save discussion topics and resources.

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