THE SUBJECTIVE EXPERIENCE OF EARLY ONSET ALZHEIMER’S DISEASE:
USING ONLINE COMMUNITIES TO COMBAT SOCIAL ISOLATION

by

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Abstract

This thesis explores the ways people with early onset Alzheimer’s disease (EOAD) use online communities to address social isolation. Netnography and interpretive description directed the qualitative analysis of archived discussion threads (n=569) within an online forum involving 40 participants with EOAD.

Online interaction fostered social connection and redefined life following diagnosis. Textual discourse focused on normalizing the experience of living with EOAD, promoting a community culture of belonging, and developing coping mechanisms intended to enhance self-care and preserve independence. Members found purpose in using the forum as a platform to empower users, or through learning about advocacy roles outside of the online environment. Technological concerns and caregiver involvement surfaced as potential factors impacting online interaction.

Overarching findings were conceptualized as benefits offered through the communication medium or motivated by community members. Attention was drawn to technical and practical considerations that focused on enhancing the social experience and supporting overall well-being.

Keywords: Early onset Alzheimer’s disease, online communities, social isolation, netnography, interpretive description.
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I reserve my greatest gratitude for the dementia pioneers, whose words saturate this report. I walk away from this experience humbled by their contagious fight for a life following diagnosis.
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CHAPTER 1

INTRODUCTION AND BACKGROUND

The progressive nature of early onset Alzheimer’s disease (EOAD) necessitates abrupt lifestyle changes, often disrupting the essential social ties of middle age. To advance the understanding of this degenerative disease though a subjective lens, researchers have explored the individual experience of living with EOAD, learning how functional and social losses following diagnosis contribute to isolation. Literature has indicated that individuals with EOAD can recreate a sense of community and cultivate supportive relationships within online environments. Nonetheless, there is insufficient research investigating how people with EOAD use online communities to enhance social well-being. Recognizing the need for socialization post diagnosis and the gap in research about the value of online communities, the proposed study seeks to explore the ways in which online forums may be used to combat social isolation experienced following a diagnosis of EOAD.

Background

Alzheimer’s disease (AD), the most common form of dementia, is an illness that does not discriminate. This irreversible neurodegenerative disorder affects people across a broad spectrum of ages and socioeconomic backgrounds. AD comprises 60% to 80% of all documented cases of dementia (Alzheimer’s Disease Facts and Figures, 2015). Early onset Alzheimer’s disease (EOAD) is a subset of AD, and although it is the most rare form of dementia, the effects are devastating. To provide context to the prevalence of EOAD in developed regions of the world, approximately 200,000 people in the United States, 70,000 in Canada, 26,000 in Australia, and 42,000 people in the United Kingdom
have been formally diagnosed as of 2015 (Alzheimer’s Association, 2015; Australian Institute of Health and Welfare, 2012; Chang, Patel, & Schulz, 2015; Dementia UK, 2014). These statistics may understate the magnitude of EOAD on a global scale.

Empirical data with respect to EOAD is limited as research specific to the epidemiology of EOAD is scarce, and the majority of existing scholarly works focus on prevalence and incidence of dementia as a general diagnosis. Additionally, current statistics are not representative of individuals that are exhibiting symptoms or of those currently seeking diagnosis. Duthey (2013) explains: “The assumption is that all of those with [young onset dementia] seek help early in the disease course. This is not always the case, and therefore studies will underestimate the true prevalence of dementia” (p. 14). Insufficient data on the occurrence of EOAD in developing countries further dilutes the reported global prevalence of the disease (Alzheimer’s Disease International, 2015; Zhu et al., 2015).

The World Health Organization (WHO, 2015) estimates that 47.5 million people are currently living with dementia. They predict that the incidence of dementia will increase to 75.6 million people by 2030. This projected burden is in great part due to an aging population, increased life expectancy, and a rising incidence of AD diagnosis for people in developing countries (WHO, 2015; Brookmeyer et al., 2007). The forecasted increase in AD as noted by Brookmeyer et al. (2007) encompasses all forms of AD, including EOAD, and one can infer that as the documented prevalence of AD increases, so too will the prevalence of EOAD. An increase in the measured incidence of EOAD can also be expected as populations in developing countries become better represented in the statistical data (Alzheimer’s Disease International, 2015). Panegyres, Chen and the
Coalition Against Major diseases (2014) support this assumption. They report that indigenous populations in areas of China, India, Korea, Qatar, Singapore, Taiwan, Benin, Egypt, Nigeria and Brazil have a higher prevalence of EOAD than other populations, resulting from sustained exposure to factors that negatively impact social determinants of health and increase the incidence of comorbid illnesses.

The burden of dementia is evident across a spectrum of socio-demographic and cultural backgrounds. And yet a diagnosis of AD prior to the age of 65 adds a distinct set of challenges. An acute change in professional identity, family dynamic and personal relationships can contribute to social withdrawal and feelings of isolation (Clemerson, Walsh, & Isaac, 2014; Gillies, 2001; Harris, 2002; Holst et al., 2003; Johannessen, & Moller, 2013; Moyle et al., 2011; O’Sullivan, 2011). Moreover, an absence of age-appropriate social resources or impaired access to community services can further marginalize individuals with a diagnosis of EOAD (Hayo, 2015; Roach & Drummond, 2014; Bakker et al., 2014).

Online communities have emerged as a space for information exchange and reciprocal support for individuals with a chronic illness or mutual interest. Social interaction online has demonstrated potential to negate social isolation and withdrawal by fostering connection and feelings of empowerment amongst members (Coulson, 2005; Highton-Williamson, Priebe, & Giacco, 2015; Hoffman-Goetz & Donelle, 2007; Hoybye et al., 2005; Johnston et al., 2013; Kirk & Milnes, 2015; Mo & Coulson, 2008; Obst & Stafurik, 2010; Van Uden-Kraan et al., 2008; Valtchanov, 2014). Individuals with a diagnosis of EOAD have indicated a willingness to engage within an online social environment, cultivating a sense of community and close relationships (Daley, 2014;
Rodriguez, 2013). This research project is meant to examine the social dimension of an online community for individuals with a young-onset dementia (YoD). In particular, the ways in which engaging within an online forum may help to supplement the social void created following a diagnosis of EOAD.

**Definitions of Terms**

Early onset Alzheimer’s disease, social isolation and online communities are the core concepts that root this project. They are defined below.

**Early Onset Alzheimer’s Disease**

EOAD, a type of YoD, is a progressive neurodegenerative brain disorder. Zhu et al., (2015) assert that no formal definition of EOAD exists. Rather, it is a subtype of Alzheimer’s disease (AD) that affects people under the age of 65. For the purpose of this research study, EOAD will have the same definition as AD, with age of onset being the differentiating factor. The age cutoff is regarded as a “sociological partition according to employment and retirement age” and holds no biological significance (Zhu et al., 2015, p. 2). People as young as 30 have been diagnosed with EOAD, however clinical diagnosis is most common between the ages of 45 and 55 (Alzheimer’s Association, 2015).

The pathological process of AD involves neural changes that include intraneuronal (neurofibrillary tangles) and extracellular lesions (senile plaques) (Dubois et al., 2010; Duthey, 2013). These neural changes manifest as an accumulation of amyloid deposits, which lead to the eventual atrophy of affected areas. The dense formation of plaque begins in the hippocampus, which serves as the memory and learning region of the brain. Neuropsychiatric changes in persons with AD impair cognitive, behavioral and social functions. As the disease progresses, neuritic plaques (or nerve inflammation) develop in
surrounding areas of the brain, ultimately leading to death. The causes of EOAD are not well understood, however, research indicates that genetic predisposition, family history, and social determinants of health are all contributory factors (Alzheimer’s Association, 2015). EOAD typically manifests itself through memory loss that impacts daily life, impaired judgment, increased confusion, and challenges in planning or problem solving (Alzheimer’s Association, 2015; WHO, 2015).

Reisberg (2016) identified seven stages to describe the functional, cognitive and behavioral changes associated with AD. He explains that there is an absence of symptoms in Stage One. In this clinical phase, cognitive functioning is considered normal. Stage Two is classified within the normal realm of forgetfulness: Subjective complaints are related to reduced recall, often attributed to age-related decline. It is during Stage Three that cognitive impairment becomes more obvious in professional settings and functional tasks. Known as mild cognitive impairment (MCI), cognitive and behavioral changes during this phase may progress at a slower rate and compensatory mechanisms are used to conceal lapses in judgment. Reisberg (2016) reports, “MCI subjects are commonly midway or near the end of this stage before concerns result in clinical consultation” (Clinical Stages of Alzheimer’s 2016, Stage Three: Mild Cognitive Impairment, para. 3). It is during Stage Four of the illness trajectory, mild Alzheimer’s disease, that overt deficits become apparent. During this period, an accurate diagnosis may be obtained. While individuals are able to live independently during this stage, their ability to manage instrumental tasks is compromised. Most evident is one’s inability to manage finances and home responsibilities. The mood during this stage, according to Reisberg (2016), is typically a “flattening of affect and withdrawal” (Stage 4: Mild
Alzheimer’s Disease, para. 3). Although the person is aware of their deficits, denial and fear drive the absent-like emotional state of being. Hiding their cognitive deficits as a protective mechanism, “the patient withdraws from participation in activities such as conversation” (Clinical Stages of Alzheimer’s 2016, Stage Four: Mild Alzheimer’s Disease, para. 3). Need for increased assistance bleeds into the basic activities of daily living during Stage Five (Moderate Alzheimer’s Disease), evident by an increased need for support with dressing in weather appropriate clothing, and meal preparation. Correspondingly, remote memory and orientation are compromised. Reisberg (2016) adds: “Characteristically, some of these important aspects of current life are recalled, but not others. Also, the information is loosely held, so, for example, the patient may recall their correct address on certain occasions, but not others” (Stage 5: Moderate Alzheimer’s Disease, para. 3).

Moderately severe (Stage Six) and severe (Stage Seven) AD manifests in the final stages of the illness. They are characterized by an increased need, and ultimately full dependence with basic care (toileting, bathing, and in the final stage, feeding). During Stage Six, there is persistent confusion and limited recall. Extreme emotional changes are also most apparent during this stage. Biological changes and loss of creative outlets can lead to inappropriate behaviors and angry outbursts. A breakdown of speech occurs in the final phases of moderately severe AD. With severe Alzheimer’s (Stage Seven), impaired speech is lost and basic functioning requires continuous assistance. Individuals in this stage of the illness will succumb to the disease itself or from secondary factors such as aspiration-induced pneumonia. It is relevant to note that the insidious nature of EOAD means that the progression of symptoms is variable and individual dependent,
making the experience of living with the disease unpredictable for clients and their caregivers. Because of variation and unpredictability, average timelines for each stage were not presented in this summary.

**Social Isolation**

A variety of definitions have been used to explain the notion of social isolation. In his comprehensive review of social isolation in older adults, Nicholson (2009) found that many traditional explanations were brief in their description of the concept. In reviewing a number of definitions for social isolation that identified physical, health-related or subjective measures as a contributory factor, Nicholson (2009) redefined the term to be more comprehensive. He defines social isolation as “a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and is deficient in fulfilling quality relationships” (p. 1346). It is not the intent to cast finite distinctions between physical and emotional aspects of social isolation by reducing the concept solely to objective (number of contacts or activities) or subjective (unmet social engagement) measures (Cornwell and Waite, 2009; Hawkthorne, 2006). As such, Nicholson’s (2009) refined definition best represents the complexity of issues contributing to social isolation for individuals with EOAD and will be formally adopted for the purpose of this study.

**Online Communities**

In order to accurately describe online communities, it is important to first define the traditional meaning of community. The classic definition highlights location as a defining factor. Hopkins et al. (2004) question whether community can exist “in the absence of a localized geographic dimension” (p. 372). They identify physical
boundaries as a key factor in their interpretation of the concept. Elaborating on their definition, Hopkins et al. (2004) note that communities are “groups [that] have more than just a single strand of interest to bind members, but consist of a network of people linked by a shared set of interests and concerns” (p. 372). The concept of online communities alters this traditional definition of community by eliminating the constraints of a localized geographical dimension. Plant (2004) describes online communities as “a collective group of entities, individuals or organizations that comes together either temporarily or permanently through an electronic medium to interact in a common problem or interest space” (p. 53). These public, Internet-based communication tools create social aggregations without geographical boundaries (Eysenbach et al. 2004). For the purpose of this research, the concept of online community will be used as an umbrella term that includes discussion or message board, online forum, and online communication medium. These terms will be used interchangeably in this report when referencing the online space under study.

**Project Description**

**Project Purpose and Research Questions**

The purpose of this thesis is to advance current understanding of the role of online communities by investigating the ways people with EOAD may use online forums to combat the challenges of social isolation. Secondary questions have been established to guide the data collection and analysis phases of the thesis process. They are as follows:

Primary Research Question

1. In what ways does engagement within an online community help to combat social isolation experienced by individuals with early onset Alzheimer’s disease?
Secondary Questions

2. What are the motivators to social interaction within the online forum?

3. How do conversations typically progress and how are they maintained?

4. What expressions of belonging are demonstrated?

Project Method

A qualitative analysis served as the framework which guided understanding of the subjective online social experience of individuals with EOAD. Mixed methodologies of netnography and interpretive description focused the collection of data and interpretation of findings. The lived online experience of YoD forum users was informed by a netnographic approach, in which archived textual communications and observed community behaviors were utilized to examine the ways virtual environments may be used to address social isolation. Thorne’s (2008) interpretive description concentrated study conclusions to draw applicable recommendations intended to inform nursing practice.

Significance and Relevance

Due to the advent of online technology, communities have evolved from traditional location-bound networks, providing new opportunities for social interaction in an online communication medium. This modern, interests-based interpretation of community is in large part due to the accessibility of virtual spaces regardless of geographical constraints or isolation brought on by stigma, illness or schedule (Hopkins et al., 2004). Online communities, which can take form in chat rooms, online forums and discussion or message boards, have created a space for people with chronic illnesses to seek information, share stories, and give and receive support.
The objective of this study is to explore the ways in which engaging within an online community may help to lessen social isolation experienced by Internet users with a formal diagnosis of EOAD. Findings gleaned from the analysis of the subjective experience will guide and inform disciplinary thought (Thorne, Reimer-Kirkham, & O’Flynn-Magee, 2004). To begin, health professionals must understand the ways in which online social engagement can complement traditional forms of interaction, allowing them to provide clients with the means to address deficiencies in services that fail to facilitate and support social well-being. Furthermore, within the context of an often resource-strained healthcare environment, care providers need to recognize the benefits virtual social outlets may present for people with EOAD, or alternatively, address any potential drawbacks to the open nature of the online platform so it can serve as a safe and inclusive setting for socialization. Equally, persons with EOAD should be aware of existing support services and communities in both physical and online modes of interaction. In their simplest form, online social resources can be better disseminated to individuals with EOAD. Ultimately, this investigative review has the potential to contribute to understanding and awareness about the ways in which people with EOAD use virtual arenas to help address social isolation and may also lead to innovative methods of online based services tailored to this specific subset of dementia.

Outline of Paper

The thesis is organized into six chapters. The first chapter presents the background, significance and purpose for the study. In Chapter Two, a comprehensive literature review describes how social isolation may manifest following diagnosis, and the ways in which online communities serve as a complementary tool to address social
isolation for people with a chronic condition or commonality. The review concludes by examining the gap in current literature with respect to social isolation and online communities for people with EOAD. The research methodologies, ethical considerations and study limitations are presented in Chapter Three. In addition, an overview of data collection and analysis procedures are summarized. Interpretive findings are discussed in Chapter Four. An analytic comparison of study findings in relation to related scholarly works is explored in Chapter Five. Further, a discussion of the theoretical concept that rose from the data will be presented to demonstrate how the ideas complement study findings and contribute to individual overall well-being. To conclude this report, study implications and future research recommendations are considered in Chapter Six.
CHAPTER 2

LITERATURE REVIEW

This chapter is a review of relevant literature on the health implications of social isolation, and threats early onset Alzheimer’s disease (EOAD) may impose to an individual’s well-being. The chapter begins by explaining the search and retrieval strategies for the literature review. In addition to the focus on health and social isolation issues, literature is presented on using online communities to address social needs of individuals with a chronic illness or other shared interest. The chapter concludes with a focus on the three studies most closely related to the research question. This review draws attention to the importance of considering the implications of social isolation for individuals with EOAD. Further, the use of online communities as a complementary method of engagement demonstrates a potential to counter the affects of social isolation for this population, which serves as the focus for this thesis.

Search and Retrieval Strategies for Literature Review

In order to conduct a comprehensive literature search and gain access to a large archive of scholarly works, library databases were consulted from both the University of Pennsylvania and Trinity Western University. Preliminary investigation of existing literature was completed using CINAHL, PubMed Plus, PsychINFO, Proquest Dissertations and Google Scholar. To elicit the greatest number of relevant research articles, key terms may have varied by database (Table 1). Initial terms used were Dementia and Social Isolation. Variations on both terms were introduced in subsequent searches. In later stages of the search, Online Communities and its associated terms were added. PubMed Plus offers a feature that searches for similar articles. This option was
used with the most relevant articles found at any stage during the search. Please refer to Appendix A for a visual representation of the search strategies.

Table 1

*Literature Review: Search Terms and Variations Used*

<table>
<thead>
<tr>
<th>Key Term</th>
<th>Variations Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Onset Alzheimer’s Disease</td>
<td>Dementia, Younger Onset, Younger Onset Dementia, Alzheimer’s, Early Onset AD, Young Onset Alzheimer’s, Younger Onset Alzheimer’s, Memory Loss</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>Social Withdrawal, Desocialization, Social Distance, Loneliness, Detachment</td>
</tr>
<tr>
<td>Online Communities</td>
<td>Virtual Community, Virtual Communities, Online, Online Forum*, Internet, Virtual Space*, Blog*, Message Board*, Communication Medium</td>
</tr>
</tbody>
</table>

A deductive approach was applied to the literature search. The writer first explored whether social isolation was an issue for individuals with EOAD, and if so, how social isolation manifests and what supports may be in place to help combat its effects (Bakker et al., 2014; Clemerson, Walsh, & Isaac, 2014; Gillies, 2001; Harris, 2002; Holst & Hallberg, 2003; Hayo, 2015; Johannessen & Moller, 2013; Mitchell, 2012; Moyle et al., 2011; O’Sullivan, 2011; Roach & Drummond, 2014). The process for selecting articles relevant to this topic is described in Table 2.
Table 2

*Article Selection Process for Early Onset Alzheimer’s Disease and Social Isolation*

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Criteria for Selecting Articles for Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is social isolation an issue for individuals with early onset Alzheimer’s disease (EOAD)?</td>
<td>Inclusion and Exclusion Criteria for Abstract Review</td>
</tr>
<tr>
<td>How does social isolation manifest in individuals with dementia or EOAD?</td>
<td><em>Inclusion Criteria:</em> Subject headings with the terms Social Isolation, Loneliness, Social Withdrawal, AND Subjective Experience, Patient Perspective AND Dementia, Alzheimer’s Disease or Early Onset Alzheimer’s or Young Onset, Younger Onset.</td>
</tr>
<tr>
<td>What services exist to address the social isolation concern?</td>
<td><em>Exclusion Criteria:</em> Titles that allude to the risk of getting Alzheimer’s disease as a result of social isolation. Article titles that speak to the biological/pathophysiological process of Alzheimer’s disease. Subject headings that solely investigate the caregiver, spouse or child(s) experience in caring for or living with a loved one with dementia, Alzheimer’s disease (AD), or EOAD. Articles not related to Dementia, Alzheimer’s disease or EOAD.</td>
</tr>
</tbody>
</table>

1. Article titles and abstracts fitting the inclusion criteria were analyzed for the following:
   *Study Objective:* Subjective perspective of navigating the illness, or more specifically, a specific aspect of dementia.
   *Data Collection:* Studies using data obtained from individuals with the disease (dementia, AD, or more specifically, EOAD) were considered for further review. Exceptions were made if the individual and caregiver perspectives were examined.
   *Age of Subjects:* Age of participants was considered, however, due to the limited number of studies with people under the age of 65, there was no age cutoff.
   *Results:* Studies in which the findings addressed the social elements of dementia or more specially, EOAD were set aside for a comprehensive review.
2. Scholarly articles in which the abstracts met the above criteria were comprehensively reviewed to extract relevant findings addressing the social elements of dementia or, more specifically, EOAD. These findings were discussed in the literature review.

To provide a conceptual foundation for the intended research, a second, broader search approach was undertaken. Using the term Chronic Illness, and variations of the terms Social Isolation and Online Communities, the writer investigated how individuals with a progressive disease have used online forums to combat social isolation (Coulson, 2005; Highton-Williamson, Priebe, & Giacco, 2015; Hoffman-Goetz & Donelle, 2007; Hoybye et al., 2005; Johnston et al., 2013; Kirk & Milnes, 2015; Mo & Coulson, 2008; Obst & Stafurik, 2010; Van Uden-Kraan et al., 2008; Valtchanov, 2014). A variety of chronic disorders are addressed in the literature review through the lens of the individual navigating the disease or sharing in a related experience. Overarching themes in all relevant studies are saturated with findings underscoring the benefits of social engagement among groups of people with shared experiences or understandings. Table 3 outlines the process used for selecting articles relevant to the topic of online communities and social isolation with chronic illness.
Table 3

Article Selection Process for Online Communities in Relation to Social Isolation and Chronic Illness

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Criteria for Selecting Articles for Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic illness versus treatable disease</td>
<td>Exclusion and Inclusion Criteria for Abstract Review</td>
</tr>
<tr>
<td>Chronic illness versus shared commonality</td>
<td><strong>Inclusion Criteria:</strong> During the initial searches, the preliminary literature search focused solely on subject headings with the terms Social Isolation AND Chronic Disease OR the name of a specific chronic illness</td>
</tr>
<tr>
<td>Drivers to seeking online support/social engagement</td>
<td>Due to the wealth of research available on online communities, social isolation and a shared interest, the literature search was modified to focus on articles that investigated how online communities help combat social isolation for specific populations, not restricted to online communities for chronic illness(es), but also those for individuals with other shared interests.</td>
</tr>
<tr>
<td>Do online communities alleviate social isolation experienced by individuals with a chronic disease, and if so, how?</td>
<td><strong>Exclusion Criteria:</strong> Subject headings addressing biological or pathophysiological aspect of a chronic illness.</td>
</tr>
</tbody>
</table>

1. Article titles and abstracts that fit the inclusion criteria were evaluated for the following:

   * **Study Objective:** The benefits of online forum or online support group engagement. In particular, how social support was achieved in a virtual setting OR how social isolation was addressed by engaging within an online forum.

   * **Data Collection:** Methods such as archived textual communication, and interviews that focused on the individuals navigating the illness/engaging within the online community.

   * **Results:** Benefits or drawbacks to social participation within an online forum and how these findings were represented or interpreted in the findings.

2) Studies in which the abstracts met the above criteria were comprehensively reviewed to extract relevant findings that
A limited number of research designs have used online forums as a locus of data collection when assessing a population with EOAD, or more broadly, dementia (Daley, 2014; Moya et al., 2008; Rodriguez, 2013). Even fewer studies address online communities as a way for individuals in this population to combat social isolation (Rodriguez, 2013). Three academic reports were found to have used online message posts to explore the subjective experience of AD, with emphasis on social benefits gained from virtual interactions. Table 4 describes selection criteria for these articles.
Table 4

*Article Selection Process for Online Communities, Social Isolation and Early Onset Alzheimer’s Disease*

<table>
<thead>
<tr>
<th>Considerations</th>
<th>Criteria for Selecting Articles for Review</th>
</tr>
</thead>
</table>
| Primary goal was to identify scholarly works with a target population of people with dementia or more specifically, EOAD. | Exclusion and Inclusion Criteria for Abstract Review  
*Inclusion Criteria:*  
Subject titles with the terms Dementia, Alzheimer’s and/or EOAD AND Online Forums or Online Communities. Articles using archived textual communication as the main source of data.  
*Exclusion Criteria:*  
Articles addressing an unrelated illness or topic. Articles that spoke primarily to the caregiver experience. Articles that did not explore an aspect of the illness via an online community (either by using archived textual communication, message posts or interviews with members of the online forum). |
| Research studies in which messages posted to forums are the primary data source. | 1. Article titles and abstracts that fit the inclusion criteria were evaluated for the following:  
*Study Objective:* Research studies in which the author(s) investigated elements of living with dementia, or more specifically, EOAD, by exploring a phenomenon related to the subjective experience within an online community. Due to the limited number of scholarly sources on the subject, Social Isolation was not a concept used in the key search terms. Rather, the studies identified for comprehensive review were analyzed to verify whether themes of social isolation were addressed (or discussed).  
*Data Collection:* Studies with online forums, and more specifically, archived textual communications, as the primary data source, or studies interviewing participants in an online community or online support group.  
*Results:* Studies including the themes of social isolation, lack of social support, or loneliness following diagnosis. |
| Studies addressing the subjective experience of navigating dementia, or more specifically, EOAD. | 2. Studies in which the abstracts met the above criteria were comprehensively reviewed to extract relevant findings as they related to online social engagement of individuals with EOAD. |
Literature Review

Social Isolation

Social isolation can result from a deficiency in emotional and physical forms of interaction. Factors impacting social isolation are found at individual, community and societal levels (AARP Foundation, 2012). Risks include impairments (physical mobility and sensory), geographic location (rural areas with limited access), and mental health concerns (dementia). The social isolation phenomenon manifests itself during major life transitions, such as loss of social network, change of role, and loss of physical health. The AARP foundation (2012) compiled a comprehensive list of scholarly research documenting a relationship between social isolation and physical and psychological states of well-being. The cited studies explain how insufficient levels of social support, social networks, and opportunity for interaction may lead to a perceived state of isolation or deficiency in social function. Further, the research referenced by the AARP foundation suggests that a lack of social support and minimal opportunity for socializing may result in maladaptive coping mechanisms. Finally, findings indicate that prolonged states of social isolation can accelerate cognitive aging and decline. An absence of physical and psychological modes of engagement can contribute to poorer health outcomes. EOAD may lead to a deficiency in opportunities for socializing or an absence of social relationships, all of which threaten an individual’s overall well-being.

Alzheimer’s Disease and Social Isolation

The scholarly articles reviewed for this research either explore the subjective experience of living with dementia or examine a specific topic as it relates to the individual illness trajectory. Social isolation following diagnosis emerged as a prominent
theme throughout the reports, in-depth semi-structured interviews and focus groups. The trend toward increasing social isolation, while present for most people with dementia, was particularly salient for those diagnosed at an early age. A diagnosis of Alzheimer’s disease (AD) before the age of 65 results in professional and personal changes that contribute to social withdrawal and isolation (Bakker et al., 2014; Clemerson, Walsh, & Isaac, 2014; Gillies, 2001; Harris, 2002; Hayo, 2015; Holst & Hallberg, 2003; Johannessen & Moller, 2013; Mitchell, 2012; Moyle et al., 2011; O’Sullivan, 2011; Roach & Drummond, 2014). Sperling et al. (2011) highlight a point worthy of consideration as one tries to understand the rapid manifestation of AD symptoms following diagnosis. They cite “the pathophysiological process of Alzheimer's disease begins years, if not decades, before the diagnosis of clinical dementia” (p. 3). Individuals in the midlife stage of human development often balance career with an active role as partner and parent. Clemerson, Walsh, & Isaac (2014) emphasize that this phase of the life cycle is “strongly situated in a social frame” (p. 460). A clinical diagnosis of young onset dementia (YoD) or more specifically, EOAD causes a disruption in social relationships and rapid change in this stage of life.

The association between functional losses and increased levels of social isolation was echoed across multiple scholarly works (Johannessen & Moller, 2013; Holst & Hallberg, 2003; Moyle et al., 2011; O’Sullivan, 2011). In Holst and Hallberg’s (2003) study, participants from Sweden with moderate stage YoD (n=11) rationalized resigning their positions following diagnoses due to difficulties managing their professional role or feelings of shame resulting from lapses in judgment and work performance deficiencies. Withdrawal from previously held recreational activities and social engagements often
follows occupational departures. After diagnosis, most individuals give up or lose their right to drive. Participants with YoD (n=20) in Johannessen and Moller’s (2013) qualitative report attributed reduced levels of independence to the logistical complications of remaining mobile, along with increased fear of getting lost. Similarly, interviews and focus groups by O’Sullivan (2011), with a study sample of individuals from Auckland, New Zealand with young (n=7) and older (n=4) onset dementia exposed comparable findings, stating, “when memory deficits are coupled with a deteriorating ability to do things and to use objects in general, younger people become more withdrawn and isolated from their social world” (p. 156).

Social relationships following clinical diagnosis may also become more difficult to maintain. Individuals often experience severing of previously-held friendships, resulting in social withdrawal (Clemerson, Walsh, & Isaac, 2014; Harris, 2002; Holst & Hallberg, 2003; Johannessen & Moller, 2013; Moyle et al., 2011). Several factors contribute to growing social withdrawal. Lapses in cognitive functioning leave those navigating the illness apprehensive about participating socially. In a letter summarizing the experience of living through dementia, Gillies (2001), explains: “Increasingly, [people with Alzheimer’s disease] sought to avoid situations whereby their memory problems would become apparent, like social interactions where names and faces would be forgotten, and where others might expect a reasonable level of conversation” (p. 112). Moyle et al. (2011) drew similar conclusions. Their purposive sample of people in Queensland, Australia with early stage or probable dementia (n=70) associated absence of relationships with feelings of loneliness and social isolation. Equally, the informants attributed their symptoms of memory loss to reduced social interaction. In addition to the
functional insecurities experienced following a diagnosis of YoD, participants (n=23) in Harris’s (2002) United States-based study expressed feelings of shame about what they felt was an inability to enter into or maintain relationships. Alternatively, reactions from one’s social network may contribute to feelings of isolation (Harris, 2002; Holst & Hamburg, 2003; Mitchell, 2012; Moyle et al., 2011). Mitchell (2012) conducted semi-structured interviews to better understand the family (couples n=6) and professional (n=6) perspectives on the challenges presented by YoD. The Australia-based sample indicated that friends and/or family often withdrew from the person with dementia, citing an inability to cope with the change or incapacity to manage expectations. The adjustments to professional identity, family dynamic, and social connections threaten a person’s sense of belonging following diagnosis (Holst & Hallberg, 2003; Mitchell, 2012). Participants in Holst and Hallberg’s (2003) study describe a grieving process that follows such social losses. They associate the evolving social dynamic with an inability to effectively communicate with others, leading to feelings of compromised self-worth. The decline in social interaction and absence of relationships after diagnosis create an impetus for people to seek new forms of engagement and social ties.

Individuals with YoD describe a desire to engage with others who are in a similar situation (Clemerson, Walsh & Isaac, 2014; Hayo, 2015; Johannessen & Moller, 2013; Mitchell, 2012). And yet, existing community-based services cater to older persons with dementia. This age-based limit to group socializing opportunities was emphasized in Hayo’s (2015) UK based review of people living with YoD. The author stressed:

Families living with young-onset dementia experience discrimination and marginalization that is exacerbated by the way in which services are designed. The
interests, needs, issues and activities suitable for someone in their 70s or 80s are unlikely to be the same as those for someone in their 40s or 50. (p. 39)

Roach and Drummond’s (2014) Canada-based sample of nine individuals with YoD and 11 family members shared similar narratives. They criticized the current community-based services, noting that the programs “cater either for younger people without memory difficulties or for older people with dementia” (p. 892). Equally, participants (n=8) of British descent in Clemerson, Walsh and Isaac’s (2014) report revealed their surprise about a lack of appropriate community-based services for younger people with dementia, noting that the absence of suitable services contributed to feelings of social isolation. A United Kingdom-based study by Bakker et al. (2013) summarizes the unmet social needs for persons with YoD. The authors explored perspectives of individuals with YoD and their families (n=215) to identify care needs for this population. Findings revealed that individuals with a diagnosis of YoD “experienced high levels of unmet needs in areas such as daytime activities, social company and intimate relationships” (p. 1991). A diagnosis of YoD and limited community services significantly affect existing social relationships as well as the potential for new social opportunities.

Social Isolation and Online Communities

Starting in the 1990s, the Internet became a shared communication medium connecting individuals with a common interest. Plant (2004) states that “the ubiquity of the Internet and the human desire for connection, knowledge and information, has also created a new social phenomena, that of the online community” (p. 52). In this regard, online communities satisfy two central human desires: To connect with other individuals and obtain knowledge (Valtchanov et al., 2014). Owing to the fundamental human need
to connect and learn, a quarter of Internet users with a chronic condition sought online methods of communication with individuals with a similar condition (Ziebland & Wyke, 2012). The benefits of online interaction include social engagement, information exchange, relationship building and maintenance, and a sense of empowerment over the illness trajectory (Coulson, 2005; Highton-Williamson, Priebe, & Giacco, 2015; Hoffman-Goetz & Donelle, 2007; Hoybye et al., 2005; Johnston et al., 2013; Kirk & Milnes, 2015; Mo & Coulson, 2008; Obst & Stafurik, 2010; Van Uden-Kraan et al., 2008; Valtchanov, 2014).

Exchanging social support is a primary outcome of online social engagement (Coulson, 2005; Mo & Coulson, 2008; Kirk & Milnes, 2015; Highton-Williamson, Priebe & Giacco, 2015). Coulson (2005) found that messages posted by online community members (n=153) with Irritable Bowel Syndrome from North America and parts of Europe concentrated on reciprocity of support in “areas of symptom interpretation, illness management, and interaction with health care professionals” (p. 583). Alternative supportive behaviors may also contribute to the well-being of online community members. Mo and Coulson (2008) reviewed 1,138 archived conversations posted to an online support group for people diagnosed with HIV/AIDS. The authors found that members from the United States, parts of Europe and Australia sought informational, emotional and esteem support. In addition to offering factual information, the researchers determined that “online support groups also provide a useful context through which members could discuss the anger, fear, and frustration resulting from stigmatization, and feelings of isolation” (p. 374). A systematic review of online social networks reached similar conclusions, finding that individuals with psychosis use virtual communities to
seek peer support and share experiences about the social and emotional aspects of living with the illness (Highton-Williamson, Priebe & Giacco, 2015). Virtual observation of an online forum dedicated to individuals with cystic fibrosis (CF) discusses the social benefits of online engagement with similar others. Analysis of messages posted by youth with CF (n=97) and parents (n=182) revealed that, “for some, the opportunity to express their feelings and frustrations was cathartic in itself as they were able to tell their story to an audience who could understand and relate to their experiences” (Kirk & Milnes, 2015, p. 7). A level of empathy is often achieved amongst people with a shared affliction. A review of chat room-mediated, health-related discussions for Aboriginal women in Canada found that users could relate to one another’s situations and offer suggestions for coping with life circumstances (Hoffman-Goetz & Donelle, 2007). Social exchanges over related experiences or perspectives, regardless of personal background, can contribute to a perceived state of well-being, reducing feelings of isolation.

Online forum participation also increases the number of social contacts for people with a chronic illness (Hoybye et al., 2005; Van Uden-Kraan et al., 2008). For some, engaging with members of an online forum supplements their pre-existing social networks, while for many others, online communities can potentially substitute for lost social ties resulting from the limitations associated with their respective diagnoses (Highton-Williamson, Priebe & Giacco, 2015; Van Uden-Kraan et al., 2008). A review of emails exchanged by a group of Scandinavian-speaking women with breast cancer (n=15) described how social bonds develop online over time through storytelling and conversation exchange, cultivating a new social world with similar others (Hoybye et al., 2005). Hoybye et al. (2005) explained how deep social ties were evident when
exchanges shifted from information sharing to discussions focused on the more intimate aspects of the breast cancer illness trajectory. Participants of this email exchange resided in parts of Scandinavia, Denmark, Greenland and the United States, demonstrating that close relationships can evolve online regardless of distance and location. In their review of online support networks for individuals with Psoriasis (n=260), Idriss et al. (2009) describe how over time, personal exchanges foster a level of comfort and trust amongst members and demonstrate the greatest potential to cement social bonds and open opportunities for alternative modes of communication. Ultimately, these exchanges inspire members to cope with, and regain power over their condition.

Online communities can potentially facilitate contact with a more heterogeneous group of people. A virtual method of engagement not only diversifies socio-demographic and cultural characteristics, but also expands the views and experiences offered by members (Coulson, 2005; Van Uden-Kraan et al., 2008). Variation in illness understanding is demonstrated by the individual experience with the disease, which is explained through personal stories, and the advice and support offered to other members. In a Netherlands-based study, Van Uden-Kraan et al. (2008) examined archived messages published on online support groups for individuals with breast cancer (n=3), fibromyalgia (n=3) and arthritis (n=2). The authors found that disclosure of personal experiences and coping strategies within an online community created opportunities for members to connect over similar understandings, helping them feel “less crazy and alone in coping with their disease” (Van Uden-Kraan et al., 2008, p. 408). Similarly, opportunities for socializing could enable the online support group members (n=44) to help one another manage their illness. Hoybye et al. (2005) add that these advanced levels of engagement
foster a sense of control by linking online community members with practices that promote well-being. Van Uden-Kraan et al. (2008) categorized five contributory processes that emerge from online social participation, which together facilitate empowerment. These include exchanging information, encountering emotional support, finding recognition and understanding, sharing experiences and helping others, and amusement. Johnston et al. (2013) drew similar conclusions from their interviews with online forum moderators (n=18) and from member surveys in online health communities (n=153). The authors attribute the participant empowerment to the benefits gained from information exchange and social support, finding that the degree of utility was dependent on the level of participation, with positive empowerment gains correlating with higher levels of engagement. Research on online social interaction demonstrates that people want to talk to others navigating a similar course. Members of an online community create environments where social support may be exchanged, and feelings of empowerment over their illness trajectory are fostered, reducing isolation and enhancing individual control of outcomes.

Alzheimer’s Disease, Social Isolation and Online Communities

Academic research on AD, utilizing online modes of communication as a locus for data collection, is limited. The literature search uncovered three scholarly articles that used textual conversations to explore the individual experience of AD. Research objectives centered on understanding how interpersonal relationships develop and how coping mechanisms are used in online support groups. In addition, the studies explored how self and community were reconstructed within a virtual environment. These three studies thus serve as foundational knowledge for this thesis by demonstrating the manner
in which individuals with AD have utilized online spaces, and further, showing the
benefits gleaned from this virtual mode of interaction.

In the first of the three studies reviewed, Moya et al. (2008) explore the formation
and progression of social relationships within an online support group for individuals
with AD and their caregivers. The setting and participant sample were selected out of
convenience, and no individual registration was required for people to participate. Moya
et al. (2008) report on a review of one month’s worth of synchronous chat room
conversations posted by members residing in Canada, Britain and Australia. To
complement their analysis of conversation transcripts, the authors also interviewed eight
group members, including both patients (n=4) and caregivers (n=4). The age range of
interview participants was 40-65 years old.

Walther’s theory of hyper-personal relationships was used by Moya et al. (2008)
to examine the formation of social relationships within a computer-mediated
environment. The theory positions that online spaces can foster relationships “that range
from impersonal to interpersonal to the more hyper-personal” (p. 93). Impersonal
relationships are defined as task oriented – minimal focus is placed on developing
relationships with others. In contrast, interpersonal relationships are casual in nature –
 exchanges are casual and friendly. Walther (1996) further explains that hyper-personal
relationships develop in virtual settings “when individuals disclose more intimate details
about their lives and consequently forge stronger bonds” (as cited in Moya et al., 2008, p.
93). The theory posits that the feasibility of hyper-personal relationships within an online
environment is dependent on the motives for joining, in conjunction with the level of
participation and disclosure from community members (Moya et al., 2008).
Findings from Moya et al.’s (2008) research describe the key motives to online engagement as accessibility to similar others and desire for support. Members joined the support group to discuss common experiences and difficulties of coping with AD. One participant eloquently explained: “No matter how hard you try, it is impossible to relay to someone else what you are feeling and going through, unless they too are going through the same thing” (p. 102). Initial interactions helped to establish impersonal relationships. In turn, a high level of participation and disclosure amongst support group members facilitated the formation of hyper-personal relationships. The primary motive for contact with members of the community shifted from knowledge exchange to maintaining the social bonds that had developed from sustained communication, showing that genuine relationships could be established and maintained within an online environment (Moya et al., 2008). The results demonstrate that people living with AD could engage and establish relationships within a virtual arena. Nonetheless, the researchers did not explicitly address the ways in which hyper-personal relationships cultivated within an online space may help to reduce social isolation for members of the community.

The second paper reviewed, a dissertation by Daley (2014), used Lazarus and Folkman’s transactional model of stress and coping as a framework to investigate how coping strategies differ by caregivers/partners and individuals with AD. The stress and coping framework was designed to evaluate coping methods in stressful situations. Lazarus and Folkman’s model suggests that coping begins with a cognitive appraisal of the stressor, in which the individual evaluates the implications of the potential threat to their health and well-being (primary appraisal). An assessment of available resources to manage the stressor follows (secondary appraisal). The individual may employ problem-
focused coping, in which the focus is on managing the stressor through planning and information gathering and decision-making (Daley, 2014). Alternatively, the person may attempt to reduce the negative emotional state by implementing an emotion-centered coping style in which the inclination is to avoid, or distance oneself from the problem. Problem-focused coping attempts to alter the situation, while emotion-focused coping is used to alter the thoughts or feelings related to the situation (Daley, 2014).

Daley (2014) reviewed messages posted to three online groups supported by the Alzheimer’s Association. These included the caregivers’ forum, spouse or partner caregiver forum; and a discussion board for individuals with dementia. The sample demographic was heavily weighted towards female users (88% of posts), with only 12% of the studied posts written by male users. A quantitative content analysis of 568 message posts revealed seeking social support was the coping category most regularly practiced (Daley, 2014). Social support was one of four coping strategies created to categorize emotion-focused coping. Daley’s (2014) core finding was consistent with the research articles reviewed in which social elements of online communities were examined. It was found that the key motivator for engagement within an online forum was to seek comfort from individuals navigating a similar situation. The author justifies this conclusion, explaining how connecting with individuals who can personally relate to one’s experience can be attributed to reducing depression and anxiety and increasing self-esteem. Supportive exchanges that can lead to a positive outlook on a situation demonstrate a potential in addressing isolation for this population; nonetheless, the objective of Daley’s (2014) dissertation was to determine the types of coping styles used in online support groups, and therefore the concept of social isolation was not addressed.
In the third and final study considered, Rodriguez (2013) explored how people with EOAD reconstruct the concepts of self and community through online illness narratives. Rodriguez (2013) explains how previous research has looked at how the self had changed or was lost following diagnosis. He positions that the self can be “constructed through language and communication” and emerges from everyday social interactions (p. 1216). Through illness narratives, Rodriguez (2013) demonstrates how people with EOAD were able to share stories in which a salvaged self, a self that maintains aspects of the persons healthy identity, transpired.

The notion of social isolation surfaced from an inductive analysis of 354 messages posted to a public domain. Rodriguez’s (2013) findings explain how the participants’ (n=32) desire to share stories about social isolation helped them realize a sense of community online. The phrase “you are not alone” arose frequently, supporting the author’s conclusion that a sense of community was achieved. Rodriguez (2013) further describes how these comments assisted in reestablishing a sense of human connection at a time when members of the community were experiencing social withdrawal.

The analysis of archived message posts revealed motivating factors for online engagement, underscoring the effects of functional and social losses following diagnosis. Equally, the use of illness narratives captured the manner in which community may be reconstructed in an online environment for individuals with EOAD. The study conclusions suggest that forum interactions have the potential to address the social needs of its members. However, Rodriguez’s (2013) analysis does not unpack the illness
narratives to further explain how these modes of interaction can enhance individual social well-being, creating a space for further research about this phenomenon of interest.

Findings from Rodriguez’s (2013) research of social forums describe how the concept of self and community may be reconstructed in an online setting. Moya et al.’s (2008) results demonstrate that personal relationships can be cultivated in virtual spaces to supplement traditional modes of interaction. Finally, Daley’s (2014) dissertation explains the types of support sought out online by caregivers and individuals with dementia. In addressing different concepts of online engagement, findings from all three studies establish the potential for online modes of interaction to address aspects of social isolation. However, none of the studies explicitly or collectively examine how these modes of interaction may fill a social void created by a diagnosis of EOAD. To contribute to existing knowledge, the author will focus study intentions on uncovering the ways in which social elements of online communities may help combat isolation experienced by individuals with EOAD.

**Literature Review Summary**

A wealth of scholarly research demonstrates that social isolation following a clinical diagnosis of dementia is a key concern as expressed by individuals navigating this disease. Participants from the studies reviewed attribute the negative shift in their social well-being following diagnosis to professional and functional losses, as well as to a lack of age-appropriate community services. A prolonged disconnection from pre-established social ties can lead to a loss of supportive relationships and sense of belonging. The cycle of events pulling individuals with dementia away from social interaction and support can, in turn, have a profound impact on their overall well-being.
To offer theoretical context for the intended research, literature that explored the social elements of online communities for individuals with similar challenges to EOAD was reviewed. Results from these studies confirm that online communities can help address the social needs of people navigating a common course. Nonetheless, there is insufficient research that explores computer-mediated methods of interaction as a way to combat social isolation for people with EOAD. This research study aims to contribute to existing knowledge by exploring the ways in which online communities can positively contribute to one’s overall well-being by fulfilling a need for social interaction.

**Chapter Summary**

Literature that describes the subjective experience of EOAD with a focus on the social losses following diagnosis addresses the disparity in services for people with YoD. Social isolation after diagnosis, in addition to professional and social changes, can threaten a person’s well-being. Although a diverse collection of scholarly work has addressed the benefits and potential drawbacks for people with a chronic illness engaging online, research into the phenomenon of social isolation as it relates to EOAD is insufficient. The current study is designed to supplement this existing knowledge by exploring the ways in which online forums may be used to address social isolation for individuals with EOAD. The following chapter will present an in-depth view of the study’s research methods.
CHAPTER 3

RESEARCH DESIGN, METHODS, AND PROCEDURES

The purpose of this research project was to advance current understanding of the ways people with early onset Alzheimer’s disease (EOAD) use online forums to address the challenges of social isolation. The primary research question addressed the key aim of the research, and secondary questions guided the data collection and analysis phases. The research questions were as follows:

Primary Research Question
1. In what ways does engagement within an online community help combat social isolation experienced by individuals with early onset Alzheimer’s disease?

Secondary Research Questions
2. What are the motivators to social interaction within the online forum?
3. How do conversations typically progress, and how are they maintained?
4. What expressions of belonging are demonstrated?

This chapter explains the rationale for selecting a qualitative study design and more specifically, mixed research methodologies. In addition, the sampling method is described, along with the process of capturing data and analyzing findings. The chapter concludes with addressing scientific quality, limitations and ethical considerations of the research.

Research Design

A qualitative study design served as the framework that guided exploration and understanding of ways in which online forum engagement may enhance one’s social well-being. Malterud (2001) posits that qualitative inquiry best serves “the exploration of
meanings of social phenomena as experienced by individuals themselves, in their natural context” (p. 483). Social elements were studied through archived textual data written by individuals participating in an online forum that serves as a social outlet and arena for information exchange. A qualitative approach leads to a comprehensive inductive description that demands interpretation (Cypress, 2015). To that end, the methodologies employed to acquire and analyze the data centered upon a deeper understanding of the meaning behind the communicative exchanges within the online social space (Kozinets, 2015).

*Netnography* is a qualitative research methodology “that adapts ethnographic research techniques to the study of cultures and communities emerging through computer mediated communications” (Kozinets, 2002, p. 2). A netnographically informed approach is focused on social aggregates, or experiences of the entire group. As such, the online social experience for members of the YoD community was examined collectively rather than at an individual level (Kozinets, 2015). Netnographic data may be archived (text), elicited (researcher participation) or produced (field notes or observation). For the purpose of this study, the main sources of information were observations of textual discourse and community behaviors. Analysis and contextualization of communicative exchanges were supported by both methodologies.

Interpretive description directed the coding scheme and classification of findings. As the primary interest was in the practical implications of research outcomes, an interpretive approach led the analysis for “the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding” (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004,
p. 3). To complement the interpretive description of findings, netnography directed the in-depth understanding of social discourses within the online community by grounding the interpretive conclusions in textual representations that conveyed the subjective realities of forum members (Kozinets, 2015).

In light of the online communication medium, the contemporary research methods of netnography and interpretive description were utilized to guide the collection of data and analysis of findings. Taken together, interpretive description and netnography offered a rich and dynamic understanding of ways in which online social engagement may serve as a method for combatting social isolation and how knowledge gleaned from this study can help to guide nursing practice. Kozinets (2015) justified the use of multiple methodologies, positioning netnography as an adaptable method. Thorne (2008) concurred, noting, “interpretative description exists as a coherent methodological framework within which a fairly wide range of options for design decisions can be enacted and justified” (p. 75).

**Sampling**

The objective of the study was to explore the experience of individuals under the age of 65 who have been diagnosed with EOAD by analyzing messages posted to an online forum within a one-year time frame. The forum selected was created by a North American based Alzheimer’s association and tailored primarily for people with young onset dementia (YoD), including EOAD. Study data was composed of archived textual communication exchanged within the online forum between January 2015 and January 2016. Polit and Beck (2012) propose that the sample size for a qualitative study is dictated by informational needs, and may refer to a sample of persons, interviews or
events. The primary concern for the current study was the wealth of posts published by individuals with EOAD, and more importantly, the depth of the content within the messages exchanged when determining the appropriate sample size. Thus, conversations ("threads") were the items sampled.

Thorne (2008) stresses that there is no prescriptive rule regarding sample size for an interpretive description study; rather, it falls upon the researcher to determine and justify the appropriate size of the sample. A netnographic approach advocates for collection of data until no new insights are generated (Kozinets, 2010). A year’s worth of initial conversations ("threads") (n=664) was hypothesized to be the appropriate period of time to gather a diverse amount of textual data that would allow for a rich and comprehensive view of interactions. The time frame was revisited once six months of conversations had been obtained. At this stage, new understandings were still being discovered and as such, another six months of textual interactions were gathered. Because the intention was to explore the subjective experience of those with EOAD, threads without a post by someone with a diagnosis EOAD were excluded from analysis (n=95). As such, a total of 569 original threads and 4,796 individual messages were included in the analysis, of which 2,039 messages were posted by someone with a self-reported diagnosis of EOAD.

A total of 230 people engaged with the forum during the January 2015 to January 2016 time frame. This includes people with EOAD (n=40), other YoD’s (n=24), caregivers (120), people who were in process of obtaining a diagnosis (n=9), those who did not disclose their diagnosis on their profile or through conversation (n=23), and people with no known diagnosis (n=14). The final sample of participants was one of
convenience. There were 40 individuals with a self-reported confirmed diagnosis of EOAD who engaged with the forum during the study year. Analysis and interpretation of textual data focused on posts written by participants with EOAD as well as posts responding to someone with EOAD. However, to understand the context of the discussion, and more specifically, the posts under analysis, perspectives were acknowledged for all of those who were a part of the online community and were active participants on the threads.

**Procedures**

**Generation of Data**

A netnographic approach directed the collection of archived textual communications and observational community behaviors. Collection and refinement of the final data used for analysis was conducted during the month of February 2016. Kozinets (2015) proposes assessing several criteria while selecting an online community. When selecting the forum and establishing data collection parameters, this researcher considered relevance of setting in relation to the research question, regularity of interaction between members, and the substance and reciprocity of communication. To capture the greatest number of narratives, primary data included initial threads and corresponding responses for individuals with YoD occurring during the twelve months from January 2015 to January 2016. As prescribed by a netnographic approach to data collection, discussion threads were copied verbatim from the online forum into a Microsoft Excel spreadsheet. The Excel table was divided into two sections: thread-specific information, and post-specific information. Thread-specific information included the number, date and subject of the thread, the name of the initial poster, and the
total number of message posts within the thread. Post-specific information contained the
name of the poster(s), corresponding information such as gender, age and diagnosis, and
post content. The final threads (n=569) were exported to NVivo, a powerful software
program used for qualitative data analysis.

The data generated from online messages mimicked that of unstructured interviews.
Fossey et al. (2002) recognize the benefits of this method: “[U]nstructured interviews are
usually conducted in an everyday conversational style, in which participants take the
lead, to a greater extent, in telling their stories, rather than the researcher directing the
interview” (p. 727). The writer’s presence online was unobtrusive. Conversations were
directed by members of the forum, and are authentic representations of the online
community participants’ social reality (Giacomini & Cook, 2000).

In a netnographic approach to data collection, observation may be passive, with
the researcher acting as a non-participant observer. Or, involvement may be closer to a
traditional ethnographic approach, in which the researcher engages with and immerses
themselves in the online community (Kozinets, 2010). For the purpose of this study, a
passive role was assumed. A passive, non-participant approach allowed the observer to
assess the types of users participating in the online forum, to evaluate of the number and
nature of posts written by the study sample, and to better interpret forum users’ motives
for visiting and maintaining contact with the online community. Finally, high-level
observations such as the subject headings of each thread, and the number of posts versus
the number of views, yielded insight into the types of conversations eliciting the most
interest through active and passive forms of engagement. At an individual level, each
participant’s preferred form of engagement was monitored by passively tracking the type
and depth of conversation people chose to contribute to. Findings were documented in a journal and in Excel during the data collection and analysis phases of the research process.

Analysis of Data

Analysis of data commenced through immersion in the categorical text. Threads and corresponding individual posts were reviewed over the course of several days to gain a feel for the data (Thorne, 2008). Non-binding codes were created to loosely catalogue text in a descriptive manner. These classifications categorized the drivers of online social engagement, and the progression and maintenance of conversations. The codes that emerged centered around motivators behind initial thread contributions, topics that drove discussion, and the nature of support and advice prompted or achieved (Appendix B). Once all relevant data was organized in a descriptive fashion, codes were categorized by the manner in which the text was communicated: Actions articulated through text (Behaviors), statements conveying meaning to oneself or others (Expressions), and anecdotal reflections that explicitly identified the benefits and drawbacks of forum participation (Reported Value of the Forum). These categories capture the significance of participant behaviors and expressions in addressing social isolation. Equally salient for interpretative findings were overt comments expressing appreciation for individual members and for the benefits of forum participation. Table 5 provides a visual representation of the coded behaviors and expressions employed by members of the forum. Forum narratives were categorized to explain the methods of engagement that initiated or sustained conversation, to discussions that shifted the social dynamic to more personal levels of engagement.
### Table 5

*Behaviors, Expressions and Self-Reported Values Communicated Online*

<table>
<thead>
<tr>
<th>Behaviors that Demonstrated Social Interaction</th>
<th>Behaviors or Expressions that Encouraged Social Interaction</th>
<th>Behaviors or Expressions that Demonstrate a Deeper Level of Engagement</th>
<th>Reported Value of the Forum or its Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiating a conversation</td>
<td>Warm welcomes</td>
<td>Humor</td>
<td>Expressions of appreciation (for member(s) of the forum)</td>
</tr>
<tr>
<td>Stimulating further conversation</td>
<td>Encouraging continued contact</td>
<td>Presence in absence (Participants indicating they had been reading threads without actively posting)</td>
<td>We are here for one another</td>
</tr>
<tr>
<td>Maintaining conversation</td>
<td>Encouraging people to join the forum</td>
<td>Discussions of a general nature</td>
<td>Benefits of the forum</td>
</tr>
<tr>
<td>Advancing conversation</td>
<td>Maintaining conversation</td>
<td>Frustration, vulnerability or loss</td>
<td>Drawbacks of the forum</td>
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<tr>
<td></td>
<td>Advancing discussion</td>
<td>Reassurance or validation</td>
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<td></td>
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<td>Acceptance</td>
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<td>Expressions of Concern</td>
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<td></td>
<td>Maintaining contact (Participants posting to update forum members their whereabouts, or general life happenings)</td>
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<td></td>
<td></td>
<td>Following up with members (who had been absent from the forum)</td>
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<tr>
<td></td>
<td></td>
<td>Sharing own experience</td>
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<tr>
<td></td>
<td></td>
<td>Shared understandings (relating to others experiences)</td>
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</tbody>
</table>
Encouragement
Empowerment
Support (Sympathy, empathy, advice – all reciprocal)

Social constructs addressing physical and emotional elements of isolation, including social network, social support and social connectedness, were consulted to move the analysis forward. A matrix served as a visual representation of the parallels between coded text and concepts which address social isolation. A two-fold approach was used to relate textual representations to the social isolation concepts emerging from the analysis. First, the excerpts categorized under each code were reviewed to examine variations and make sense of the developing conceptualizations (Thorne et al., 2004). Second, concepts addressing social isolation were refined by identifying construct definitions that best represented what was visible within the archived text. This led to a shift from a descriptive overview of the forms of social interactions online, to an interpretative understanding of the significance of these methods of engagement (codes), and how they may address the social needs of the participants (what the themes signify). The modification advanced conclusive findings from a description of that which was observed to an interpretative understanding of a phenomenon that yields practical application implications (Thorne et al., 2004).

Forum observation was used to support the interpretive analysis of textual findings. Associations were examined that occurred between subject headings, number of posts per thread, and the amount of views each thread generated. Thread specific
information was considered to elicit insight into the relationship between the nature of conversations and their potential influence on social interaction. In addition to the archived text, statistics were generated for level of active engagement, length of membership, and number of posts per participant, in order to support and strengthen emerging understandings of the forum’s social significance.

**Considerations of Scientific Rigor**

Scientific quality was evaluated throughout the research process to verify the study’s credibility and reliability. An audit trail was developed, comprised of materials such as transcripts of online messages, theoretical and methodological notes, drafts of thesis chapters and the final report, and reflexive notes (Polit & Beck, 2012). The study’s credibility was further supported by through use of the reflective process, triangulation through the application of multiple data collection methods, and ongoing peer debriefings. As suggested by Thorne et al. (1997), a reflexive journal was maintained to record reactive processes and counter any potential biases experienced during the course of the study. Reflexive commentary was documented in the journal during each data collection session and throughout the analysis process. The notes contain the researcher’s observations of individual users, personal reflections on the conversations that took place, and salient points that surfaced during data collection and analysis.

Method triangulation was achieved through online message posts and virtual observation of sample participants. Third party checks by a peer and faculty members were welcomed over the course of the research process. Shenton (2004) proposes that individuals removed from a research study may bring fresh perspectives that can challenge the assumptions made by the investigator. He elaborates: “[T]he researcher’s
closeness to the project frequently inhibits his or her ability to view it with real
detachment” (p. 65). Regular contact was maintained with the primary advisor and
second reader over email and conference calls to discuss and critique the research design,
methodology, and study findings. This enabled the researcher “to refine her methods,
develop a greater explanation of the research design and strengthen her arguments in light
of the comments made” (Shenton, 2004, p. 67). Finally, to minimize risk of error and
confirm that all initial threads and corresponding message posts were accounted for and
represented in the final product, computer-mediated communications between January
2015 and January 2016 were compared with the final direct copy transcripts in Excel.

**Limitations**

Safeguards were implemented into the research process to yield constructed truths
representative of the participant experience. However, there remain inadequacies to the
project that must be addressed. Data were generated from an online environment and
therefore limited the amount of personal information that could be obtained through
voluntary disclosures. A portion of the study participants elected not to share their
demographic information, which leads to an incomplete view of the full community of
forum participants. Equally, the authenticity of the demographics provided, such as
gender, age and diagnosis, could not be accurately verified. However, there was no
reason to believe that sampled participants misrepresented their diagnosis or situation.

As a result of the netnographically informed unobtrusive approach to data
collection, validation of study interpretations and conclusions by participants was not
possible. Although a credibility check through participant validation is encouraged in
qualitative research, Thorne et al. (1997) argue that this step is not required for the
purposes of interpretative analysis of the findings. Furthermore, conclusions gleaned from the findings only pertain to the sample of users who were active participants on the forum. Without speaking to all members of the online community, including those who passively engage, the potential social benefits observed by the author were limited to a small percentage of members who contributed to discussion. Ultimately, the core themes best represent the social benefits for those with a prominent online presence. The use of only one online forum may further reduce understanding of the potential social gains online communities may offer. This is not to say that the online space was limited to local users, but it did attract individuals within North America who have been personally affected by, or care for someone with dementia. The chosen forum was unique amongst similar online communities in that it offered a high level of social interaction, communications, and connections which could be used to understand the implications of these forms of engagement on social isolation (Kozinets, 2015).

**Ethical Considerations**

Ethical considerations for this study were informed by netnography, Trinity Western University’s (TWU) ethics board, and the online forum’s security and privacy guidelines. Archived textual communications and community observations fell under the category of reasonable use of publically available information as stated in TWU’s Research Ethics Board Policy and Procedures, Section 3.1.f; thus, formal ethics approval was not required. Nonetheless, the security and privacy guidelines for the forum were consulted and adhered to. Public access and usage of messages posted to the forum are addressed in the association’s Terms of Service. They highlight that the rights to the content are waived once it is posted to the message board. Expanding on that point, the
disclaimer states that the provider or other third party media users have the right to the content for any reason. However, Roberts (2015) maintains that ethical issues must be considered, so the benefits and risks to the online community and its members are thoughtfully addressed. The content accessed for the purpose of this study was written conversations that were posted to a publically accessible online message board.

Individual privacy cannot be guaranteed, and there is a risk that cited text can be searched within the forum and traced back to the forum user. For this reason, measures to reduce the possibility of negative outcomes were implemented. Fictitious names were used to protect the anonymity of community members (Kozinets, 2015). As an additional safeguard, the name of the online community was omitted in the final product of the report. Personal information beyond what was provided by the users in text or on their basic profiles was not requested. Identifiers such as age, marital status, location and employment status were not used to label an individual participant; rather, this information was applied generally in describing the final sample as a whole. The objective was to respect the participants’ privacy while providing a rich and dynamic image of how, if at all, demographic attributes such as marital and employment status may influence one’s willingness to engage online.

**Chapter Summary**

This chapter justifies the use of a qualitative research design in the study’s pursuit to understand the subjective social experience of online forum engagement. The use of mixed methodologies for this study is explained, including how netnography best served the online research methods, while interpretative description guided the data analysis to inform clinical thought. The data were composed of archived textual posts and
observational findings. The text analysis evolved from broad, descriptive categories to an in-depth interpretation of the effects of online social engagement on individual well-being. To conclude the chapter, ethical considerations, scientific rigor, and study limitations as they relate to online research were discussed. Additional precautions were introduced to preserve the anonymity of participants. An audit trail, mixed collection methods and regular contact with the author’s advisor challenged assumptions and premature interpretation of study findings. Nevertheless, the passive nature of data collection presented limitations. The inability to validate the findings, in addition to the use of only one community, limits the authentication of research findings. However, given the ability for one to access this community without geographical constraints and the methodological approaches applied, the absence of these precautions should bear minimal effect on study outcomes. The following chapter will offer an in-depth discussion of findings.
CHAPTER 4

FINDINGS

This chapter presents findings about the ways in which engaging with an online community may help address the social needs of people with early onset Alzheimer’s disease (EOAD). Three central themes were derived from analyzing a year of archived textual conversations. They are as follows:

I. Fostering Social Connection
II. Redefining Life After Diagnosis
III. Factors Impacting Forum Participation

Theme I considers the ways in which social connections are fostered by relating over shared understandings, cultivating a sense of belonging, and forming relationships that extend beyond the illness. This finding is supported by the theoretical concept of social connectedness, in which social relationships necessitate belonging and relatedness. Social support is conceptualized through Theme II, revealing how participants found purpose and redefined life after diagnosis through discussion centered on enhanced coping and self-care. Theme III explains how technological barriers and caregiver involvement may impact forum participation, threatening the social benefits offered by the online community.

Members of the Forum

The forum was established to serve as a communication medium for individuals with a young onset dementia (YoD). Although dedicated to a specific population, the discussion board is an open online space in which anyone is allowed to actively partake, or passively observe the discussions. Consequently, members of the forum consist of
caregivers, individuals with various YoD diagnoses, and those without a YoD diagnosis but a connection to the disease (others). A brief description of each group, their associated characteristics and forum contributions, is presented in Table 6. The interpretive analysis will focus on the benefits and potential barriers to online social interaction for individuals with a diagnosis of EOAD. However, every member of the online forum who engaged with a person with EOAD had the potential to influence their online social experience and therefore all perspectives were considered. As a point of reference, the term *participants* is used in this chapter to refer to individuals with a diagnosis of EOAD, *forum member(s)* are persons who are part of the online community, and finally, the word *individual(s)* will broadly refer to a population of people with EOAD or alternatively, a specific member of the forum.

Table 6

*Characteristics and Contributions of Members of the Forum*

<table>
<thead>
<tr>
<th>Forum members</th>
<th>Characteristics</th>
<th>Forum Contributions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with Early Onset Alzheimer’s Disease (EOAD) (n=40)</td>
<td>Consists of individuals with a self reported formal diagnosis of EOAD</td>
<td>Forum contributions are elaborated on in the themes, however, length of membership, and existing forum relationships factor into the level of participation for members</td>
</tr>
<tr>
<td>Individuals with a Young Onset Dementia (YoD) (n=24)</td>
<td>Individuals with an alternative young dementia diagnosis. These may include Mild Cognitive Impairment (MCI), Lewy Body Dementia, Frontal Lobe Dementia, Chemo-Induced Dementia, and Vascular Dementia</td>
<td>The context and content of discussion contributions from individuals with an alternative YoD diagnosis did not differ from the those with EOAD</td>
</tr>
<tr>
<td>Caregivers (n=120)</td>
<td>Unique position within the online community. For most individuals that identified as caregivers, their relationship with this specific</td>
<td>For most, contributions to the YoD discussion board were limited and long-standing members were quick to redirect</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Site visitors</td>
<td>Their partners were newly diagnosed and were seeking advice (they are redirected to a forum that will better serve their needs)</td>
<td></td>
</tr>
<tr>
<td>Caregivers</td>
<td>There are a few caregivers who have been members of the forum for a long time (&gt;5 years). They maintain regular contact and offer support. Interestingly, interaction with members of the forum has continued even after their partners were no longer with them (their greatest contributions are in the deeper engagement category)</td>
<td></td>
</tr>
<tr>
<td>Others (n=23)</td>
<td>Others includes those with Late Onset Dementia (one member), suspected diagnosis, no diagnosis, relatives of people with suspected diagnosis, and moderators</td>
<td>The member with late onset dementia is very active. Her contributions mimic those of members with a YoD, including EOAD</td>
</tr>
</tbody>
</table>

**Note.** The sample size for each forum member category includes those who confirmed a diagnosis of or relationship with YoD. The association with YoD was unknown for 23 individuals.

**Description of Participant Sample**

Demographic information for forum participants with a diagnosis of EOAD was taken from in-text disclosures. The amount of personal information divulged varied. Of the 40 individuals with a confirmed diagnosis of EOAD, 22 revealed that they resided within North America, and 18 individuals did not disclose their location. A diverse range of states, cities and rural areas were represented. Twenty-five participants were female,
11 were male, and four did not disclose their gender. The average age of participants was 54.3 years. Sixteen individuals identified as married, five were single and 19 did not disclose their marital status. Employment status included those who were employed (n=3), self-employed (n=3), employed part time (n=1), not employed (n=12), and unknown (n=21). Most of the participants identified as parents, however only four had adolescent or adult children living at home. The length of formal diagnosis and stage of illness varied. Several participants stated that they were in their first year of diagnosis, while others disclosed that they had been diagnosed from two to six years. Nine individuals noted retrospectively they had exhibited symptoms for years prior to clinical diagnosis. Participants cited the process of obtaining a formal diagnosis took an average of three years. The presented themes will focus on the social benefits and potential barriers of active forum participation for individuals with a diagnosis of EOAD.

**Addressing Social Isolation within an Online Community**

**Theme I: Fostering Social Connection**

Fostering social connection emerged as a key social behavior displayed online. Active forum engagement fulfilled a fundamental need to relate to others and belong, promoting social connectedness between members (Rettie, 2003). Participants connected socially by relating over shared understandings, cultivating a sense of belonging and forming relationships that extended beyond the illness.

**Relating over shared understandings.** Seeking information and interacting with others who are navigating similar challenges were key drivers to interaction on the forum. Participants revealed that it was not lack of social contacts or family support that led them to initiate and maintain communication with online community members, but rather
an absence of connection with individuals who could relate to their experience. Kyla (Female, EOAD) explains:

I think my greatest need at this stage is a support group or even one friend with early onset Alzheimer’s. I feel so alone in this. There is no one who really gets it. My husband tries and I am grateful for that. My sister pretends it's not happening and everything is fine. I come from a small community of 20,000 and know no one else with this disease. I am grateful that I have found this site because it does help some.

Needing to engage with similar others was underscored by Barbara’s (Female, EOAD) initial message on the discussion board.

In the past few months I have been coming to this site to get my "private" encouragement from all of you guys and finally decided today to join. I was in a very low moment through the night and into this morning, and went searching for Participant A’s devotional website and it gave me EXACTLY what I needed. Through my tears I sang "Alleluia" over and over and over and received His peace. Thank you Andrew. I am new here so I don't know the ins and outs of all the postings and such but from what I have read there is compassion and understanding here that I dare say will never be totally found anywhere else.

(Barbara, Female, EOAD)

The notion of shared understandings emerged from forum narratives. This concept encompasses individual perspectives and lived experiences, both of which were relevant to but not identical across members. Rather, living with YoD was a collective reality for all of the members engaging with the online community, irrespective of their ability to
relate to a specific experience or view presented. Individuals in the group understood how they were personally affected by dementia, now and for the future, and as such were considerate of each other’s personal experiences and truths.

Being able to communicate with others who share an understanding of the illness trajectory helped to normalize the experience of EOAD in a way that a participant’s support system could not provide. The progression of the disease is both unique to each individual and unpredictable. While not all members of the forum have experienced the same course, they were able to find common understandings and concerns which, when discussed, allowed them to make sense of their own illness trajectory. Debbie (Female, EOAD) explains:

Each of us finds our own perspective and builds our own world as best we can and sets a course. The illness itself has anxiety aspects which are to the moon for some of us. Being able to hear from others with the illness through the boards makes me so happy, or bucks me up enough to keep going.

The functional and behavioral changes following diagnosis could be unpacked and processed by other members of the community. For example, EOAD participants talked about feeling apathetic, a topic they understood well and that was a shared experience, but that was not well understood by people in their support systems. When apathy was the subject of a thread, discussions quickly became animated, with participants revealing how significant this feeling of indifference was to their lives. Cameron’s (Male, EOAD) post describes his thoughts with the situation:

I believe this is so hard for our caregivers to understand. We cannot even explain it. This is such a challenge in getting them to believe. I went from washing my
car all the time and keeping it like new to absolutely not care at all. I sometimes wonder if [it is] because we are facing this death spiral and nothing else is important any more. I keep searching for this answer. Not sure I will ever know. Maybe by the time I figure it out I will no longer even understand. It stinks to be like me as I always searched and wanted to know all the answers. I always had to know and felt there was always a logical explanation for everything. Trying to figure all those things out around this disease has made me realize some things have no answers. Very hard to [accept] that.

Revealing that he understood this experience personally as well, Andrew (Male, EOAD) replied:

Cameron, I also struggle with the same thing you are talking about. It is like the brain and body just don't connect. I may want to do something but for some reason this just doesn't happen. I feel that I often flit from one thing to another, never completing anything. This is quite frustrating. Thanks for starting this thread, [I]t was good to talk with others about it.

Similarly, posts about fears became animated conversation. Participants allowed themselves to be vulnerable on the forum by sharing present anxieties or future uncertainties about specific situations.

I think my biggest fear is losing my independence. Even the thought of losing that and depending on someone (especially my sister) "taking care" of me freaks me out. I can't wrap my head around that. This fear is what makes me consider the right to die a dignified death. Has anyone else considered this option? If so, why? How do others handle their fears of things which are for sure going to
happen? It's not like "a worst case scenario" it is a sure thing. I'm really struggling right now, not with where I'm at but where I will be at in the future.

(Linda, Female, EOAD)

Linda’s comment was met with empathy, mutual understanding and acceptance. The concept of death with dignity was not a practice every member agreed with. Nevertheless, they supported her perspective because they understood the future implications of EOAD on one’s quality of life. Additionally, members of the community recognized how important these discussions are while one still has some control over individual outcomes. The controversial topic of right to die progressed into a discussion that emphasized the frustrations brought on by the disease. Cameron’s (Male, EOAD) comment describes his life before and after diagnosis.

I lost my career where I was one of the top leaders in the field.

I loved to tinker with electronics. I can no longer do it because things go [poof].

I loved boasting but no longer process the complexity of using one. And yes they are much harder to use then a car.

Forget the golfing as I cannot find the ball or I take too long to swing.

I lost my friends.

I went from being handy around the house to useless.

I went from taking care of my wife to becoming a burden to her and making her deteriorate.

I no longer have fun by going and doing things, much of it because of not [being able to] fit in.
I also know what is ahead of me, and this list can take me a full day if you need more.

This is by far the most devastating way to die. It has been working on me since age 39, official diagnosed at 49. This is a slow torture with lots of pain.

I do believe we should be upfront with what is real.

This raw expression of defeat was met with supportive responses, not reducing the individual’s feelings to a moment of frustration, but acknowledging the painful reality of the illness trajectory. What followed were comments that highlighted the person’s strengths, with emphasis on the strides he has made as an advocate for the disease. Fiona (Female, Lewy Body Dementia) stressed: “Cameron, I have to disagree with the useless part. Maybe you’re not fixing things around the house but you are not by any means 'useless' and perhaps are serving a greater purpose! A purpose that impacts us all!”

The challenges of EOAD were thoughtfully deliberated, but members of the community equally welcomed upbeat conversations and humor. Individuals made self-deprecating jokes that were not pitied; rather, they were met with humor over the relatable experience. Debbie (Female, EOAD) wrote: “Evelyn--I don't know what my question was!” Evelyn (Female, MCI) replied, “LOL! This happens to me, too!” These comments take on a new meaning for persons with YoD whose functional losses result from their illness rather than normal age-related changes. As such, the humor in these occurrences may not be received in the same manner by existing support systems as they were understood by forum members who could personally relate to the experience.

**Cultivating a sense of belonging.** The human need to belong is threatened when an individual is faced with a diagnosis of EOAD (Rettie, 2003). The social ties that
participants had once associated themselves with devolve, creating a need to supplement remaining, diminished social circles. As one participant eloquently stated, “I do not long for "services." I long for a place to belong. As my life becomes more complicated because of my dementia and my loss of pragmatic skills, I find I am swimming in a world of broken connections” (Debbie, Female, EOAD).

The online community promoted a culture of acceptance by offering a new place to fit at a time when long-held sources of belonging were waning. Drawing on individual experiences, long-standing members recognized the delicate state of new users, and that the community needed to be tolerant while new members processed their diagnosis. Fiona’s (Female, Lewy Body Dementia) post functioned as a set of guiding principles for participants in the online space.

We do not want a seemingly cookie cutter-type board where everyone thinks the answers to living well are the same. This a support group forum and it is of vital importance that individualism be expressed on the board and that the board stays safe for persons to freely express themselves in accordance with how they are feeling or what they may be struggling with. New persons need to be accepted, validated and supported for where they are in their process of just getting diagnosed wherever that may be.

Forum narratives revealed that participants found they were accepted as their present selves. The welcoming atmosphere promoted by members of the community, as well as the manner in which unconventional approaches were received, reinforce this understanding. Participants were not judged for communication lapses, use of alternative coping mechanisms such as medical marijuana, or electing not to follow best practices
although they are heavily emphasized. This culture of openness indicates a unique level of comfort and reception between members. Mary’s (Female, EOAD) quote and the subsequent replies support this notion.

Hey Guys from a wet Atlanta. I have yet another question. When you got your diagnosis and once you became familiar with all it entails, who if any here said or thought, well it’s a death sentence so I am [going to] be me and do what I want, eat like I want, start crossing off those things on my bucket list and so on? Just wondering; that is where I am, yep I take my meds but I have not quit smoking, I eat like I want to and do what ever suits my fancy after my responsibilities are attended to . . . Now those who wish to impose judgment need not reply. It has been fun being me not a mask or who so in so wants me to be no more people pleasing attitude. It is like living for today only which I think is how we are suppose to do anyway we have no promises of tomorrow . . . Surely there are kindred spirits like me amongst our board of all kinds of folks.

Members welcomed the candid comment. Replies to Mary’s post demonstrated that others could relate to her experience and highlighted the open-minded environment cultivated by the community. Fiona (Female, Lewy Body Dementia) summarizes: “((((((Mary))))) I greatly appreciate your candor and honesty. I am in no position to judge. If there is anywhere in life that we should not be judged it is here on this board! There is not a perfect way to deal with what we have to deal with on a day-to-day basis.”

Participants’ enthusiasm to verbalize their gratitude for individual members nurtured group membership. Expressions of appreciation saturate the data. These comments demonstrate the value that members add and equally, they emphasize the need
for continued engagement. Below, Cynthia (Female, Caregiver) introduces a few long-standing forum members, emphasizing their instrumental roles within the community.

You are a new friend-Member, but you are already bringing us the gifts of a different perspective and of positives that lighten the spirit and remind us not to pitch a tent and camp out in the gloom. It looks like YOU are a gift to US. Aren't we blessed that you found and came to this place? You will find many new friends; amongst them is Mary who has an upbeat approach and stands like a stalwart warrior using her most hearty tool--humor; Andrew uses his gentle and very thoughtful ways in good perspective reaching out in humility and understanding to give to others. You will meet Helen, she is a very strong person who was diagnosed with dementia quite some time ago. She is one of the Peer Volunteers here and lives the "Best Practices," with diet, exercise and socialization, and has had excellent results. She also is an advocate and very active within the Alzheimer's community, and also has attended and been involved in Conferences up to the Washington D.C. level. Some of the other "old-timers" are Fiona and Debbie and so many more that I'd better stop introductions or this will go on for pages. Just know we all welcome you with open arms and open hearts.

Highlighting the contributions of each member, as so many of the posters have done, cultivates feelings of belonging for recipients. Equally, this provided individuals with a sense of forum identity. These encouraging words were recognized and appreciated, demonstrating the impact and the value of forum contributions on members of the community.
**Forming relationships that extend beyond the illness.** Forum members would initiate interaction with a focus on the illness. Discussion, in particular for new comers, would center on the diagnostic process, treatment and self-management. However, exchanges would often progress from conversations about diagnosis and illness management to discussions of a general or more personal nature. It was at this stage when meaningful social ties between forum members became evident. The factors which brought people to the forum were not the same reasons that drove continued interaction. Rather, established social relationships were the stimulus to sustained forum engagement.

As conversations on the forum progressed and became more personal, participants were able to remold their social environments. EOAD disrupts the once seamless fit into a social world that becomes less familiar following diagnosis. The forum provides the opportunity for dialogue with a network of individuals who are closer to participants’ truths and can relate to their experiences, thereby filling a growing social need created by the progression of EOAD. A finding that emerged from the archived textual communication is that participants felt that they had created connections worth maintaining. This was best exemplified by unprompted updates or daily check-ins by members.

Sorry I've been off the boards for quite a few days. I've had bronchitis and it has worsened my EOAD symptoms. I've not been able to follow my daily schedule and it has messed me up. I even missed writing for about 4 days which made going back to writing so much more difficult. I am on the upswing but still not out of the water yet. I have to speak at the State Capitol for our State Alzheimer's Advocacy day next week. I hope to be better and able to do that. Thankfully it is
a very short speech (10 minutes) so should be able to at least do that. Just wanted everyone to know why I've not responded much. God Bless. (Andrew, Male, EOAD)

Members also demonstrated how significant their online connections had become by reaching out to individuals who had not recently engaged with the forum. The level of initiative participants took to maintain contact with one another validates the individual importance of the relationships cultivated online. Equally, these levels of engagement demonstrate that the members of the forum care about one another’s welfare and had become integral to each other’s social network. This point is highlighted by Debbie’s (Female, EOAD) post.

While I am here thinking about you, last time you took a trip I think I actually held my breath when you were gone from [the] boards. I was so WORRIED and kept hoping you would find "internet access and let us know how it is going"!

Ha! But that was how important having a friend like you on this forum was to me.

Social connection was confirmed in alternative ways. Some relationships had developed and people were sensitive to their online friends’ change in demeanor. They would note the change in behavior and ask if they could help. This signified that people with EOAD could develop relationships virtually and were able to read between the lines of each other’s textual exchanges, reaching out by responding online or noting that they would email them.

The willingness to move social relationships beyond the forum was demonstrated by written comments about participants connecting through different means, including
email, phone, chat room, and meeting up through travels. Debbie’s (Female, EOAD) comment highlights her appreciation for the alternative modes of communication that resulted from the social ties established on the forum.

I love all of the people on this message board, and those who provide the board to lift each other up. Thank you everyone for helping me whenever I feel low or lost. Thank you to my online Guardian Angel friends I met on these forums who seem to send me an email with exactly the right words whenever I get too low.

Equally, individuals expressed gratitude for the emails and private calls, or alternatively offered to have conversations with someone who seemed distressed or in need of further assistance.

Cameron’s (Male, EOAD) post shows his willingness to connect with members in order to discuss concerns one on one.

I so wish you the best of times Kyla. We all complain sometimes and fail to recognize some of the challenges we all face. When you think ours may be bad, there are those even worse. I would be more than happy to speak with you by phone if I can help you in any way. Just feel free to connect to me privately. I am more than happy to call you.

Members’ connecting through alternative means shows a level of comfort both in the relationships that were created and the individual’s ability to be their authentic selves.

Participants expressed hesitation in traditional social environments, citing reduced memory recall and a difficulty in keeping up with face to face or telephone conversations.

Continued engagement enabled members to create social ties with individuals that they
could feel comfortable communicating with through written or traditional forms by removing the hesitations imposed by the illness.

The actions, behaviors and expressions exhibited through forum narratives revealed how social connections were fostered amongst members of the online community. A shared understanding of life with EOAD rooted the social bonds that developed online. Equally, the opportunity to engage with similar others helped to normalize the experience of living with the disease, notwithstanding the variability of individual practices or perspectives shared on the communication medium. Rather, members of the online forum cultivated a sense of belonging by creating a space where individuals could feel accepted as their present selves and valued for their contributions. A shift from illness-focused discussions to conversations of a more personal nature helped to progress the relationships initiated online. This, in combination with the efforts made by participants to maintain contact with members of the forum or by alternative means demonstrates that embedded social ties had developed. Over time, social interactions nurtured a sense of empowerment over individual outcomes, encouraging a thoughtful reevaluation of life following a diagnosis of dementia.

**Theme II: Redefining Life After Diagnosis**

The concept of social support underlies many of the discussions that took place on the forum. Albrecht and Adelman (1987) define the theory of social support as “verbal and nonverbal communication that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance perception of personal control in one’s life experience” (p. 19). This definition stresses communication as a way to increase control over individual outcomes. Albrecht and Adelman’s (1987) explanation
of the concept supports a key finding that emerged from the textual communications: Members supporting one another to move from an isolated to an empowered state through enhanced coping and self-care, ultimately finding purpose following diagnosis.

**Enhanced coping and self-care.** A decline in functional abilities leads to a palpable loss of independence for individuals with YoD. The opportunity to discuss the changes that accompany a diagnosis with similar others presented methods intended to enhance coping and self-care. Consequently, these discourses encouraged the adoption of compensatory mechanisms aimed at preserving a level of independence. Forum narratives underline the fears and anxieties that stem from an acute awareness of ongoing changes and future ambiguities. An understanding of personal stories provided context to the individual experience by offering a range of coping and self-care mechanisms employed to manage aspects of EOAD. Participants expressed frustration about the relative inaccessibility of information online versus practical knowledge that could help to reduce the uncertainties surrounding the illness by enhancing coping and self-care. For example, Andrew (Male, EOAD) explained how he did not fit the averages presented online by highlighting the precautions he took to slow the progression of the illness.

I was diagnosed in late 2009 and I'm still doing okay. So that has been 5 years. I'm on the highest dose of all medications now. Like so many others on this board, I practice the Best Practices (exercise, mental activity, socialization, taking my meds daily, and Mediterranean diet). This has really helped me plus I try to reduce stress and stay positive about my condition. Sure I'm not the same man I was before EOAD, but I still enjoy life and do many things.
Forum discussions focused on methods to maintain autonomy by reducing daily stressors, improving nutritional intake, increasing physical activity and enhancing socialization – all with a goal of maximizing quality of life by delaying the more advanced stages of the illness trajectory. Debbie (Female, EOAD) clarifies:

Help is on the way. Everything changes, we are going to take control of how this illness is perceived, relieve each other's fears, and invent new ways of living this out without the circus and crying and fighting. When you feel better, and you will, we'll cook up some good ideas to begin creating the world we need. Might not be perfect, but we will aim for super good.

Learning from one another or, alternatively, learning together, nurtured the consistent need to accommodate the changes presented by EOAD. Through trial and error, conversations that centered on specific topics evolved from conceptualized ideas to tangible change. For example, through extensive research and continued dialogue, a group of forum members created what they identified as “Best Practices.” This included lifestyle modifications such as daily exercise, a Mediterranean diet, limiting stress, and increasing socialization. For many of the regular members, these practices were thought to delay illness progression. These forms of collaboration empowered members to enhance control of individual outcomes by improving coping and self-management of the disease. Evelyn (Female, MCI) explains:

I call us Dementia Pioneers. We are the first generation who is pro-active in our own treatment of dementia or cognitive impairment. Many of us are on the memory medications. We also follow lifestyle habits that we call Best Practices. That helps with our functioning and help to prolong the early stages.
There is a reciprocal gain from discussion that unfolds online. Members offer one another coping mechanisms to better manage individual situations. This collaborative method of participation adds purpose. It enables members to feel as though they are making a positive contribution to one another’s current and future management of the illness.

Finding purpose. Helping others to reduce uncertainty and find purpose following diagnosis is empowering for all involved. Dialogues exchanged demonstrate that each member had something to contribute for the benefit of others and the common goal of maximizing quality of life following diagnosis. Throughout textual exchanges, members did not preach, but rather led by example. Andrew (Male, EOAD) emphasizes this point:

Again, I pray that you will become an advocate for our cause and perhaps even move forward with writing a book about your story. Take notes about all your experiences, jot down your frustrations, explain your future plans, and discuss your feelings. My first book took almost 3.5 years to write. The second one will be about 2 years by the time I send it to a publisher. I also plan to do another devotional book for dementia patients on the Psalms. I will choose the best ones from my blog and work them over into something suitable for a book. As a Marine, I will never give up! Like so many on these boards, I am a fighter, an Alzheimer's Warrior as many on the boards have put it. We must all continue in our fight and find something that gives us purpose and fills us with passion. I am inspired by so many on these boards and I know I don't say that enough!
These discussions are empowering for those who were encouraged by the actions or words of forum members. Positive reinforcement and exposure to advocacy opportunities inspired members to find purpose. In some cases, this involved becoming “Dementia Pioneers” – redefining for themselves and future members what it means to lead a fulfilling life following diagnosis. Andrew (Male, EOAD) post supports this notion:

Debbie, I think you'd be great on that panel. You'd bring a unique perspective to living with the disease. You are positive, always searching for different ways to attack [Alzheimer’s], and very secure in how you live your life. You are just what they need! Do it and continue to carry the torch that life isn't over just because you've been diagnosed. We are still who we are and we need to be heard! [Go] get [them] and be a wordy and long-winded as you need to be! God bless.

Members became familiar with, or were encouraged to seek out advocacy roles, leading to community engagement and social connection with other individuals who have been impacted by the disease. Alternatively, dialogue that concentrated on finding purpose following diagnosis encouraged participants to find ways to lead a fulfilled life.

Debbie and Mary, we are truly redefining what it means to live with dementia!

These boards and all the friends we make help us survive so much better. Thanks for reminding us about living our lives so much differently and better! God bless.

(Andrew, Male, EOAD)

Continuous dialogue is equally cathartic for those leading discussion and pushing for change. In writing about their experience with the illness, and the advocacy roles they have taken on, members contributed to improving outcomes for individuals with
EOAD. As an unintended outcome, this method of engagement on the forum created an opportunity for members to contribute. Participants found purpose in helping others navigate the illness by serving as a resource, guide and support system for members of the online community. Fiona (Female, Lewy Body Dementia) summarizes this purpose as “through helping others we help ourselves.”

Forum dialogues were saturated in supportive exchanges that facilitated participants to redefine life following diagnosis. Discussions inspired members to create or share methods that would allow them to enhance coping and self-management of the illness. Ultimately, sustained forum engagement led to individuals finding purpose following diagnosis – either through exposure to advocacy opportunities or establishing a role within the forum to help others manage life with EOAD.

Theme III: Factors Impacting Forum Participation

Technological barriers and caregiver involvement emerged as factors that may impact online engagement, potentially limiting the benefits offered by the medium or members of the community. Technical faults presented obstacles for new members and disrupted the natural flow of conversation. Further, the participant – caregiver dynamic generated ongoing issues within the online community, creating a need for thoughtful consideration of the open nature of the online space.

Technological barriers. The online communication medium requires equipment and familiarity with technology for interaction. Without these prerequisites, the structure and method of communication can be alienating. Kayla (Female, EOAD) clarifies a personal barrier to more consistent communication: “I am not on often. I can’t afford Internet. Sad but true.” Furthermore, the presentation of threads and posts may impede
successful communication and community integration for incoming members.

Participants routinely expressed frustration over the lack of alerts for new posts. Fiona (Female, Lewy Body Dementia) explains: “I am feeling the same way. Not seeing if a post was responded to is important. How are we to know if a newcomer was reached out to or not [without] clicking in?” The absence of notifications when new threads were posted or alternatively, a post within a thread that a specific member was a part of, further limited the natural flow of conversation. This was evident in a number of threads. Conversations would end abruptly at times, without addressing a pertinent question posted or acknowledging the need for support being sought out by a newcomer.

The design of the discussion board has the potential to contribute to feelings of isolation by impeding interaction for incoming and existing members due to a lack of notifications when new posts emerged. Despite these aforementioned shortcomings, there is some value to the forum layout. The ability to access previous threads introduces members to a wealth of information and coping strategies that had been previously discussed. This was of particular value for members who did not have a strong online presence through posting, but instead passively engaged by reading threads that were most relevant to them.

**Caregiver involvement.** The open nature of the forum led to participation from individuals who did not have a YoD, but were carers for a person with dementia. Messages written by caregivers that expressed frustrations associated with the caregiver experience were a persistent source of tension within the online community. There were multiple incidences where participants perceived text posted by a caregiver as distressing or inappropriate. These messages were seen as a threat to the well-being of all members.
by reducing interaction and alienating individuals who unsuccessfully campaigned for moderators to reinforce membership guidelines. Evelyn (Female, MCI), a long-standing member of the community temporarily left following an unsuccessful campaign to eliminate the distressing posts, shares:

Every time I think about returning to this site I feel an overwhelming sense of sadness and defeat. I still feel hurt about being told to start my own group, when I expressed my feelings and concerns about distressing spouse vents on our [young onset Alzheimer’s disease (YOAD)] board. I truly believed this YOAD board was my own group. I felt like I was punched in the gut. It's been hard to try to stay in a positive mode.

Caregiver participation had the potential to threaten a space that individuals with YoD felt was exclusively theirs. Members had created an environment that cultivated social relationships as a result of shared understandings and a sense of belonging. Caregiver engagement on the forum distracted from a focus on maximizing quality of life to an emphasis on the more distressing components of the disease. Participant D summarizes:

How is it missed that we are trying to figure out the basic reality of living with dementia? This forum is a platform for positive change When people are encouraged to share their story, the way life is unfolding for them, what helps and what does not, they should be able to do it without having to battle dead concepts of what people who don't have dementia think it is like. Show some respect to us! Our children may come down with dementia and we are fighting for a better world for them, too. Does the magnitude of these discussions sink in yet? It does for people with dementia, big time. This particular forum, for younger onset, is a
blessing, a laboratory, a research project, a schoolroom, a sanctuary. This forum is the only major source of connection for younger people in our country! We are not griping or wallowing in self-pity. Neither are we here to congratulate [caregivers], or respond to their complaints about our language, or process. It seems like all the support there is in existence is already for the purpose of uplifting [caregivers].

The sentiments in this post highlight the social benefits gleaned from online participation with similar others. Equally, the poignant statement stresses the frustrations experienced by members who had felt their contributions were being devalued by insensitive comments. Nonetheless, despite the tensions created by certain comments posted by caregivers, their involvement on the YoD forum cannot be reduced to upsetting remarks. The participant – caregiver dynamic is far more complex. Caregivers with a regular presence on the YoD forum offer insightful contributions to the discussions and are viewed as integral members of the community. These individuals were equally sympathetic to the tension created by the upsetting posts and rallied for wounded members to return. Further, their support helped the members refocus their objectives. Monica’s (Female, Caregiver) comment highlights this sentiment – encouraging members to remember the value of their forum contributions.

The peoples of the world need to hear your voices and to learn from you. Care-partners / care-takers / care-givers, no matter where in the world; they need your in-put and guidance in order to learn how to become better care-partners; better care-takers; better givers of care. I do not live in the USA. English is not my native tongue. But I am listening, attentively and carefully, to each of you. I sit
here in a different corner of this earth with this [association name removed] forum web link. I hear your voice... To me, your voice is universal; it is the voice of a person living with dementia. A voice that comes to me from the heart.

Caregivers who remained in frequent contact with members of the forum after their spouses had passed add a positive dimension to the participant – caregiver relationship. Monica (Female, Caregiver) explains her rational for continued forum interaction: “My beloved died last year and I’ve felt the need to stay here in [name of association removed]... I feel I am with him when I am with you all.” Her contributions to forum discussions were welcomed. Although Monica held the title of Caregiver, her supportive approach offered a unique and non-intrusive perspective to the discussions. Like Monica, most of the caregivers who had established social ties with members of the YoD community were careful not to invade a space that was established to serve a population living with the disease; rather, they would offer suggestions based on their loved ones experience or alternatively, engage in conversations of a more personal nature. It was evident by the reactions of some of the forum members that caregiver posts could be perceived as harmful, creating a potential deterrent to continued interaction on the online platform. Nonetheless, this perception was not found consistently across caregivers, because most had become integral members of the YoD community by thoughtfully contributing to conversations.
Overarching Conceptualization of Study Findings

Medium and Participant Driven Outcomes

The forum is part of a greater online community and group of message boards that serve as communication mediums for people with dementia, caregivers and health professionals. Specifically, the setting under study was dedicated to connecting persons with a YoD (including EOAD). Figure 1 represents the factors necessary to mobilize the social benefits gleaned from forum engagement, or alternatively, impede online socialization.

Figure 1. Medium and Participant Driven Outcomes of Online Forum Engagement
The figure describes how study findings could be organized in terms of the outcomes facilitated by the communication medium or motivated by members of the online community. The structure of the forum was a necessary condition for the formation of a social network and method of interaction. These medium-driven outcomes functioned as a framework in which social relationships could be cultivated through sustained engagement. As a space for people linked by a common interest, the online forum constructs a social network for individuals with YoD (Kozinets, 2015). The setting necessitates textual exchange amongst members to initiate and maintain communication. Conversation is the key mode of social interaction for forum participants, who dictate the nature, pace and flow of dialogue. Nevertheless, the participants stimulated and sustained discussions that cultivated social connection and support necessary to address the social needs of individuals and enhance overall well-being. To this end, the analysis focused on the social outcomes driven by the participants of the online community.

An analysis of archived textual exchanges revealed behaviors and expressions employed by members to encourage or maintain discussion. More importantly, a meaning-focused interpretation exposed ways in which the actions and statements of members, who provided substance to the discussions, inspired deeper levels of engagement. Conversations that advanced to real life following diagnosis elicited the most posts and consequently views, demonstrating the greatest potential to address members’ social needs. These forms of communication fostered social connection and helped participants redefine life following diagnosis. To this end, participant-driven outcomes centered on the social impact of deeper levels of engagement between
members, an opportunity that would have been lost without the online communication medium.

A desire for information and contact with similar others were key factors attributed to initiating contact with the online community. And yet findings demonstrate that the social benefits gleaned from relationships established online motivated continued interactions. Fostering social connection within an online environment evolved over time. Loose social ties were created over shared understandings and a sense of belonging. Members of the community engaged in discussions that centered on management of the illness which normalized the individual experience of living with EOAD. Equally, textual exchanges emphasized acceptance and placed value on individual contributions to promote belonging. Through sustained forum engagement, participants were able to remold their social environments, cultivating relationships that extended beyond the online context. The methods of engagement employed validated that members of the forum had become central components of one another’s networks, further demonstrating the positive impact of online methods of social interaction.

The relationships cultivated online were grounded by the concept of social support. Discussions amongst members focused on troubleshooting individual issues or mutual problems related to YoD. Members brainstormed methods to manage components of the illness, or alternatively, exposed one another to techniques intended to slow its advancement. Equally, interactions centered on suggestions directed at delaying the progression of functional and behavioral changes with a goal of preserving independence. To this end, these discussions exposed participants to a variety of mechanisms aimed at managing the disease through enhanced coping and self-care. In
addition, forum narratives demonstrate the added value of individual contributions. Members shared ways to get involved with the YoD community, offering alternative methods to address social isolation. Ultimately, social interactions in which reciprocal support was exchanged, ideas were shared and coping mechanisms were cultivated created a sense of purpose within the forum, filling a social void and serving as a method of empowerment for members.

The open nature and online setting of the communication medium did create potential barriers to effective communication. The forum layout presented concerns over unseen posts, potentially alienating new members. Further, the participant – caregiver dynamic challenged the intentions set by the individuals of the YoD community. Tensions caused members to temporarily leave the online space, and negatively affected remaining individuals. However, most caregivers that engaged within the forum were supportive of other members and integral to the online community.

Chapter Summary

The goal of the presented research was to advance current understanding of the ways in which people with EOAD use online communities to combat the challenges of social isolation. Analysis of social exchanges led to an understanding of how the communication medium facilitated social participation online. Social network and social interaction emerged as products of the online setting, which created a space for individuals with EOAD to interact and connect over common interests and concerns. Nonetheless, it was the outcomes motivated by the members of the community that demonstrated the greatest potential to maximize the benefits of online social interaction. An interpretive analysis of archived textual interactions revealed how participants
fostered social connection and supported one another to redefine life following diagnosis. Potential obstacles to online socialization did emerge from a review of forum narratives. Technological barriers and caregiver involvement were considerately examined to better understand factors impacting online social engagement. The following chapter will compare current study findings to previous literature that explored the concept of social isolation and online communities. In addition, the theoretical concept that emerged from the analysis will be presented.
CHAPTER 5

DISCUSSION

The objective of this research project was to advance current understanding of the ways people with early onset Alzheimer’s disease (EOAD) use online communities to address the challenges of social isolation. The primary research question addressed the main purpose of the study while secondary questions focused the analysis of findings. They were as follows:

Primary Research Question
1. In what ways does engagement within an online community help to combat social isolation experienced by individuals with early onset Alzheimer’s disease?

Secondary Questions
2. What are the motivators to social interaction within the online forum?
3. How do conversations typically progress and how are they maintained?
4. What expressions of belonging are demonstrated?

Chapter five will begin with a discussion of study findings in relation to research presented in the preliminary literature review, as well as supplementary studies reviewed following the analysis. The discussion will present similarities and differences between study findings. The theoretical construct of social connectedness will be used to explain the effect of social interaction online and its influence on overall well-being. To conclude, limitations that are inherent to analysis of online settings and archived textual interactions will be considered.
Relation to other Comparative Research on Social Isolation and Online Communities

Several parallels exist between current study findings and previous research that explored facets of online social interaction amongst other populations. The desire to establish connections with similar others emerged as a key motivator to online engagement. This finding was repeated across several studies and reinforced within the textual discourse on the forum. An understanding that emerged from this study was how interaction with community members who were experiencing similar functional and behavioral losses helped to normalize the individual experience of living with EOAD. Kirk and Milne (2015) reported similar findings. The authors highlight the benefits of social interaction within an online support group when participants with cystic fibrosis could relate to individual perspectives and experiences with respect to the illness trajectory.

This study explored different aspects of online social interaction than Rodriguez’s (2013) research into the reconstruction of self and community online for individuals with EOAD. As such, the understanding of key motivators to interaction with an online community did vary. Rodriguez (2013) found that a lack of connectedness and feelings of isolation were the stimulus to seeking out virtual means of interaction. There were examples within the current data in which members expressed feeling socially isolated or alone. However, most participants stated that they had pre-existing support systems that they could continue to rely on. What findings in my study demonstrate is the need for socialization with others who can personally relate to the experience of living with EOAD.
The progression of social relationships within an online social space is explained in Hoybye et al.’s (2005) review of email exchanges amongst women with breast cancer. The authors describe how social ties evolve over time by explaining the progression of informal to intimate social relationships amongst members of the email chain. Depth of social ties may be understood by the strength of the connection between people. Loose social ties are defined as informal relationships enacted for a specific purpose. They were demonstrated in the initial email exchanges, in which the conversations focused on the medical aspects of the disease. Strong social ties were evident within the email chains when discussion shifted to conversations of a personal nature. Strong social ties are visible in my study findings and best exemplified by an individual’s willingness to share more personal aspects of their experience with the illness, or lives in general.

Loose versus embedded social ties can also be understood by Walter’s theory of hyper-personal relationships. Moya et al. (2008) used the theory to explain the development of social relationships within an online environment. An understanding of the progression of impersonal to hyper-personal relationships is explained in the same way social relationships were perceived to evolve within the YoD forum. Impersonal relationships were motivated by information exchange and a limited or invisible presence online. Discussions that advanced from a medical focus to topics of a more personal nature demonstrated the emergence of hyper-personal relationships amongst members of the YoD forum. Evolving social relationships were also understood by the participants’ efforts to maintain contact online or alternatively, move the relationship beyond the online context. An understanding that developed from the analysis of textual discourse is
that members of the YoD forum with the strongest social presence were able to cultivate hyper-personal relationships.

In their analysis of published memoirs, Ryan, Bannister, and Anas (2009) examined the social experience of individuals living with dementia. Specifically, the written content of 13 memoirs was examined to explore changes in social identity through the process of writing. The narratives describe how “writing renews an individual's status as a contributing social partner and imparts new roles and meaning, which can bring feelings of empowerment and control” (p. 152). A key outcome from my study was an understanding of the ways in which sustained online social interaction helped individuals find purpose. This was demonstrated by the members’ exposure to, and participation in advocacy roles outside of the online community. Alternatively, helping users navigate the illness trajectory created a role within the online setting, allowing some members to create purpose through continued online engagement. The discoveries from the illness narratives reviewed in Ryan, et al.’s (2009) report support this assumption:

Writing provides an opportunity to engage in meaning – making dialogue with others, an activity which facilitates the integration of diagnosis and altered abilities into a new sense of self. By deconstructing the self and building it back up through the process of writing, an individual is able to achieve new clarity, empowerment and roles. (p. 150)

Josefsson (2005) argued that online social environments support an individual’s desire to help others, serving as an important coping strategy. A desire to help others navigate the illness trajectory supports the understanding that online interactions were a cathartic
process for members of the YoD community. Further, Kirk and Milnes (2015) describe how forum narratives revealed a concern in managing the illness and therefore, conversations focused on adaptive methods to lead a more fulfilled life. This supports the conclusion drawn in my study, in which members of the YoD community focused discussions on managing their illness by enhancing coping and self-care. This outcome may be motivated by the desire of participants to preserve independence and maintain a sense of individual control.

The potential to connect with a heterogeneous group of individuals through online platforms was found in Coulson’s (2005) study. The open nature and accessibility of the YoD forum would support Coulson’s (2005) understanding. However, the sample used in my study was rather homogeneous. The individual experiences and coping mechanisms shared by the members of the forum did provide a varied approach to illness management. Nonetheless, only a small number of forum members from one region of the world, and in the same stage of the disease process, regularly contributed to conversation.

The conclusions drawn from the studies presented in the preliminary literature review and introduced in the discussion support the understanding of the ways in which people with EOAD use online communities to address social isolation. Key motivators to engaging within the online forum, as well as the central outcomes of sustained interaction, were comparable across studies. Fostering social connection, redefining life following diagnosis and potential factors impacting forum participation can be explained by the theoretical construct of social connectedness.
Social Connectedness and its Influence on Overall Well-being

Previous literature and current study findings explain how functional and behavioral changes following diagnosis of EOAD may increase the risk of social isolation. The manifestation of social isolation can be described by the concept of social disconnectedness. Social disconnectedness is the lack of involvement with other people, groups and environments (Hagerty et al., 1993). The construct does not imply a loss of social network; rather, it is an absence of relatedness within existing social structures (Hagerty et al., 1993). The social health of individuals with EOAD can lead to a state of social disconnectedness as the illness progresses and existing social ties no longer fulfill needs. Online social platforms can supplement traditional social structures by connecting individuals with EOAD with similar others. The inverse of disconnectedness, social connectedness, may be applied as an emerging concept to describe the understanding of the ways in which forum interaction nurtures a fundamental human need to belong and relate with others – promoting overall well-being (Rettie, 2003).

The online communication medium and members of the community emerged as co-dependent factors in addressing the social needs of users. The communication medium created a network of people with a common purpose and introduced a virtual method of interaction. Together, they functioned as fundamental components necessary to involve individuals with EOAD and encourage active participation. The social dynamic amongst forum members emerged as the element with the greatest potential to influence outcomes of online interaction. YoD forum members fostered social connection and helped one another to redefine life after diagnosis through continued engagement, cultivating a means to negate components of social isolation. Conclusions
drawn from the analysis of archived conversations and observational discoveries are supported by the theoretical concept of social connectedness. Social connectedness best explains the manners in which online interaction may help to support or enhance overall well-being of community members (*Figure 2*).

*Figure 2*. The Theoretical Concepts that Support the Understanding of Medium and Participant Driven Outcomes of Online Social Interaction

Social connectedness has been conceptualized in multiple scholarly works with variations in the definition of the construct. An understanding that the pursuit of social connectedness is motivated by the individual need to belong and relate to others reinforces the interpretation of the social experience within the YoD community (Val Bel et al., 2009). It is significant to highlight that social connectedness may be achieved
without physical social presence (Rettie, 2003), which corroborates the understanding of strong social ties demonstrated by behaviors and actions presented through textual discourse on the forum. The concept of social support was not used to deconstruct the content of the supportive interactions or measure the common functions of the concept. Rather, Albrecht and Adelman’s (1987) definition served as a framework to explain how reciprocal support exchanged was communicated in a manner that encouraged members of the YoD community to enhance coping and self-care, with a goal of preserving individual control over outcomes.

The outcomes of online social interaction can be supported by the theoretical concept of social connectedness. Equally, the effects of online engagement on social isolation may be understood by their potential to influence individual well-being. Fostering social connection, finding purpose and factors impacting online participation influence and constitute components of well-being. Overall well-being can be understood as a “dynamic process that gives people a sense of how their lives are going, through the interaction between their circumstances, activities and psychological resources” (New Economics Foundation, NEF, 2009). The two main components of overall well-being are personal well-being and social well-being. These categories can be further broken down to more specific indicators of overall well-being. Personal well-being is the measure of “people’s sense of how they are feeling within themselves and experiencing their lives” (NEF, 2009). Social well-being is an indicator of “how people experience their connections with others and the strength of those relationships” (NEF, 2009). An unobtrusive netnographic-informed approach limits this study’s ability to fully appreciate the influence of online social interaction on personal well-being. Without
speaking to the members of the community, indicators of personal well-being may only be assumed by the comments posted to the discussion board, or alternatively, as implied through the textual discourse. These limitations notwithstanding, it is understood that the positive exchanges which enhance coping and self-care and empower participants to find purpose contribute to positive functioning, which enhances personal well-being. Social interaction on the forum enhanced positive functioning by engaging members in discussions that were aimed at preserving autonomy and finding meaning in a life with dementia.

Similarly, sustained interaction with members of the forum assisted in enhancing social well-being by creating a space in which supportive social connections could be cultivated and maintained, and equally, a culture of belonging could be promoted. NEF (2009) summarizes:

> It is also crucial that people feel a sense of relatedness to other people, so that in addition to the personal, internally focused elements, people’s social experiences – the degree to which they have supportive relationships and a sense of connection with others – form a vital aspect of well-being. (NEF, 2009).

The identified factors impacting online participation have the potential to negatively influence overall well-being. This was visible with members who felt that caregiver presence on the forum could create an unsafe space which threatens the participants’ personal and social well-being. This warrants future consideration so that online social platforms can be considered safe and nurturing environments that can help to improve personal and social aspects of well-being.
Limitations

There are restrictions that were imposed as a result of the study design, or which emerged from study findings that may impact the understanding of the social benefits associated with engaging within an online social environment. To begin, a significant difference in the number of written posts per thread versus the number of views was uncovered by observational findings. For example, on average, a thread would contain approximately ten message posts. Conversely, that same conversation would have upwards of 600 views. This understanding limits study findings to those with the greatest online presence, whose forum contributions are best represented in the data. The expectation that study discoveries would be reflective of the most active members of the community is implied. In his comprehensive explanation of a netnographic-informed methodology, Kozinets (2010) suggests distinguishing between different types of users when analyzing online message posts. He categorizes forum users as newbies, minglers, devotees, and insiders, differentiating each group by their social ties to the online community and interest in activity consumption. Devotees and insiders are considered “the most enthusiastic, actively involved and sophisticated users and thus the most important data sources for researchers” (Kozinets, 2010, p. 58). To that end, the findings from this study best reflect the social benefits of online engagement for the group of individuals who regularly contributed to forum discussions.

Another point for consideration is the characteristics of online forum users. Many of the most active members self-identified as writers, having either previously self-published works or were in the process of writing a book to describe their experience with EOAD. This finding may be indicative of the type of users textual forms of online
interaction attracts. A relatively small and homogeneous sample, in conjunction with the use of only one online community limits the understanding of the online social experience for people with EOAD. Further research using a more diverse range of online spaces, study participants, and data collection methods would help to confirm or disprove the limitations presented in this study.

**Chapter Summary**

The findings presented in this study complement the conclusions drawn in the research reviewed in the preliminary literature review. A desire to interact with others with EOAD was a key motivator to forum interaction and membership. Active participants were able to cultivate strong social ties with members of the community and find a sense of purpose through online participation, through opportunities that presented on and off the forum. The positive outcomes of engaging within an environment of similar others are supported by the theoretical construct of social connectedness. A state of relatedness and belonging was nurtured within the online community, positively contributing to overall well-being. The central outcomes of online interaction within the YoD forum contribute to personal and social well-being aspects of overall well-being. Benefits of online social interaction must be thoughtfully considered so that social connectedness may be promoted and overall well-being is supported to maximize the social outcomes of online interaction. The following chapter will conclude this thesis with recommendations pertaining to nursing research, practice and technical considerations for the forum.
CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

This research study was designed to advance current understanding of the ways people with early onset Alzheimer’s disease (EOAD) may use online communities to combat the challenges of social isolation. An analysis of 12 months of textual discourse in conjunction with community behaviors explained the social elements offered by the online communication medium or motivated by members of the young onset dementia (YoD) forum. Two derivatives of the online environment – social network and social interaction – set the tone for social outcomes driven by the members of the community. The social dynamic within the online community demonstrated the greatest potential to address the social needs of forum users. Social benefits of online interaction were achieved by fostering social connection and redefining life after diagnosis. Central themes of this study were best understood in relation to the theoretical concept of social connectedness. The fundamental understandings of the ways in which members of the online community helped one another reduce social isolation were as follows:

I. Interaction within an online community designated for individuals with a YoD allowed for engagement with similar others – establishing a sense of connection over shared understandings. Discussions focused on the more personal experiences related to the illness trajectory. These conversations offered the opportunity for members to discuss aspects of the illness with people who could directly relate to the experience or understand the perspectives presented because of their personal understanding of life with dementia.
II. The online community became a space in which individuals with EOAD felt they could be accepted as their presented selves. This culture of acceptance was maintained through the welcoming and supportive nature of forum members. Persistent acknowledgement of the significance of member contributions further promoted feelings of belonging.

III. Members with a visible online presence were able to cultivate strong social ties with one another. Embedded connections were demonstrated by the individual initiative to maintain contact with members of the community on the forum or through alternative means. The social connections fostered within the online social space support the assumption that hyper-personal relationships could develop and be sustained through virtual platform.

IV. Discussions on the forum allowed for an opportunity to consider aspects of the disease that could only be understood by those who were in the process of living through them. It was through these interactions that participants could address uncertainties and brainstorm or learn about coping methods to enhance control over individual outcomes. Equally, this opportunity for engagement created a purpose for members, who served as dementia pioneers and guides for new users.

V. Potential constraints to online social engagement did emerge. Technical concerns, which included the online setting and structure of the discussion board, occasionally served as an obstacle to online interaction. In addition, the open nature of the online forum allowed for participation by individuals who did not have a dementia diagnosis, but rather, were a caregiver for someone with the disease. Certain caregiver posts, which were perceived as distressing in nature,
caused tension within the community and reduced membership, threatening the 
social benefits of the online communication medium. No simple solutions could 
be drawn as many caregivers were also positive members of the YoD forum to 
whom other participants relied on and trusted for their expertise. Nonetheless, the 
central findings did establish potential for future research and practice changes.

**Implications and Recommendations**

Several potential implications for future research and nursing practice are 
cautiously suggested based on the results of the study. Recommendations pertaining to 
the two levels of the nursing profession in addition to technical considerations are 
discussed below.

**Nursing Research**

The archived discussions reviewed for the purpose of this thesis revealed how 
textual discourse within the YoD forum addressed aspects of social isolation. Further 
research would supplement or advance current understanding of the social benefits of 
online methods of social engagement.

To add a dimension to the findings that emerged from a review of archived 
conversations, the author recommends future studies focus on interviewing forum 
members to better understand individual perspectives of the ways in which online 
communities may help to meet their social needs. Further exploration of the social 
benefits of passive engagement is also recommended. This may be accomplished by 
interviewing members of the community who read the discussion threads but do not 
partake in discussion. Positioned differently, it would be significant to understand the 
reasons behind the lack of active participation within the forum discussions – if there are
barriers that could be addressed or whether the needs of inactive users are being met through passive engagement. This investigation may help to explain the relatively low levels of active participation visible within the online forum.

This study focused on an online forum with asynchronous channel of communication for her data collection (Moya et al., 2008). The messages posted to the discussion board could be read and responded to at any time. It would be of interest to explore online methods of interaction in which synchronous communication is practiced. Research into the benefits of virtual spaces such as video support groups or chat rooms where synchronous forms of communication are applied may help to explain the similarities and differences in the benefits of immediate versus delayed social exchanges. Further, it could help to inform future online interventions that can support both synchronous and asynchronous modes of communication.

Finally, in reading the dialogue amongst members of the YoD forum, the writer was exposed to alternative online communities. These include more informal groups that were established by some of the YoD forum members and video chat rooms that add a more intimate approach to online social interaction. It would be additive to examine the social structures of these settings and compare the benefits of video chats and online spaces that are exclusive to people with YoD to the benefits gleaned from the forum under study.

**Nursing Practice**

Several considerations for nursing practice emerged from this research study. To begin, it is essential for members of the profession to recognize the importance of creating or promoting social opportunities for individuals with EOAD to connect with
similar others. This study demonstrates the significance online social spaces can have for an individual with EOAD, both as a space to connect with and learn from others with a YoD diagnosis. The intention through this research was not to promote online communication as an isolated method of social engagement. Rather, the findings demonstrate the ways in which interaction within an online forum can help supplement the social needs of this population, reducing the challenges of social isolation experienced following diagnosis. To that end, people with EOAD should be better informed about online social platforms. Health professionals who work with people with a YoD may want to familiarize themselves with some of the established online communities so that they may be shared with individuals and their caregivers at any point of contact.

In understanding the social impact of functional losses for individuals with EOAD, there is a potential to enhance professional education of online social domains. Exposure to existing online social spaces can offer insight into the types of online communities that exist, or alternatively, the need to establish new online communities. Online social platforms can be informal and anonymous, such as online forums with limited moderator presence, or more structured methods of interaction such as support groups guided by a health care professional. Equally, computer mediated communication can be offered through video, offering a more personal approach to online interaction.

Limited opportunities for people with EOAD to connect with similar others in their communities establishes a need for health professionals to consider virtual methods of reaching and connecting people. There is great potential to reach and connect individuals with EOAD through virtual means, in both informal and more formal
contexts. Organized online support groups for people with EOAD to connect through written correspondence or by means of video may be an affordable intervention for social interaction. Equally, nurses who are involved in working with clients who have EOAD may want to consider consulting with local Alzheimer’s associations so that potential issues with pre-existing online social spaces can be thoughtfully considered and rectified to maximize participation and social well-being.

**Technical Considerations**

Recommendations aimed at addressing technical concerns emerged from observational analysis of the forum layout, in addition to the archived discussions in which technological issues were mentioned. The following technical considerations are offered as suggestions for mitigating potential barriers to successful online engagement.

I. Reconfiguring the structure of the forum so that members are alerted when a message written by or directed at them has been posted. Offering the option to turn these alerts off would be beneficial for those who may find the feature overwhelming.

II. Increasing moderator presence so that comments that may appear as harmful to the members of the community can be removed in a timely manner and caregivers can be redirected to a more appropriate space where their needs can be met.

III. A clearer differentiation between the discussion boards may be beneficial. For example, the caregiver forums could be in different of section from the YoD discussion board. This may help to reduce confusion and caregiver presence on the YoD forum.
IV. Increasing the accommodation ability of the forum to allow for video/audio posting.

V. Creating alternative methods for forum communication such as art, photos, sketches or memes when words are not available or sufficient.

Chapter Summary

The forum serves as an online communication medium for individuals with a diagnosis of EOAD. Social interactions centered on exchange of information, personal experiences of living with a progressive disease and methods to manage symptoms and preserve independence. Members of the community were themselves the key drivers of social relationships fostered within the online environment. Social connection was achieved by relating over shared understandings, cultivating a sense of belonging and building relationships that progressed beyond the online context. The online forum provided access to, and dialogue with other individuals who were navigating a similar course. Acceptance without judgment was promoted, creating a space for people to feel accepted as their present selves. It was therapeutic for individuals with EOAD to be able to share their experiences, fears and anxieties with others who could personally relate to the experience of living with a YoD. These exchanges offered a level of understanding that could not be realized through existing support systems or accessed from health professionals. In addition, textual discourse with community members with YoD exposed participants to new approaches to disease management, ultimately helping to preserve a level of autonomy through enhanced coping and self-care. Engaging in the forum discussion created new social opportunities within the online space or alternatively, exposed members to social opportunities in their communities. For some
members, a sense of purpose was realized through roles assumed within the online space, while for others, exposure to alternative opportunities for engagement was attained from the dialogue exchanged.

The online community creates an innovative opportunity for social engagement, in particular with others who can personally relate to the experience of living with EOAD, thereby helping to reduce the effects of social isolation. Nevertheless, there are technical constraints and concerns regarding caregiver participation which may impede seamless conversation and integration within the online environment. There are caregivers on the forum who contribute invaluable support and have established connections with some of the longer standing online community members. Increasing moderator presence in addition to more clearly differentiating the YoD forum from other discussion boards may help to mitigate this issue.

Social interaction through an online communication medium has demonstrated a potential to enhance overall well-being. Online methods of engagement may be understood as a positive, supplementary form of socialization for individuals with EOAD. Further research is recommended in this area of study to advance understanding of the benefits of active and passive methods of engagement in more diverse online environments.
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isolation for youth with chronic conditions: are we thinking virtually?. *Pediatric
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191.

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younger people with dementia. *Contemporary Nurse: A Journal For The
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## Appendix A

### Preliminary Literature Search

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<tr>
<th>Database Searched</th>
<th>Key Words Used</th>
<th>Results</th>
<th>Number of Articles Chosen for Review</th>
<th>Number of Articles Used</th>
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<tr>
<td>CINAHL</td>
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<td>&quot;social withdrawal&quot;</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Young onset dementia OR Early onset dementia OR Alzheimer's disease AND</td>
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<td>1</td>
<td>(1) Narrating Dementia:</td>
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<td></td>
<td></td>
<td>Self and Community in an Online Forum</td>
</tr>
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<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>community) OR (online forum)</td>
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<td>PubMed Plus</td>
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<td>114</td>
<td>5 (none about AD – all 5 articles discussed a chronic illness and online use)</td>
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<td>Up Close and Hyper-Personal: The Formation of Hyper-Personal Relationships in Online Support Groups.</td>
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<td>Number of Articles Used</td>
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<td>&gt;6,550</td>
<td>None (narrowed search)</td>
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<td>5</td>
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### Appendix B

**Classification of Codes**

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<thead>
<tr>
<th>Descriptive Codes</th>
<th>Classification of Codes</th>
<th>Description of Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(Nodes)</strong></td>
<td><strong>Behaviors, Expression, or Self-Reported Values</strong></td>
<td></td>
</tr>
<tr>
<td>Acknowledgement</td>
<td>Behavior</td>
<td>A brief response that demonstrates that the message posted seen/read.</td>
</tr>
<tr>
<td>Acknowledgment of post with an expression of gratitude</td>
<td>Behavior</td>
<td>Responding to a forum participant's message and expressing an appreciation for the words shared.</td>
</tr>
<tr>
<td>Expressions that address the value of the forum</td>
<td>Expressions, and Self Reported Values</td>
<td>Comments about the forum - statements about the benefits of the forum for the individual or group on a personal or general level.</td>
</tr>
<tr>
<td>Confiding in the Group</td>
<td>Behavior</td>
<td>Sharing of intimate details of one's personal life or experience with illness.</td>
</tr>
<tr>
<td>Empowerment</td>
<td>Behavior</td>
<td>Comments intended to inspire a specific member or all members of the online forum.</td>
</tr>
<tr>
<td>Encouragement</td>
<td>Behavior and Expressions</td>
<td>Positive messages of support.</td>
</tr>
<tr>
<td>Encouraging continued contact</td>
<td>Expressions</td>
<td>Expressions that suggest or encourage members to maintain contact with the online community.</td>
</tr>
<tr>
<td>Encouraging people to join the forum</td>
<td>Expressions</td>
<td>Expressions that suggest and/or encourage new posters to become active participants of the forum.</td>
</tr>
<tr>
<td><strong>Expressions of Appreciation</strong></td>
<td><strong>Expressions and Self Reported Values</strong></td>
<td>Expressions of thanks, gratefulness or compliments geared towards a specific member or members of the forum that describe how the person(s) has helped someone on the forum, or the value they add.</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Expressions of Concern</strong></td>
<td><strong>Expressions</strong></td>
<td>Comments that express concern about a member who may appear to be stressed or unlike themselves OR concern for members who have not visited the board in a while.</td>
</tr>
<tr>
<td><strong>Expressions of Frustration</strong></td>
<td><strong>Expressions</strong></td>
<td>Could be general expressions of venting about an experience, the illness or someone in the participants life.</td>
</tr>
<tr>
<td><strong>Humor</strong></td>
<td><strong>Behavior</strong></td>
<td>Comments intended to lighten the mood. The humor may be in the form of self-deprecation or of a general nature.</td>
</tr>
<tr>
<td><strong>Advancing the Discussion</strong></td>
<td><strong>Behavior</strong></td>
<td>Engaging in the conversation - Responding to someone’s post and pursuing further conversation by adding to their thoughts with comments that extend beyond short answer acknowledgement of what they had written.</td>
</tr>
<tr>
<td><strong>Non Verbal Communication</strong></td>
<td><strong>Behavior</strong></td>
<td>Symbols used to illustrate a hug, smile or action.</td>
</tr>
<tr>
<td><strong>Offering Advice or Guidance</strong></td>
<td><strong>Behavior</strong></td>
<td>Posts that offer advice or guidance in response to members who have sought it out. Advice may be in reference to disease management, issues with family or friends, or troubles with the forum.</td>
</tr>
<tr>
<td><strong>Expressions of Reassurance</strong></td>
<td><strong>Expressions</strong></td>
<td>Comments intended to comfort the reader they are directed at. These include remarks reassuring someone that they did the right thing, reacted the right way or said the right thing at the right time.</td>
</tr>
<tr>
<td><strong>Relating to others by sharing a common experience</strong></td>
<td><strong>Behavior</strong></td>
<td>Expressions that demonstrate that someone identifies with, or relates to the persons experience by sharing their own version of a similar occurrence, or feeling described as “I understand what you are going through because I have experienced something similar.”</td>
</tr>
<tr>
<td><strong>Seeking Advice</strong></td>
<td><strong>Behavior</strong></td>
<td>Posts in which the author is seeking advice about formal diagnosis, treatment (medications) or navigating issues such as family dynamics.</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Seeking Support</strong></td>
<td><strong>Behavior</strong></td>
<td>More general expressions seeking to engage with people navigating a similar course.</td>
</tr>
<tr>
<td><strong>Expressions of Acceptance</strong></td>
<td><strong>Expressions</strong></td>
<td>Comments that illustrate that a member’s behavior is accepted without judgment. Conversely, this also may entail expressions by a participant of feeling accepted.</td>
</tr>
<tr>
<td><strong>Thinking of Others</strong></td>
<td><strong>Behavior</strong></td>
<td>Comments that demonstrate that members of the forum who have not visited the forum recently are missed.</td>
</tr>
<tr>
<td><strong>Staying in Touch</strong></td>
<td><strong>Behavior</strong></td>
<td>Messages/comments intended to update the online community on the member's whereabouts. Additionally, these are messages that follow up on previous threads/conversations.</td>
</tr>
<tr>
<td><strong>Discussions of a General Nature</strong></td>
<td><strong>Behavior</strong></td>
<td>Comments or conversations that are not related to the disease.</td>
</tr>
<tr>
<td><strong>Discussions about Coping Mechanisms</strong></td>
<td><strong>Behaviors and Expressions</strong></td>
<td>Expressions that address how the forum participant(s) are coping with functional and/or social losses following diagnosis.</td>
</tr>
<tr>
<td><strong>Discussions about Diagnostic Process</strong></td>
<td><strong>Behaviors and Expressions</strong></td>
<td>Comments that address the individuals process for obtaining a diagnosis. These comments are always in response to a member (often new to the forum) asking generally what people's experience was for obtaining a formal diagnosis.</td>
</tr>
<tr>
<td><strong>Discussions about Treatment</strong></td>
<td><strong>Behaviors and Expressions</strong></td>
<td>Discussion surrounding treatment of illness. This may include medical interventions and/or cognitive therapies.</td>
</tr>
<tr>
<td>Sharing Information</td>
<td>Behavior</td>
<td>Sharing articles, links, video or audio with the group that addresses current research, treatment, side effects etc. as they relate to dementia.</td>
</tr>
<tr>
<td>---------------------</td>
<td>----------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sharing own Experience</td>
<td>Behavior</td>
<td>In response to a question or general comment, a forum participant will respond by sharing his or her own experience with the topic at discussion.</td>
</tr>
<tr>
<td>Expressions of Sympathy</td>
<td>Expressions</td>
<td>An acknowledgement of someone’s post with expressions of compassion</td>
</tr>
<tr>
<td>Expressions of Empathy</td>
<td>Expressions</td>
<td>An ability to identify with a person’s feelings through expressions of understanding of the emotions or experiences shared by the person on the forum.</td>
</tr>
<tr>
<td>Initiating a Conversation</td>
<td>Behavior</td>
<td>Questions, comments or statements posted as initial threads that are intended to stimulate conversation.</td>
</tr>
<tr>
<td>Stimulating Further Conversation</td>
<td>Behavior</td>
<td>These are messages that encourage further discussion by poster by having open ended or clarifying questions.</td>
</tr>
<tr>
<td>Vulnerability</td>
<td>Expressions</td>
<td>Raw expressions of fears or sadness over experienced losses. These may or may not relate to the disease.</td>
</tr>
<tr>
<td>Warm Welcomes</td>
<td>Behaviors and Expressions</td>
<td>Sincere or kind expressions welcoming new members to the board.</td>
</tr>
<tr>
<td>We are here for one another</td>
<td>Expressions and Self Reported Values</td>
<td>Expressions that illustrate that the members of the board are there for one another, that the online space is one where people with Dementia can feel comfortable and supported.</td>
</tr>
<tr>
<td>Presence in Absence</td>
<td>Behavior</td>
<td>Comments that indicate that a user is passively engaging with the online community by reading posts without commenting.</td>
</tr>
</tbody>
</table>