“I found it the only place that spoke the same language”: A thematic analysis of messages posted to an online peer support discussion forum for people living with dementia

Catherine V. Talbot[1]

Neil S. Coulson[2]

[1]Bournemouth University

[2]University of Nottingham

Corresponding author: Dr Catherine Talbot, Bournemouth University.
Ctalbot@bournemouth.ac.uk

Keywords: Alzheimer’s, cognitive impairment, peer support, qualitative

Declarations: The authors declare no competing interests. Ethical approval for this research was granted by the Bournemouth University ethics board [ID:29602].

Acknowledgements: We would like to thank Talking Point for giving us permission to use their data in this research.

Abstract

Despite the proliferation of online support communities, little is known about how people with dementia engage with them. The aim of this study was to explore the content of messages exchanged between members of the asynchronous Talking Point online discussion forum. Using the sub-forum ‘I have dementia’, 100 conversation threads were randomly selected yielding 863 individual messages for analysis. Our dataset was subjected to reflexive thematic analysis, which generated three themes: journeying through dementia, reciprocal peer support and therapeutic creativity. The findings suggest that individuals used the forum to share their experiences of obtaining and adjusting to a dementia diagnosis, their current symptoms and how they addressed the challenges of daily living as well as the impacts on mood, confidence, and connectedness. The forum was viewed as a safe space to reflect on the future and what it might hold for them and loved ones. Throughout these discussions, users supported each other, particularly in relation to the emotional impact of diagnosis and shared experiential information and advice, with referrals to external sources of support commonplace. Discussion around the role of therapeutic creativity was evident and its role as a coping mechanism described. Through engagement, a sense of community and companionship was evident and new members welcomed, supported, and encouraged to join in. The forum appears to be filling an important gap in post-diagnostic support provision, particularly for those with rare forms of dementia. Clinicians, support workers, and organisations could consider recommending online support forums to people with dementia.

Introduction

Dementia affects approximately 55 million people worldwide, with numbers set to rise to 139 million by 2050 [1]. In addition to the impacts of dementia on cognition and activities of daily living, the diagnosis can also have a powerful social impact on the person including a loss of social roles, reduced self-worth and self-esteem, reduced engagement with meaningful activities, and heightened feelings of isolation [2, 3].

A diagnosis of dementia can be life-changing, therefore access to appropriate information and post-diagnostic support is vital. Peer support plays a vital role in dementia care, having positive emotional and social impacts that are rooted in identification with others, commonality of experience and reciprocity of support – something which researchers have found stands in stark contrast with the quality of support from professionals [4, 5]. Yet, reports from people with dementia and unpaid carers suggest that accessing suitable support services is challenging, identifying a lack of clear information to enable them to locate suitable support [6]. This issue is exacerbated for certain groups of people with dementia, such as people with young-onset dementia who can find it difficult to access age-appropriate peer support services [7].

Given the growing number of people being diagnosed with dementia, it is important to identify cost-effective, far-reaching means of facilitating peer support and access to appropriate information. Online spaces for people with dementia may provide one solution, with recent studies reporting that people with dementia are using a range of social media [8-12], blogs [13], emails and online chat rooms [14], and digital devices [15, 16]. Online spaces have become increasingly important since the COVID-19 pandemic, when digitally mediated interactions became a necessity for many [17], and people with dementia experienced increased isolation and advancing symptoms [18, 19]. Preliminary research shows that some people with dementia have adapted to this new digital landscape, yielding benefits of enhanced wellbeing, increased access to support, and facilitating identity and self-worth [20]. There is therefore a pressing need to better understand the value of online spaces for people with dementia.

Asynchronous text-based online forums may provide a useful resource for people with dementia. Not only are they available 24 hours per day, seven days per week but forum users can take their time crafting their messages [21], since there is no urgency to communicate. When posted, messages may reach a sizeable group of people facing similar challenges, who can give relevant information, advice, and support [22].

Although there is potential for asynchronous online forums to benefit those affected by dementia, research in this area is currently lacking. One exception is that of Rodriquez [23] who illustrated how individuals with early-onset Alzheimer's disease used a forum to share stories, information, and adaptive strategies, as well as their hopes and fears. More recently, Johnson [24] *et al.* considered who engaged in a dementia-related online support forum and through deductive analysis related this to the expression of distinct categories of social support. To date, however, there has been little attention given to exploring online forums which cater to individuals living with a range of different forms of dementia. We know very little about what forum users discuss and there is an absence of inductive qualitative analysis of forum messages. Such an approach may yield important insights and in recognition, Mehta [25] *et al*. sought to encourage researchers to focus their efforts in this direction, offering important but limited examples of the topics discussed within a UK-based online forum. Our work seeks to embrace the challenge and opportunities set out by Metha [25] *et al.* and explore the topics discussed by users of an asynchronous online forum for individuals affected by different forms of dementia. Therefore, in this research we ask: "How are people with dementia using an online peer-support discussion forum?"

Method

Data collection

Data were messages posted to Dementia Talking Point, an asynchronous volunteer moderated discussion forum based within UK which seeks to support individuals living with dementia and family carers. This forum was chosen because it is well used, with over 77,500 members and 126,500 threads to date; and has also been the focus of emerging research in this area [26].

A single specific sub-forum ('I have dementia') which focused on individuals living with dementia was selected for analysis. While there are other sub-forums focused on specific groups (e.g., 'younger people with dementia and their carers') and topics (e.g., 'equipment and technology'), we focused on the 'I have dementia' sub-forum because we wanted to take a broad approach to the topic and felt this sub-forum provided the depth and breadth of data to answer our research question.

Our data retrieval approach followed the guidelines set out by Smedley and Coulson [27] in which conversation threads were selected using a random number generator. In total, 100 threads were chosen for inclusion in the dataset from a potential pool of 1678 conversation threads, yielding a total of 863 individual messages (range 1-34 messages per thread) posted between July 2009 and October 2021, generated by 251 unique usernames. Whilst the dataset represented only 6% of the potential pool of conversation threads, our random sampling approach provided an opportunity to include both shorter as well as longer threads; older as well as more recent threads. In addition, the total number of individual messages analysed is in keeping with other published papers employing a similar analysis [28, 29]. Each conversation thread selected for analysis was downloaded and saved as it appeared, including original formatting [27].

Analysis

The two authors worked collaboratively to analyse forum posts using reflexive thematic analysis [30]. We recognize that we were *active* instruments in the research process and acknowledge the value of our experiences in shaping this work. The first author has professional experience conducting research with people with early-stage dementia, and both authors have been affected by dementia in their personal lives. For us, online forums have personally been a valuable source of information, support, and community. Throughout the six phases of analysis, we engaged in reflective discussions about our personal connections and professional interests in dementia, and how this influenced our work.

We began by reading and re-reading posts several times to support an in-depth familiarization with the data. Each message was read and considered within the original conversation thread and any salient issues noted. Secondly, preliminary codes which described basic interpretation of the dataset were generated, and applied to the dataset by both authors independently, with the first author (CT) using NVivo and the second author (NC) coding by hand. Both authors then virtually (via Microsoft TEAMS) to organize codes and data into clusters to generate initial themes and this process was facilitated through the use of MindMeister (a free online mind mapping tool). We then reviewed and revised the themes to ensure they captured the dataset appropriately. The analysis was an iterative process, which involved repeatedly moving from the raw data and generated themes, and vice versa.

Ethical considerations

Ethical approval for the current study was obtained from the Bournemouth University Ethics Committee (ID: 29602). The ethical issues raised by the study focused upon issues of privacy, confidentiality, and informed consent [31]. Specifically, when considering the extent to which the specific online discussion forum was considered in the ‘private’ or ‘public’ domain, two key factors were considered. First, neither the over-arching discussion forum nor the sub-board required any form of registration to view posted messages. Second, there were more than seventy-two thousand registered members of the forum. Taken together, it was determined that the discussion forum could reasonably be regarded as in the ‘public domain’ and therefore informed consent was not deemed necessary. Furthermore, considerable care was taken to protect the privacy and confidentiality of members through ensuring that no usernames were reported in the results and no quotes could be traced back to the original conversation thread, sub-board, or forum. Finally, details of the study and proposed data collection procedures were outlined and permission to undertake the analysis granted in writing from the Talking Point forum administrative team.

Results

Three over-arching themes were generated through our reflexive thematic analysis: 1) Journeying through dementia; 2) Reciprocal peer support; 3) Therapeutic creativity. Our themes speak to the value of Talking Point for people with dementia, providing a valuable resource for those affected.

Journeying through dementia

Forum users disclosed their personal journey with dementia. Users were at notably different points of their journey with dementia, with some having recently received their diagnosis and others having lived with dementia for several years. We produced three sub-themes that reflect key timepoints on users’ journeys with dementia: (1) Reaching diagnostic point; (2) Life with dementia; (3) Looking to the future.

Sub-theme 1: Reaching diagnostic point

Users turned to Talking Point to share their personal experiences of obtaining and adjusting to a diagnosis of dementia. They described the medical tests they had taken, often over prolonged periods of time, to finally reach the point of diagnosis. Following diagnosis, some users expressed confusion about their results and what this meant for their lives. One user was left with many questions, expressing abandonment and feeling of ‘now what?’.

> *I was diagnosed with dementia last Friday, given a test result of 81 out of Hundred? What's this really mean, I'm 68year old male…I've not had anything in writing yet, will they tell me what type dementia or do I have to ask? Does everybody diagnosed have to contact help themselves, I just feel abandoned already. It took 6months to get to this point, now what?*

Others documented the challenging emotions and thoughts they were experiencing, using the platform to make sense of their new diagnosis. They described feeling angry, upset, isolated, scared, and some struggled to accept their diagnosis.

> *I'm just 53 and was diagnosed vascular dementia just 1 week ago, after 14 months of tests. The thing is I don't believe the doctors at the hospital that I have and also keep wondering if I heard them right! My partner was with me and he said that is what they said. They offered me a nurse for a couple of months, I don't know what for? I have to go back next month and start lots of new medication. But I cannot accept the diagnosis, is it me?*

The impacts of dementia are often not just confined to the individual with the diagnosis, but also have powerful effects on loved ones [32]. Consistent with this, users explained the challenges of disclosing their diagnosis to others, with some users delaying disclosure to certain family members. Those who had disclosed their diagnosis to others shared the struggles that these individuals faced in accepting and adjusting to the diagnosis.

> *I have early onset Alzheimer's and was diagnosed 8 weeks ago. At first, after the initial shock, I seemed to take it in my stride. The hardest thing was telling my husband. We haven't told our adult children… My husband is in the angry stage and I'm afraid that the DIY's getting the brunt of his frustration. :(*

Sub-theme 2: Life with dementia

One way in which people with dementia used Talking Point was to discuss their current symptoms. These symptoms varied across users, including difficulties with apathy, behavioral changes, communication, memory, hallucinations, language, word-finding, and coordination.

> *I also have what we call "memory episodes" Where I lose blocks of time, where I have conversations that I don't remember, where I wonder to places where I don't know where I'm going*

People with diverse dementia types posted on the forum, including those with rarer forms of dementia. Talking Point appeared to be a particularly valuable space for users with rarer types of dementia to share their experiences and connect with others, given that services are typically tailored towards those with more common types of dementia [33]. For example, one user described the feelings of isolation they were experiencing due to not 'fitting' the typical Alzheimer's disease profile:

> *I have often felt so alone knowing that my symptoms and how I am does not fit the Alzheimer's on its own profile…. I can only hope that our memory clinic will now learn more about it and it will help others.*

Users often explained that their symptoms created challenges with everyday activities (e.g., reading, travelling) and the related impacts this had upon their mood, confidence, and connectedness. They also described the impact that dementia had on their identity, with many reflecting on aspects of themselves that they believed to be lost:

> *My patience has bottomed out-I used to be known as a very patient, understanding person!!!! where did I go? My grandchildren will never know who I once was. And I don't want them to know who I am, now.*

The negative consequences of dementia were further exacerbated by a lack of support, particularly for people in certain localities and those with rare forms of dementia (e.g., young-onset dementia).

> *There seems to be little support for dementia sufferers under 90 years of age in my neck of the woods. I am just wondering if I am hoping for too much?*

For these users, Talking Point appeared to provide a space where they could speak honestly and openly about dementia, which was not always easy in their offline environments

> *Somehow it's easier to acknowledge things I notice in myself and keep to myself and to TP, than to hear about changes I am not even aware of.*

Nevertheless, users frequently positioned their experience with dementia as a ‘fight’ which many were determined not to give up on. They shared the many ways in which they adapted to dementia and were able to continue doing everyday activities. For example, users described using audiobooks, voice-activated software, keeping notes and lists around the house, and doing mental exercises. They also documented the many activities they continued to do with reasonable adjustments, evidencing their ability to *live* with dementia. In particular, users discussed their experiences of artwork, crafting, gardening, photography, singing, walking, and cooking.

> *I sing in an unaccompanied choir. I have been singing for so long that I can still read the music first time. But what I cannot do now is to organize all the different sheet music into the right order - it is a mixture of books and loose sheets. My friend who sings next to me does all that now for me and it allows me to keep up my favorite pastime.*

By sharing these experiences of *living* with dementia, some users hoped that they could help individuals who had recently been diagnosed.

> *But there are many others with different hobbies, such as [NAME] who writes poems and brain games, and we need to hear from them so that we can help others who are starting on the dementia journey*

Sub-theme 3: Looking to the future

Many users recognized the temporality of their current state due to the progressive nature of dementia, often reflecting upon what their future would hold. Users discussed getting their affairs in order so that they could effectively prepare for the future. Early diagnosis enabled these individuals to prepare wills, power of attorney, and letting loved ones know their personal wishes.

> *An early diagnosis allows you to still participate and plan for the eventual inevitable. For me that was getting my personal affairs in order while I was still able to do so (i.e., wills, general and medical power of attorney, ensuring which trusted healthy family member you wanted to put on your bank accounts to manage your affairs when you're no long able to, etc., and to just let loved ones and friends know your desires and wishes for when you progress…That proved to be highly beneficial to my loved ones. It also gave me peace of mind.*

Others disclosed their emotional experiences when looking to the future, reporting a sense of helplessness due to the inevitability of symptom progression. They described being constantly alert to any sign of progression, being fearful of the unknown, and considering at what point they should stop 'battling' dementia. For one user, there was a sense of bereavement for the future life they could have had without dementia:

> *Now the realization has hit I have become tearful, withdrawn from friends and grieve for our future life.*

One concern related to the futures of loved ones, particularly the longstanding impacts that dementia may have on them. Some users were particularly concerned about lacking awareness during the later stages of dementia, while loved ones must cope with the emotional and practical consequences.

> *The things I read are real and uncompromising accounts at what this awful disease does to people, and their loved ones/carers ECT. Is this my future?? Is this, is what to come?? Will I be such a burden for my family??*

In contrast, some users documented a feeling of acceptance about the future. By accepting the future and living in the moment, they felt able to enjoy and be grateful for the current moments in their lives:

> *Alzheimer's wise, it progresses! Sometimes feel as if I am elsewhere, but no idea where that is! It could be on another planet for all I know! But I no longer panic at the first sign of yet another change. Just a quiet acceptance of what will be will be. As too how long there will be for this in betweenness of knowing and yet being in another place, who knows? Hopefully a few years yet. For the time being I can still enjoy life*

Reciprocal peer support

Our next theme describes how users of the Talking Point forum supported each other on their journey through dementia. The online conversations often began with an individual sharing their own personal story or 'battle'. In many conversation threads, there was no explicit request for support but the tone and content of replies to this 'first post' appeared to align with the explicit or presumed support needs of the forum user who initiated the conversation.

This collective intuition was evident across much of our dataset and formed the basis of the reciprocal peer support which was in abundance.

We organized this theme into three sub-themes, reflecting the types of support being provided: 1) Emotional support; 2) Experiential information and advice; 3) Companionship within the community.

Sub-theme 1: Emotional support

This sub-theme captures the many ways through which the sharing of a problem, experience or challenge elicited a range of emotional support which served to benefit users during times of need. In response to the personal stories, experiences, and problems (described in the previous theme) posted on the forum, other users would frequently reciprocate by posting a reply which shared their own personal story. Sometimes, the replies posted made explicit reference to points of similarity or shared experience. In such instances, there was an evident degree of understanding and empathy expressed.

> *I'm sorry that you have been diagnosed with AZ and it is understandable that you and your husband are having to cope with the enormity of this. The most insidious thing about AZ is that you don't know what the progression of the disease might be or how long it might and sometimes it is as though you are in a heightened state of alert watching for any minor*

It was not uncommon for the original user to make a subsequent post acknowledging how valued this support was to them. As the reply from one forum user illustrates:

> *The folks on this site are the best. I really That the folks here are so understanding and helpful. Thanks to all.*

However, in other responses it was apparent that whilst the user did not have first-hand experience of that which had previously been described, they nevertheless wished to express their sorrow and regret for what the user was going through. In most instances, this was dementia-related but sometimes other life events or challenges were shared.

Many examples of messages conveying encouragement were evident across the threads and forum users appeared to offer a sense of hope through their replies as they tried to support other users. More generally, there were numerous examples across many threads of good wishes and positive thoughts being offered to other users during challenging times.

> *Sending you vibes and love through t'internet [NAME]*

In some replies, these good wishes were framed in a more religious manner with explicit statements of how the forum user would keep the individual in their prayers.

Sub-theme 2: Experiential information and advice

As previously noted, many threads did not begin with an explicit request for support. However, the notable exception to this came in the form of messages requesting information or advice from other users. The focus of these requests varied considerably but often centered on issues we described in our first theme, *Journeying Through Dementia*, such as the aftermath of diagnosis. For example, one user posted the following message as they tried to come to terms with a recent diagnosis:

> *They offered me a nurse for a couple of months, I don't know what for? I have to go back next month and start lots of new medication. But I cannot accept the diagnosis, is it me? Or do others feel the same, and advice greatly appreciated, thankyou*

In response to this message, we found other users offering a range of experiential information and advice:

> *I think it might be good to accept the help of the nurse for the month. You'll be able to talk to her and ask questions etc.*
>
> *I was diagnosed with Alzheimer's back in July at 58. It's always traumatic to hear a diagnosis of any dementia. I went to my Gp and sat down with her and went through the letter the hospital had sent he and she explained it to me. You Gp should be able to confirm exactly what the hospital have said if you're at all unsure. We only take in a fraction of what's said when you're sat in front of a specialist. Hope this helps. There's lots of help out there to support you and Talking Point is always here.*

In many messages posted in response, other forum users would make explicit referrals to other sources of information, advice, and support. These included other sub-sections of the Talking Point forum as well as external support such as third sector organizations or services.

Sub-theme 3: Companionship within the community

There appeared to be a widespread acknowledgement that the Talking Point forum represented a community of individuals who all were all bound together through their shared experience of dementia. As one user explicitly noted, “I found it the only place that spoke the same language”; highlighting the value of the peer support which Talking Point facilitated. In response to messages where users described a lack of support, isolation or loneliness, other forum users would encourage them to connect with others who could truly understand by posting messages and joining in the conversation. These messages were particularly evident where the individual initiating the conversation thread was new to the forum. As one reply exemplifies:

> *Hello [Name] and welcome from me too. There are hundreds of us on here willing to listen to you when you want to talk. Any problems let us know. Most of us have dealt*

> *with the problems and many will have experienced them for themselves. Keep posting and join in.*

In other responses, there was no explicit encouragement to participate but rather a simple reminder that the Talking Point forum existed and others with shared experience were available.

Since the messages we analyzed were posted over several years, it was not uncommon to see the same usernames appearing across different threads and engaging in conversations around many different topics. Whilst these topics naturally included issues relevant to dementia, many conversations were quite unrelated. It appeared that through the passage of time and continued interaction through the Talking Point forum, many users had developed bonds of friendship and the forum offered a place for companionship and sense of community.

Therapeutic creativity

In recent years researchers have emphasized the value of art activities in helping people with dementia to cope with their illness [34, 35]. This was mirrored in the forum, where users often documented their creative activities such as painting, photography, crafting, collage, and textiles; in turn, developing creative communities within this sub-board. These creative activities were frequently referred to as ‘therapy’ for users, providing important stimulation and enjoyment, an alternative means of self-expression, and a distraction from the negative emotions that arose while living with dementia

> *Painting takes me to another place without problems, worries or anything nasty!*
>
> *I do agree that crafting can be so good for the soul. I saw this recently on another forum: "knitting keeps our hands busy so our minds can rest".*

By publicly sharing their creative endeavors, users hoped to inspire others living with dementia:

> *I enjoy doing lots of different crafts and thought people might get some ideas of creative activities they can do and also a place to show each other what we are doing to inspire each other*

It was clear that creative activities were a valuable coping mechanism for these users. However, some users noted that there were limited options for creativity in their local area, highlighting a 'postcode lottery' in support provision and a pressing need for a greater number of creative groups for people with dementia

> *Sadly in the North East of England where I live there are very few places where these ideas can be seen in practice, unless you travel many miles and then that causes tiredness before you even start.*

Interestingly, for some users Talking Point seemed to provide a safe space for creative self-expression about dementia, including poems and short stories. Other researchers have noted that creative storytelling can bring clarity to authors, and written self-expression may be less demanding than speech for people with early-stage dementia [36]. Therefore, Talking Point may provide some users with valuable opportunities to elaborate on their insights through metaphors and creative language to better understand and communicate their feelings – an opportunity which they may not otherwise have in their everyday lives.

Discussion

We found that the online forum Talking Point is a valuable place for people affected by dementia. It provided a space where users could document their journeys with dementia, sharing their experiences of obtaining and adjusting to diagnosis, their current symptoms, how they adapted to everyday life, and their concerns for the future. On the online forum, users engaged in reciprocal peer support, exchanging emotional and informational support, and developing a sense of community and companionship. The value of creative activities as a coping mechanism was often discussed on the online forum and for some users, Talking Point provided opportunity to engage in creative self-expression.

We observed that Talking Point provided a critical avenue through which people with diverse types of dementia could access peer support. We noted that Talking Point members did not necessarily need to ask a question or make explicit that they need support; the community appears to realise this and offer to help. Emotional and informational support were notable. In terms of information support, there was considerable signposting to support organizations. Access to such online peer support is vital given that access to appropriate offline dementia support services is lacking, particularly for people with rare types of dementia such as young-onset dementia [33]. Our findings are particularly timely since the COVID-19 pandemic and the related emphasis on online spaces for people with dementia [20]. These findings suggest that online forums such as Talking Point are filling an important gap in offline support provision. Therefore, clinicians, support workers, dementia organisations, friends, and family members of people with dementia could consider recommending online forums to help people cope with dementia. That is not to say that online peer support should replace offline peer support, but rather online forums may provide an additional cost-effective means of peer support.

Alongside the positive stories of people *living* with dementia, there were many posts of people struggling, such as the impact it had on their sense of identity and the challenges of symptom progression. This contrasts with the findings of research on other online spaces such as Twitter, which has primarily been used as a vehicle for advocacy, to challenge stereotypes and reframe dementia as a manageable disability [10, 11]. Others have critiqued dominant discourse of ‘living well with dementia’, noting how a relentlessly positive view of living with dementia portrays only a limited picture [37]. Our findings therefore suggest that Talking Point provides a space where alternative stories of dementia can be shared, particularly for those who may not connect with the dominant ‘living well’ narrative. One explanation for this may be that the online forum is specifically targeted towards those affected by dementia and is therefore less public facing when compared with other online spaces. The anonymity afforded by the online forum may also facilitate unconstrained self-disclosure, due to being ‘distanced’ from friends and family members [38].

A key finding of our analysis is that users documented their creative activities and engaged in creative self-expression on the forum. To our knowledge, this finding appears unique to dementia and has not yet been reflected in research on online forum usage by people with other chronic health conditions. Our findings highlight the value of creative activities in coping with dementia, supporting research showing the value of arts-based activities in promoting psychological well-being and affirming self-worth [35, 39]. However, it was evident from our data that not everyone has equal access to arts-based activities.

Limitations of our study

Our research is not without its limitations. Firstly, we sampled a comparatively small number of threads from a single sub-forum from one dementia organization. It is possible that analysis of other forums for people with dementia will yield further insights. In addition, we focused our analysis on the sub-forum ‘I have dementia’. Future analysis of other sub-forums about certain topics (e.g., technologies for people with dementia) or groups (e.g., LGBTQ+ people with dementia, young-onset dementia) could provide access to experiences that are not represented in our data.

The use of online data in our study means that it is not possible to verify the diagnoses of users, including the severity of their dementia. As dementia progresses, it is likely that forum usage will change. Longitudinal work which explores online experiences over time is required to further elucidate this process, having important design implications for how digital support can be adapted as dementia progresses. Furthermore, while many users were very positive about the supportive function of Talking Point, our research does not directly evaluate how people with dementia view it as a resource, as well as when and for whom it is effective. Relatedly, our three themes only capture the positive aspects of the online forum, suggesting that our research may not have uncovered negative consequences of this forum. For example, it is possible that some people may not feel inspired by the stories of those living with dementia; instead, feeling excluded from this forum and disengage. Alternatively, it is known that levels of engagement with online support forums varies and therefore, there likely exists a considerable number of users who did not post any messages and whose experiences of online support remain unknown [40]. In future, qualitative interviews with people with dementia could be conducted to gain further insight into their experiences of using online forums.

To conclude, the findings from our study capture how online peer support forums, such as Talking Point, may represent a valued post-diagnostic support venue. We document how such an asynchronous text-based communication platform may provide opportunities for individuals affected by a range of types of dementia to come together to seek and provide reciprocal support, in so doing sharing their journey through dementia as well as the various coping strategies employed. Clinicians, support workers, and organisations could consider social prescribing online support forums for people with dementia.

References

1. World Health Organisation. World failing to address dementia challenge. 2021. Available at https://www.who.int/news/item/02-09-2021-world-failing-to-address-dementia-challenge (31 May 2022, date last accessed)
2. Spreadbury JH, Kipps C. Measuring younger onset dementia: What the qualitative literature reveals about the 'lived experience' for patients and caregivers. *Dementia* 2019; 18: 579–98.
3. Roach P, Drummond N. 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *J Psychiat Ment Hlt* 2014; 2: 889–95.
4. Clarke C, Keyes S, Wilkinson H et al. Healthbridge: the National evaluation of peer support networks and dementia advisers in implementation of the National dementia strategy for England, 2013.
5. Keyes SE, Clarke CL, Wilkinson H et al. 'We're all in the same boat…': A qualitative analysis of peer support in dementia care. *Dementia* 2016; 15: 560-77.
6. Willis E, Semple AC, de Waal H. Quantifying the benefits of peer support for people with dementia: a Social Return on Investment (SROI) study. *Dementia* 2018; 17: 266–78.
7. Cations M, Withall A, Horsfall R et al. Why aren't people with young onset dementia and their supporters using informal services? Results from the INSPIRED study. *PLoS One* 2017; 12: e0180935.
8. Craig D, Strivens E. Facing the times: A young onset dementia support group: Facebook^{tm} style. *Australas J Ageing* 2016; 35: 48–53.
9. Talbot C, O'Dwyer S, Clare L, Heaton J, Anderson J. Identifying people with dementia on Twitter. *Dementia* 2020a; 19: 965–74.
10. Talbot CV, O'Dwyer ST, Clare L, Heaton J, Anderson J. How people with dementia use Twitter: A qualitative analysis. *Comput Hum Behavior* 2020b; 102: 112–9.

11. Talbot CV, O’Dwyer ST, Clare L, Heaton J. The use of Twitter by people with young-onset dementia: A qualitative analysis of narratives and identity formation in the age of social media. *Dementia* 2021; 20: 1–16.
12. Thomas B. Whose story is it anyway? Following everyday account of living with dementia on social media. *Style* 2017; 51: 357–73.
13. Kannaley K, Mehta S, Yelton B, Friedman DB. Thematic analysis of blog narratives written by people with Alzheimer’s disease and other dementias and care partners. *Dementia* 2019; 18: 3071–90.
14. Clare L, Rowlands JM, Quin R. Collective strength: the impact of developing a shared social identity in early-stage dementia. *Dementia* 2008; 7: 9–30.
15. Lim FS, Wallace T, Luszcz MA, Reynolds KJ. Usability of tablet computers by people with early-stage dementia. *Gerontology* 2013; 59: 174–82.
16. Joddrell P, Astell AJ. Studies involving people with dementia and touchscreen technology: A literature review. *JMIR Rehabil Assist Technol* 2016; 3: e10.
17. Beaunoyer E, Dupéré S, Guitton MJ. COVID-19 and digital inequalities: reciprocal impacts and mitigation strategies. *Comput Hum Behavior* 2020; 111: 106424.
18. Giebel C, Cannon J, Hanna K et al. Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging Ment Health* 2020; 25: 1–8.
19. Talbot CV, Briggs P. ‘Getting back to normality seems as big of a step as going into lockdown’: the impact of the COVID-19 pandemic on people with early to middle stage dementia. *Age Ageing* 2021; 50: 657-63.
20. Talbot CV, Briggs P. The use of digital technologies by people with mild-to-moderate dementia during the COVID-19 pandemic: A positive technology perspective. *Dementia* 2022; 21: 1363-80.
21. Vilhauer RP, McClintock MK, Matthews AK. Online support groups for women with metastatic breast cancer: A feasibility pilot study. *J Psychosoc Oncol* 2010; 28: 560-86.

22. Coulson NS, Knibb RC. Coping with food allergy: Exploring the role of the online support group. *CyberPsychol Behav* 2007; 10: 145-48.

23. Rodriquez J. Narrating dementia: self and community in an online forum. *Qual Health Res* 2013; 23: 1215-27.

24. Johnson J, Black RW, Hayes GR. (2020). Roles in the discussion: an analysis of social support in an online forum for people with dementia. In: *Proceedings of the ACM on Human-Computer Interaction*; 4: 1-30.

25. Mehta N, Zhu L, Lam K, et al. Health forums and Twitter for dementia research: Opportunities and considerations. *J Am Geriatr Soc* 2020; 68: 2881-89.

26. Donellan WJ, Warren J. Emotional word use in informal carers of people living with dementia: linguistic analysis of online discussion forums. JMIR 2022; 5: e32603,

27. Smedley R, Coulson NS. A practical guide to analysing online support forums. *Qual Res Psychol* 2021; 18: 76-103.

28. Smedly R, Coulson N, Gavin J, Rodham K, Watts L. Online social support for complex regional pain syndrome: a content analysis of support exchanges within a newly launched discussion forum. Computers in human behavior 2015; 51: 53-63.

29. Eades CE, Clarke KM, Cameron DM, Coulson N, Evan JMM. Analysis of spontaneous, user-generated data about gestational diabetes on online forums: implications for diabetes prevention. Diabetic Medicine 2020; 37: 2058-2066.

30. Braun V, Clarke V. *Thematic analysis: A practical guide*. London: Sage, 2022.

31. British Psychological Society *Ethics guidelines for internet-mediated research*. 2021. Available at https://www.bps.org.uk/news-and-policy/ethics-guidelines-internet-mediated-research (31 May 2022, last accessed)

32. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. *BMJ Support Palliat Care* 2020; Oct 14.

33. Giebel C, Hanna K, Tetlow H et al. "A piece of paper is not the same as having someone to talk to": accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities. *Int J Equity Health* 2021; 20: 76.

34. Beard RL. Art therapies and dementia care: A systematic review. *Dementia* 2012; 11: 633-56.

35. Levenberg K, George DR, Lokon E. Opening Minds through Art: A preliminary study evaluating the effects of a creative-expression program on persons living with dementia and their primary care partners. *Dementia* 2021; 20: 2412-23.

36. Ryan EB, Bannister KA, Anas AP. The dementia narrative: Writing to reclaim social identity. *J Aging Stud* 2009; 23: 145-57.

37. Bartlett R, Windemuth-Wolfson L, Oliver K, Dening T. Suffering with dementia: the other side of "living well". *Int Psychogeriatr* 2017; 29: 177-9.

38. Suler J. The online disinhibition effect. *CyberPsychol Behav* 2004; 7: 321-6.

39. Deshmukh SR, Holmes J, Cardno A. Art therapy for people with dementia. Cochrane Database Syst Rev 2018; 9: 1-29. CD011073

40. Preece J, Nonnecke B, Andrews D. The top five reasons for lurking: improving community experiences for everyone. *Comput Hum Behavior* 2004; 20: 201-23.