# **Exploring online identity construction for the caregivers of adults living with dementia and the value of interactions with health and social care professionals**

## Abstract

Becoming an informal caregiver for an adult living with dementia has been shown to have a significant impact upon the conception of identity. This study aimed to identify how identity is constructed online amongst caregivers of individuals living with dementia, and how healthcare interactions can influence identity development through the analysis of online web blogs. 16 online blogs (172 entries) were selected through purposive and snowball sampling and discourse analysis was used to analyse online identity construction for informal caregivers of adults living with dementia. Six areas of online identity construction were identified: changing family role; powerful expert social campaigner; being an advocate; guardian of their relative’ selfhood; sustaining creative and spiritual individuality and wider community member in online and real life. Further to this, the importance of health and social care service interactions in the development of caregiver identity revealed that professionals must ensure person-centred service contacts for caregivers. This is a challenging task in the pandemic climate where interactions between health and social care professionals and caregivers are limited due to isolation measures. It is evident that the blog format can provide a forum through which the identity of the caregiver of an adult living with dementia can evolve. The six areas of identity construction reveal the multifaceted nature of identity for the caregiver, and the value of belonging to an online community both in relation to identity construction and support. This finding is especially applicable in the current pandemic when accessing a face- to- face community is challenging for caregivers who may be shielding or living in isolation. The findings of this research can aid health and social care professionals in understanding the development of caregiver identity, and in providing appropriate support during service interactions, on accessing virtual and face to face community support.

Key words: Dementia; Dementia Services; Family Carers;

*What is known about this topic?*

Becoming a caregiver of an adult living with dementia impacts on constructions of identity.

Identity development for these caregivers can be influenced by interactions with health and social care professionals.

*What this paper adds?*

Online data sources can reveal the development of online identity for the caregiver of an adult living with dementia.

There is value in belonging to an online community when face to face interaction is limited, such as during a pandemic.

Health and social care professionals must develop a thorough understanding of caregiver identity to offer robust, person centred support to caregivers of adults living with dementia, which incorporates online resources.

## Introduction

As the number of people living with dementia increases, from 47 million to 75 million by 2030 (WHO, 2017), the number of those impacted by the condition is far greater, as the majority of dementia care worldwide is still provided by informal networks.

Becoming a caregiver is known to impact upon constructions of identity in both positive and negative ways (Beeson, Horton-Deutsch, Farran & Neundorfer, 2000; Martin, McEwan & Irons, 2006; Hayes, Boylstein, & Zimmerman, 2009; Sabat, 2010; Molyneaux et al., 2012; Lawson, Collerton, Taylor, Burn & Brittain, 2018). An enhanced relationship with the care receiver and an intense sense of meaning and self-purpose (Graham & Bassett, 2006; Sabat, 2010; Lawson et al, 2018) are positive aspects of identify construction that can enhance carer well-being. However, it has also been recognised that certain aspects of the caregiver identity, for example, a sense of losing one’s previous self, can have a negative impact and affect the ability to continue with care duties (Lawson et al., 2018). The sense of identity change can be more intense for carers of a person with dementia and have a more profound impact, as dementia has an added emotional requirement to protect the selfhood of the individual, which is absent in other conditions (Ory et al., 1999; Etters, Goodall & Harrison, 2008; Wadham, Simpson, Rust & Murray, 2016.)

### Defining Identity for caregivers of adults with dementia

Defining identity is complex. Stryker and Burke (2000), define identity as the, ‘meanings that persons attach to the multiple roles they typically play in contemporary societies.’ Identity narratives can be inherently contradictory and conflicting due to their status as a product of human perception (Berger & Luckmann, 1991). However, theorists (Somers, 1994) argue that individuals create stable, ‘ontological narratives’, of identity through which human beings understand continuous individuality. Further to this, Rodriquez (2013) has identified that language and communication are vital to the narrative of self and that identity only exists as a by-product of social interaction (Goffman, 1963).

There are many different theories of identity development for the carers of adults living with dementia. Some have suggested that the identity process is shaped by notions of duty (O'Connor, 2007, Lawson et al., 2018) or from the devotion of a positive and long- term relationship or even from anger or resentment (Opie, 1992). Other researchers have suggested that the caregiver and the care receiver develop a, ‘mutual dyadic identity’ (Coeling et al., 2003), which is individually negotiated between the informal carer and the adult living with dementia. Some researchers have posited that the caregiver identity, ‘develops and evolves’ (Eifert et al., 2015), through interaction including online interaction (Czekanski, 2017). Therefore, online identity construction represents an important and under researched area.

To further understand how identity is constructed online the theory of selfhood formulated by Harré (1991) can be employed, as this perspective explores identity from both a personal and public perspective. This identity model suggests that there are three aspects to the creation of individuality. Self-1 represents the immediate self (Harrè, 1998). Ideas about self-worth and personality (Harrè, 1998) make up Self-2. Finally, self-3 is characterised by how individuals represent themselves and interact with others. Within this research project, the presentation of identity for carers of adults living with dementia, in relation to self-2 and self-3, has received consideration.

### Online identity construction for caregivers of adults living with dementia

The theory of performative social interaction and identity formation proposed by Goffman (1963), offers a useful framework for understanding online identity building. The notion that identity is always a performance designed for an audience (Goffman, 1963), which considers both cultural and structural constraints, reflects the medium of online blogs and social media sites. The posts uploaded to the site are always inherently public, ‘mediated and codified’ (Pearson, 2009). Researchers (Ellison et al., 2006; Cover, 2012; Van Nuenen, 2016) have identified that creating the notion of a stable identity online is a process of production which is continuously, ‘performed and stabilised’ (Cover, 2012,). Therefore, the self being crafted online may differ from the identity of the blogger in real life (Viégas, 2006; Gil-Or et al., 2015). However, the work of Ellison et al. (2006) and others (Stefanone & Jang, 2008), has identified that bloggers are often accurate in their online identity formulations as the need for truthful self-portrayal, social validation, and comment are often key motivations for maintaining an online presence. The multiplicity, simplicity and incoherence of the online persona (Cover, 2012) has been acknowledged due to the constraints of the medium (Ellison et al., 2006). However, the power of the online forum to enable a blogger to construct a stable narrative self has been noted (Campbell and Howie, 2016) and researchers have argued the dichotomy between the, ‘real self’, identity and, ‘online self’, should be discarded (Cover, 2012). Therefore, blog analysis may offer the ability to access a more representative construction of identity than is available via more traditional qualitative methods, such as interviews and questionnaires.

Researchers such as Rodriquez (2013), Sabat (2010), Eifert et al. (2015) and Skaalvik et al. (2016), have previously explored identity formation for the caregiver of an adult living with dementia and for individuals with a dementia diagnosis, during social interactions and within traditional interview formats. However, the exploration of identity formation for carers of adults living with dementia has not been explored in alternative mediums. Anderson et al. (2017) and Kannaley et al. (2018), identified that participation in online blog communities can have an important impact on identity formation for caregivers. However, this finding has not been explored comprehensively in previous research, which has largely focused upon content analysis or the purpose of the blog medium. The COVID pandemic has accelerated the uptake of digital formats of communication, as isolation measures have impacted on the context of daily interactions. Therefore, how caregivers construct their identity is increasingly linked to online formats and spaces. Whilst online identity may or may not reflect the real-life identity of the caregiver, in the current technological climate online identities are easily as important as real-life identity constructions.

### The importance of understanding online identity development for caregivers of adults living with dementia.

It has been demonstrated that identity development and wellbeing for caregivers can be heavily influenced by interactions with health and social care professionals (Carduff et al., 2014; Raivio, Laakkonen & Pitkälä, 2015). Therefore, it is important that health and social care professionals recognise the impact that becoming a caregiver can have on constructions of identity for this carer group. In addition, it is crucial for service providers to understand how their interactions with carers and the person living with dementia can impact on the construction of caregiver identity, to enable the provision of appropriate and tailored support (Laparidou, Middlemass, Karran & Siriwardena, 2018).

Although previous research has explored the content of blogs for caregivers of adults living with dementia (Kannaley, Mehta, Yelton and Friedman, 2018; Anderson, Hundt, Dean, Keim-Malpass & Lopez, 2017), no research has specifically addressed the topic of online identity formation for this carer group. Further to this, no research has addressed how health and social care professionals shape online caregiver identity during formal interactions. To address this research deficit, we aimed to identify how identity is constructed online and how health and social care interactions can influence identity construction amongst carers of individuals living with dementia, through the analysis of online web blogs.

## Methods

### Identification of blogs

Google search engine was utilised to identify appropriate web blogs using the inclusion criteria: that the blogger was an informal care giver for an adult living with dementia and that the blogs were written in English. The search terms: ‘dementia’, ‘caregiver’ and ‘blogs’ were used in the search. Blogs written by individuals living with dementia or by non-caregivers were excluded.

### Sampling

Snowball and theoretical sampling techniques were utilised to identify appropriate bloggers. Sampling criteria aimed to achieve maximum variation in the relationship of the caregiver to the individual with dementia, alongside caregiver ethnicity and gender. These factors have been previously highlighted as important in determining both caregiving experience and identity formation (Collins & Jones, 1997; Chappell, Dujela & Smith, 2015; Sherrell, Buckwalter & Morhardt, 2001). The sample aimed to represent the experience of different family members, caring in different ways, for different periods of time. Further to this, was the aim to examine the different ways online blogging is used across both long and short timeframes. Many online entries were analysed to explore the different experiences and motivations of each of the bloggers and ensure the sample reflected broad and nuanced care experiences. During the process, a research diary was kept detailing each search and the reasons why each blog was chosen to ensure transparency (Collier & Mahoney, 1996) in the sampling process. Initially, the aim was to select 5 entries from each blog to ensure a fair representation of the content. However, the number of entries selected for final analysis from each of the blogs varied in the sample. This was due to entries varying in length from a few pages to a short paragraph. Where blog entries were shorter, more entries were selected to ensure adequate representation. Blogs written by individuals in the UK were prioritised to ensure findings reflect the context of National Health Service and social care provision.

### Analysis

The principles of discourse analysis enable a deep understanding of the format, constraints, and purpose behind the construction of the blog medium; allowing access to how discourse is used by caregivers to construct identities, ideologies and mediate, ‘power issues’, within society (Jones, 2012). The key components of discourse analysis, such as the use of semantic fields and imagery, were mapped to extracts from the data and the overall purpose of each blog was identified within the texts and coded into a table.

While completing the initial reading of all the blog entries, coding categories relating to identity were developed and applied to the data. It would not be productive to analyse in such detail the high number of entries originally selected (172) due to reaching saturation (Morse, 1995). Therefore, blogs were selected for further analysis (76) based on their ability to comprehensively address the aim of the research. From further consideration of the initial emerging coding categories, a model of identity was devised. This was utilised as a coding framework and applied to the purposively selected blogs via tabulation. This allowed the richness of the data to illuminate the different aspects of the identified key themes. During this process, theoretical approaches to identity formation, for example Eifert et al. (2015), were used to help understand and interpret the data. Alongside this process, key interactions with healthcare professionals were identified and analysed to explore how healthcare professional interactions were impacting on identity formation.

A second reviewer examined approximately 20% of the blog content, alongside the coding framework, to enhance the trustworthiness of the findings. Subsequent discussion of the codes and data interpretation helped to confirm and clarify preliminary findings that were incorporated into the results. For example, the centrality of the familial role within identity formation emerged. Extensive quotations have been included in the findings section to support the credibility of findings. A public and patient involvement group was engaged to assess the coherence and clarity of the emerging themes.

### Ethical considerations

Ethical considerations are significant within research analysing online blogs and feature in several contemporary ethical debates (Roberts, 2015; Carter et al., 2016; Sugiura, Wiles & Pope, 2017). It has been argued that blogs are inherently designed to be publicly accessible. This strongly suggests that they should be considered within the public domain (Nicholas, 2008).

The preliminary ethical review provided by Newcastle University was completed in advance of the project and stated that no further ethical review was required, with the proviso that only publicly available information and no personal information was accessed during the research project.

 Only blogs within the public domain and which were publicly accessible were analysed. No blogs which required registration with an online forum, or a login were accessed. The importance of ensuring that anonymity was maintained for blog writers (Lafferty & Manca, 2015) was recognised and therefore, data has been fully anonymised and only quotations which avoid the identification of bloggers have been utilised.

## Findings

Over 48 blogs were originally identified. 15 were excluded as they were written by individuals living with dementia and not by caregivers. 12 were excluded as they were written by American or Australian citizens. However, one American blogger was included in the sample due to the depth and breadth of the blog entries and the emphasis on the emotional impact of caregiving and not the specific health and social care context. 5 blogs which met the criteria were discarded due to a limited number of available entries within those specific blogs.

Table 1: Details of online web blogs sampled.

Please see end of manuscript for Table 1

The discourse analysis process revealed the following six themes in relation to the development of online identity for the carer of an adult living with dementia. How interactions with healthcare services and professionals shape this identity was also identified. Each theme will be described and explored in turn below. The quotations supporting each theme are included in tables 2-8.

### 1 Changing family role

The changes in identity experienced are frequently discussed by the online bloggers as they transition from the familial role held before, to the role of the informal carer for an adult living with dementia. Sometimes this transition goes unnoticed until it is identified by health and social care professionals. The bloggers describe feeling as if their own identities are being lost or replaced by the role of the caregiver. While the primary familial role remains central to the carer’s identity, analysis revealed that it is partially supplanted by the dominant caregiver/care receiver nature of the relationship.

The bloggers state that they can experience this change in identity as a duality. The evolution of a new identity as a caregiver, which conflates the changing familial role and incorporates the requirements of the care receiver, is explicitly discussed by the bloggers. Advice and reassurance, from health and social care professionals, appears to help caregivers to accept their changing family role as an organiser of their relative’s care requirements. Person-centred interactions are highly appreciated by caregivers in supporting their identity as a valued and important family caregiver. Further to this, it was also identified that professionals can give caregivers the confidence to recognise how their family role evolves to include being an expert on the care of their family member.

Table 2 Quotations related to changing family role.

Please see end of manuscript for Table 2

### 2 Powerful, expert social campaigner

A vital aspect of the carer identity evident in online blogs is that of the expert social campaigner. Campaigning to raise awareness is predicated on the concept that the caregiver and individual living with dementia have specialist and expert knowledge. The benefit of the expert social campaigner to the development of the caregiver identity is identifiable in multiple blog posts. This identity is enacted both online and in real life, as bloggers raise awareness through the blog itself and in their day-to-day encounters outside of the blogosphere. Raising awareness can be focused on reducing stigma, changing government policy or raising the profile of charity work, highlighting media misinformation, providing links to useful resources and helplines or even raising awareness amongst extended family. Interactions with formal services and health and social care professionals enable the emergence of this aspect of identity formation.

Poor experiences in the acute sector were recorded by two bloggers [Blogger 7 and Blogger 16]. These experiences clearly frustrated and angered the carers to the extent that they felt the need to act and raise awareness of the poor service experienced by individuals living with dementia while in hospital. One blogger was compelled to engage with political figures to try to influence positive change within the NHS [Blogger 7]. Another [blogger16] records an extremely poor experience trying to access culturally appropriate services and details how they faced prejudice and ignorance from both professionals and service providers. Following the death of their relative, the blogger [Blogger 16] chose to campaign for the availability of better services and understanding from health professionals and developed a professional career as a facilitator of culturally appropriate services for ethnic minorities.

Table 3 Quotations related to powerful, expert social campaigner.

Please see end of manuscript for Table 3

### 3 Being an advocate

A frequently apparent aspect of the online identity constructed is being an advocate on both a personal and public level. On a societal level, the informal caregiver identity is partially constructed through the act of being an advocate from within or against formal service provision. Sometimes, bloggers work with local health and social care systems to protect their loved one, and at other times they actively advocate against the health and social care system. The advocate aspect of the caregiver’s online identity construction can be critical of Government policy, ministers and regulatory bodies.

Interactions with health and social care professionals have the potential to be frustrating for caregivers. While these interactions are often discussed as having a negative impact upon the blogger, it is evident that these adverse interactions play a vital role in the development of the carer identity in relation to being advocate on behalf of their relative. One blogger’s [blogger 2] poor experience with GP communication, led to them developing strong advocacy skills on behalf of their family member.

Table 4 Quotations related to being an advocate.

Please see end of manuscript for Table 4.

### 4 Wider community member both in virtual and real life

Being a member of a health and social care team network enabled caregivers to develop their understanding of their new identity, including their skills, abilities, and needs, alongside accessing relevant support services. The impact of negative or unsatisfactory interactions on the capabilities and confidence of the blogger was evident, revealing the vital importance of each service interaction. Specific services and individuals were identified as being particularly helpful and supportive.

Table 5 Quotations related to wider community member both in virtual and real life.

Please see end of manuscript for Table 5.

### 5 Guardian of their relative’s selfhood

A more personal aspect of the caregivers’ online identity construction is revealed through the tendency of the bloggers to utilise the blog as a medium through which to function as a guardian of their relative’s selfhood. This aspect of the caregiver’s identity is concerned with retaining the personhood of the relative living with dementia. The blogs were often used as a place to reminisce about their relative and the aspects of their identity that made up their personality and individuality. Sometimes the task of reminiscing and preserving the personhood of the relative living with dementia was explicitly acknowledged by the carer and sometimes it was an implicit objective of the blog.

Table 6 Quotations related to being the guardian of their relative’s selfhood

Please see end of manuscript for Table 6

### 6 Sustaining creative and spiritual identity

Another personal aspect of the online identity constructed is the maintenance of the creative and spiritual aspects of the carer’s identity. The blogs include discussions and photographs of hobbies ranging from writing (blogger 10) to jazz improvisation (blogger 11). The importance of being able to access hobbies and activities away from care duties is expressed across the blog entries. Spirituality through formalised religion is discussed within the blogs. Further to this, the importance of the blogging process itself, in supporting spirituality for the caregiver, is explicitly mentioned. This aspect of the carer identity is vital to ensuring the continued individuality of the blogger and in preventing the caregiver role from becoming overwhelming.

Table 7 Quotations related to sustaining creative and spiritual identity.

Please see end of manuscript for Table 7.

### 7 Wider community member both in virtual and real life

A more public aspect of the online identity constructed consists of the role played by the caregiver within multiple communities online and in real life. These multifaceted communities consisted of health and social care team networks, support groups, informal carer or family and friend networks and the online blog community itself. The value of being a community member was expressed by several bloggers, who highlighted the loneliness that could accompany the isolating role of the caregiver. The importance of being a member of a health and social care professional network, in enabling decision making and receiving advice, was discussed by several bloggers.

Being a wider community member positively contributed to the identity and social life of the bloggers. Bloggers commented that being a member of various communities, helped them to fulfil their caring responsibilities. Being a community member of a support group, ran by a charity, could provide a vital social outlet and a place to locate valuable information and support. The virtue of being a member of the online community, for the construction of the carer’s identity, was apparent in the blogs. The online forum and community offered a place for advice, support and for developing a robust social network.

It is evident from the details given in the blog posts, that positive and robust support from healthcare professionals and services can help carers develop the correct skills and abilities to become active members in the health and social care professional partnership. Interacting with healthcare professionals and services consumes a significant amount of the carer’s time and therefore, has a profound impact upon the development of their identity. It is evident that positive interactions have a significant influence on confidence levels and carer’s recognising their abilities and strengths. Conversely, even negative interactions appear to be able to have an impact on long term positive identity development.

Table 8 Quotations related to being a wider community member both in virtual and real life

Please see end of manuscript for Table 8

### Discussion

### Absence of variation in data

Previous research has indicated that gender, familial relationship, and position have a significant impact upon the experience of being a caregiver for a person living with dementia (Kirsi et al., 2000; Hong & Coogle, 2016). However, the online identities constructed by male and female bloggers were broadly comparable, with no gendered patterns emerging from the data. We hypothesise that this may be due to the caregivers having more in common, through the choice to blog itself, than their division due to gendered experiences.

### Online identity construction analysis

The six areas of identity depicted by the bloggers reveal how caregivers construct and perceive of their identity in the online format. That identity construction was grounded in the familial role corresponds with the findings of other researchers (O'Connor, 2007; Eifert et. al 2015; Skaalvik et al., 2016). The changing nature of the family role has been identified in findings related to caregivers of adults living with dementia previously (Graham & Bassett, 2006; Molyneaux et al., 2012). However, former findings have been limited to family carers who were children or spouses. In our study, this changing family role was evident amongst carers with a multitude of relationships with the person living with dementia. Therefore, the importance of the changing familial role in the development of caregiver identity emerges as applicable to caregivers, regardless of their previous familial role.

The importance of creativity and spirituality to caregiver identity has been identified in previous studies (Lewis, 2015; Hillman, Jones, Quinn, Nelis & Clare, 2018), in helping to preserve continuity and a sense of purpose for the caregiver (Czekanski, 2017). De la Cuesta-Benjumea (2011) argued that the primacy of these aspects of identity support the requirement for robust respite services to be available to carers, the importance of which was mentioned by the bloggers on multiple occasions. Indeed, the significance of the blog as a respite activity to support the creative and spiritual aspects of the blogger’s identity was evident in the data. Whilst the importance of blogging as a tool for identifying support and information gathering has been noted previously (Anderson et al., 2017; Kannaley et al., 2018), the inherent respite aspects of blogging as a creative outlet have not been identified. The ability of the blog to function as a place to express spirituality requires further exploration, especially as online activity becomes more prevalent in the pandemic context.

The caregiver’s representation of themselves as the guardian of their relative’s selfhood (Morhardt & Spira, 2013; Wadham et al., 2016) and the desire to raise awareness of the experience of carers and individuals living with dementia has been previously identified, although not via the medium of online analysis. Similarly, the ability of campaigning to enable caregivers to develop autonomy and self-confidence (Bursch & Butcher, 2012) has been discussed outside of the online context. This highlights the importance of these activities, in promoting positive identity formation, both in the real world and online context. That carers regard themselves as advocates for their relative living with dementia corresponds with previous findings (Hillman et al., 2018) that the caregiver strives to facilitate, protect, and preserve the selfhood of their relative (Kitwood, 1997; Hillman et al., 2018). The importance of the caregiver’s identity as a guardian of selfhood, must be acknowledged by health and social care professionals during interactions and caregivers must be referred to appropriate community groups that can support them in their campaigning role.

That public aspects of the caregiver identity are supported through community involvement and socialisation has been previously established (Acton, 2002; Golden, 2005; Hennings & Froggatt, 2016). The importance of community membership for information sharing (Czekanski, 2017) and companionship (Bursch & Butcher, 2012) for caregivers of adults living with dementia has been widely discussed. However, the online community can also be an important municipal through which social aspects of the caregiver identity emerge. Our findings indicate that a deeper understanding of the relationship between community and identity development for the caregiver, specifically in the online context, may illuminate this further. In practice, health and social care professionals should aim to signpost caregivers to online community support services and forums to enable access to social and community networks. In future practice, online services and forums should be central to professional signposting as they are accessible to caregivers who may be shielding or reducing face to face contact as part of their caregiving role.

Caregivers spend many hours interacting with a multitude of different health services and social care providers, with a variety of functions such as; organising care for their relative; seeking advice, guidance, and information; and for emotional support and counsel. The characterisation of these interactions in the blog posts reveals that they are often adversarial, complex, and diverse, requiring significant time and energy reserves from the bloggers. The impact that such interactions have on the development of identity is evident in multiple blog posts.

The identified importance of health and social care interactions exposes the significance of each service contact in the development of identity for caregivers. The importance of these interactions in developing online carer identity has not been considered in previous research within this topic area. The importance of each interaction in developing confidence and skills for the caregiver, entails that professionals should aim to prepare for each contact and support the caregiver through a person-centred approach. This is further supported by the poor experience of one blogger, as a member of an ethnic minority, where a stereotyped attitude towards the needs of the caregiver was displayed, rather than employing person centred practice. Providing person centred interactions can be challenging during pandemic periods. Therefore, health and social care providers need to adopt policies and procedures that will ensure person centred practice, during periods where isolation measures are in place.

### Further theoretical considerations

In relation to the ideas of selfhood developed by Harrè (1991), the analysis revealed that aspects of self-3 are developed through interaction with community and via campaigning and advocating publicly. Aspects of Self-2 are developed through ideas about personal characteristics as a family member, creative individuality, and the guardianship of the loved one’s selfhood. These findings expand the work of Rodriquez (2013), who explored elements of identity in relation to adults living with dementia, to include online identity formation for caregivers. Previous research (Sabat, 2010) has considered the development of constructions of self-2 and self-3 for caregivers but in a case study format and outside of the medium of the blog. Therefore, these findings develop the application of Harrè’s model (1998) in relation to caregivers, further than has been achieved previously and using a previously unexplored data source.

The online identity of each blogger was stable and cohesive across many different posts and significant time periods, ranging from months to years. This supports previous findings that the online identity is a valid and representative portrayal of the caregiver’s true characteristics (Campbell and Howie, 2016). This indicates that online spaces and identity representations should be given further attention from the research community, as an alternative to the identity represented in traditional interview methods. Although the online space is a simplistic forum which entails that identity is codified in standardised formats (Cover, 2012), this is similarly true of the interview or ethnographic medium. The online forum allows the caregiver the opportunity and control to portray their identity in the manner they choose over a period they specify, rather than being asked to represent themselves in a shorter time frame, within the confines of an interview or whilst under observation. Therefore, there is a valid argument that the online identity portrayed is as accurate as those represented in other mediums, including real life.

### Implications for practice

The findings of this analysis indicate several ways that health and social care professionals can support caregivers of adults living with dementia to construct a positive identity role. These include ensuring that caregivers are signposted to voluntary groups and active campaigning organisations; highlighting relevant online forums and resources which may support the caregiver; identifying appropriate respite facilities and funding to allow for continuance of creative and spiritual outlets for the caregiver and actively supporting the caregiver in their changing role. Ensuring that each interaction is conducted in a person centred and supportive manner is also vital. The value of online resources and forums will undoubtedly continue to develop as health and social care systems adapt to the new support features available, through advances in technology vital in the wake of the COVID 19 crisis and potential future scenarios, where face to face support may be limited.

### Strengths and limitations

A tangible strength of the method of blog analysis is the removal of researcher bias (Jones & Alony, 2008). This is due to the absence of interaction during data collection. However, selection bias (Silverman, 2013) can be present in both the blog entries chosen and the individual bloggers selected by the researcher.

Another noted strength of the blogs selected for inclusion in the project, is the variety of blog entries, which reflect wide diversity in familial relationships. A balance of male and female bloggers was sought although it is acknowledged that those who choose to blog may represent a particularly literary section of the caregiver community. However, the dominance of female bloggers in the sample, ensures that the findings will be more applicable to female caregiver’s identity constructions online. The involvement of a patient and public group and a second researcher in the analysis process are identified as tangible strengths of the research method. Discussions with a second researcher allowed the author to clarify emergent findings and discuss areas of identity formation further than would have been possible in isolation. Discussions with the patient and public group identified how the findings might influence professional practice during health and social care interactions.

## Conclusion

The six themes identified reveal the multifaceted nature of online identity for the caregiver of an adult living with dementia and the value of belonging to an online community, both for identity construction and support, particularly during pandemic conditions. The analysis of online identity construction has revealed the importance of health and social care professionals ensuring appropriate respite referral and being aware of online support services and voluntary groups available to caregivers, who may struggle to access face to face support. Further to this, service interactions must be person centred and acknowledge the individual needs of caregivers from diverse sections of society. Health and social care professionals must develop a thorough understanding of caregiver identity to offer robust and appropriate support, which incorporates online resources, to the caregivers of individuals living with dementia.

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## Tables

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| Table 1: Details of online web blogs sampled. |  |
| Blog | Time period of blog | Number of blog entries online | Number of blog entries initially analysed. (n=172) | Number of blog entries analysed included in the data. (n=76) | Relationship of carer to person living with dementia |
| 1 | 7 years | 2045 | 12 | 5 | Son |
| 2 | 4 years | 79 | 6 | 5 | Daughter |
| 3 | 7 years | 234 | 12 | 8 | Daughter |
| 4 | 3 years | 335 | 17 | 5 | Daughter |
| 5 | 7 years | 24 | 6 | 5 | Son |
| 6 | 5 years | 175 | 17 | 7 | Granddaughter |
| 7 | 8 years | 208 | 28 | 9 | Son |
| 8 | 1 entry | 1  | 1 | 1 | Daughter |
| 9 | 4 years | 720+ (unable to calculate as unsorted blog entries with multiple tags)  | 26 | 8 | Husband |
| 10 | 10 years | 536 | 10 | 5 | Wife |
| 11 | 6 years | 311 | 10 | 6 | Husband |
| 12 | 2 years | 13 | 6 | 6 | Partner |
| 13 | 4 years | 38 | 7 | 5 | Daughter |
| 14 | 2 years | 22 | 5 | 5 | Daughter |
| 15 | 4 years | 14 | 8 | 5 | Wife  |
| 16 | 1 entry | 1 | 1 | 1 | Daughter |

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| Table 2: Quotations related to changing family role |
| Blog Number | Quotation |
| Blog 2 | *“I didn’t even consider myself a carer; it was dad’s social services manager who told me I was.”* |
| Blog 12 | *“The other thing I have struggled with this month is ‘who am I? Even though I have this many hats and some days it does overwhelm me I still wouldn’t change looking after \*\*\*\*\*, because that’s what I would do.”*  |
| Blog 12 |  *“I’m no longer \*\*\*\*\*’s partner or lover, I haven’t been for a very long time. I have said before I’m the carer first – that’s what people see.”*  |
| Blog 14 | *“Experts and professionals involved in dementia care have insisted to me that she is better off in a care home. This reassurance has put my mind at rest for weeks, and even months, at a time.”*  |
| Blog 11 | *“The significant difference was that whereas the Doc’s approach is firmly person centred and he is as interested in what the patient can do as what they can't, the neurologist was very clearly working to a check list. The difference between being seen by the Doc and this robot [neurologist] is that when you walk away from an appointment with the Doc you feel positive, even though there is rarely anything substantial to feel positive about. When we walked away this time [from neurologist], we felt totally negative about the experience. Essentially, the difference is about being treated as a whole person rather than a brain with a body attached to it.”*  |
| Blog 11 | *“I keep having to remind myself that the Doc always told me that I was the expert on caring for (Individual with dementia diagnosis).”*  |

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| Table 3: Quotations related to powerful, expert social campaigner |
| Blog Number | Quotation |
| Blog 3 | *“My view is that you need those with direct past and present knowledge and experience of dementia to be at the forefront of policy making, privately and publicly.”*  |
| Blog 7 | *“It’s been a busy week, dementia-wise. Two Dementia Friends awareness sessions, an Alzheimer’s Society Memory Walk, the \*\*\*\*\*\*\*\*\*\* NHS Trust AGM.”*  |
| Blog 3 | *“Whether your battles are with care home management, hospitals, care agencies, PCT’s or social services, it can easily become an all-consuming, personal quest for the care, justice and fairness your loved one deserves.”*  |
| Blog 7 | *“Did the radiographer have any idea what a diagnosis of dementia means? It made me wonder whether ALL NHS staff should have some training in dementia care. No, that’s wrong. It didn’t make me wonder that at all. It made me convinced that they should and a little frustrated that they clearly haven’t, which is why I shall be sending a copy of this blog post to the Secretary of State for Health.”*  |
| Blog 16 | *“Trying to access day care services for my Dad brought its own problems. After all don’t Asians “take care of their own?” There is a perception amongst statutory bodies that Asian communities don’t use services because of extended family networks.”*  |

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| Table 4: Quotations related to being an advocate |
| Blog Number | Quotation |
| Blog 15 | *“Mostly people with frontal temporal lobe dementia need an advocate to deal with daily living, so of course this involves taking over their life just like one makes decisions for a child so as to keep them from harm.”*  |
| Blog 3 |  *“This often also involved us demanding to see doctors or other professionals just to ensure that dad had the assessments he needed in a timely fashion”*  |
| Blog 3 |  *“Because hospitals are not places where people with dementia generally thrive, you then spend every waking hour with your loved one.”*  |
| Blog 7 | *“So please forgive me if, unlike Mum, I’ve climbed aboard this particular box of soap. The figures don’t add up. The fragmentation of dementia care is unfair and relies far too much on people who don’t have a real voice in this debate.”* |
| Blog 2 | *“I spent hours talking to doctors, nurses, lawyers, carers and care agencies, care home managers and staff, NHS and social care employees of all ranks, bank managers and equipment providers, sorting out issues, arranging appointments, cajoling and complaining, buying and explaining.”*  |
| Blog 13 | *“GPs need to concentrate on all the annoying medical stuff nowadays, they can’t be counsellor, vicar and friendly uncle AND sort out the diabetes, heart disease and possible cancers – sorry. You are essentially on your own and you have to shout pretty loud to make yourself heard above the clamour of others in a similar situation.”*  |

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| Table 5: Quotations related to wider community member both in virtual and real life |
| Blog Number | Quotation |
| Blog 4 | *“I told her about being hit so hard across the ear I cried for two hours, she suggested she should re-refer me to the carer's department at Social Services. I received a phone call the same day.”*  |
| Blog 1 |  *“(The impact of) Not getting that help quickly enough or in the correct manner had on our ability to live, love and cherish and also the implications it has 24 hours (a) day on our confidence, abilities and happiness.”*  |
| Blog 6 |  *“We are lucky in \*\*\* as we have many Admiral Nurses to assist with carers and the sufferers but in the South West there are very few.”*  |

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| Table 6: Quotations related to being the guardian of their relative’s selfhood |
| Blog Number | Quotation |
| Blog 10 | *Tears welled up as I watched \*\*\* on the video and was reminded of the man he was before we knew anything about dementia.* |
| Blog 2 | *“I concluded that, with my growing body of writing about mum, I am truly re-membering her, re-collecting her, piecing together in my mind the woman she was without her dementia, and paying tribute to her.”*  |

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| Table 7: Quotations related to sustaining creative and spiritual identity |
| Blog Number | Quotation |
| Blog 11 | *“I currently use the money to pay for home care one evening a week to enable me to go back to an improvisation group I was attending before \*\*\* lost her mobility. I do find this therapeutic.”*  |
| Blog 9 | *“My day got off to a good start when I met \*\* one of my friends from the Buddhist Meditation Group I returned home from the calm of Buddhism to the storm of Dementia.”*  |
| Blog 10 | *“Caregivers and people who blog tell their story, and while they write about the abnormal that has become their norm, they find spiritual healing in the midst of chaos. Writing is therapy for those who struggle with grief.”*  |

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| Table 8: Quotations related to being a wider community member both in virtual and real life |
| Blog Number | Quotation |
| Blog 1 | *“I was thinking that today how lonely I would be without this [online] campaign and the kindness of others who feel like I do.”*  |
| Blog 9 | *“I’m spoiled for choice with the level of support that is available to me as a Care Partner this morning. \*\*\* our social worker never works on Wednesday’s and \*\*\* my Admiral Nurse is on a course in London. Despite the unavailability of such key personnel I still have a number of professional staff I can turn to chat over my next move.”*  |
| Blog 11 | *“We have been able to return to the weekly 'Singing for the Brain' sessions that we so enjoy. \*\*\* occasionally joins in with the singing and always enjoys the social side, meeting people we have now known for several years.”*  |
| Blog 14 | *“When I started this blog, I was touched by kind messages from people I hardly knew telling me to take care of myself.”*  |
| Blog 1 | *“Lately I /we have had amazing advice and support from the amazing District Nurses’.”*  |
| Blog 9 | *“I would not have survived yesterday without significant help from friends (including cyber) professional staff, and family members.”*  |