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ABSTRACT

The Age-Friendly University (AFU) initiative was established as a framework to guide higher education in the development of programs, practices, and partnerships that support aging populations. This study examined the need for age-friendly efforts to include dementia-friendly educational opportunities by providing information about undergraduate students' personal experience, knowledge, and concern regarding dementia and Alzheimer's disease (D/AD), along with their interest in D/AD educational support. A total of 106 students responded (30% response rate) to an online survey distributed in diverse classes, with more than 50% of students indicating that they had experience with someone with D/AD, primarily a grandparent. Students showed low levels of knowledge and strong concern about developing D/AD, confirming the need for more dementia-focused efforts. Students also expressed interest in a number of educational activities. These data call for AFU institutions to offer more age-friendly, dementia-friendly programs that provide students with needed information and support related to D/AD.

KEYWORDS

Age-friendly university; dementia-friendly; Alzheimer's disease; higher education

Demographic statistics predict a dramatic rise in the incidence of dementia (D) and Alzheimer's disease (AD) as populations age. An estimated 5.3 million Americans were diagnosed with AD in 2015, and national predictions are that the number of adults diagnosed with D/AD will rapidly grow each year as the size of the population aged 65 years and older continues to increase (United States Centers for Disease Control and Prevention, 2018). As such, researchers, educators, practitioners, and policy makers have called for examining people's knowledge about D/AD and factors associated with this awareness so that interventions which target stigma, diagnosis, resilience, caregiving, and related issues may be developed. Along with shifts in aging demographics, the number of younger individuals who will have personal, familial connections and responsibilities associated with adults with D/AD will also increase. Moreover, professional opportunities for younger individuals will expand as the need unfolds for a trained workforce to provide services and programs for older adults with D/AD and their families. Thus, it is important to understand younger individuals' D/AD experience, knowledge, concern, and needs, so that supportive educational steps can be undertaken.

The Age-friendly University (AFU) initiative offers a pioneering incentive for institutions of higher education to consider how they might foster greater awareness of D/AD

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issues. Developed by an international, interdisciplinary team convened at Dublin City University, the Age-friendly University (AFU) initiative was designed to bring greater attention to aging issues in higher education and provide opportunities for students to learn about the complexities of aging, among other educational goals (O'Kelly, 2015). Similar to the domains the World Health Organization identified as components of age-friendly communities (WHO), the AFU team identified six pillars of institutional activity around which age-friendly educational programs and practices could be built: 1) teaching and learning; 2) research and innovation, 3) lifelong learning, 4) intergenerational learning, 5) encore careers and enterprise, and 6) civic engagement. From these pillars a set of 10 AFU principles was articulated (see Table 1). To date, over 65 institutions worldwide have joined the AFU network.

Advocates have argued that age-friendly community efforts are not necessarily dementia-friendly, and one approach does not fully encompass the other (Turner & Morken, 2016). That is, age-friendly efforts may overlook the specific needs of people living with dementia, while dementia-friendly initiatives may not consider the broader needs of older adults as a whole. However, both age-friendly and dementia-friendly efforts share some fundamental objectives, such as the aim to provide supportive, enabling environments. As such, there is increasing interest in bringing these two initiatives together in more intentional, integrative ways. A similar argument can be made for the need for AFU institutions to be more mindful of how they can be dementia-friendly in their approach to age-friendly programming in higher education. A starting place to this end is to identify the nature of students' D/AD experience, knowledge, and concern, as well as their interest in various dementia support programs. Such were the goals of the present research.

Some prior research has looked at students' D/AD experience and knowledge, as well as the impact of particular educational programs on their attitudes. Although informative and encouraging, the bulk of this work has been with students pursuing specialized majors and career paths or participating in specially designed curricular activities. For example, Choi and Park (2017) examined the impact of participation in a dementia-outreach research project on the attitudes of undergraduate students studying nursing, public health, and social work. Following this dementia-focused curricular experience, students showed an enhanced understanding of dementia issues and more positive attitudes toward care.

Table 1. 10 Principles for an Age Friendly University (AFU).

1. To encourage the participation of older adults in all the **core activities** of the university, including educational and research programs.
2. To promote personal and career development in the second half of life and to support those who wish to pursue **second careers**.
3. To recognize the **range of educational needs** of older adults (from those who were early school-leavers through to those who wish to pursue Master's or PhD qualifications).
4. To promote **intergenerational learning** to facilitate the reciprocal sharing of expertise between learners of all ages.
5. To widen access to **online educational opportunities** for older adults to ensure a diversity of routes to participation.
6. To ensure that the university's **research agenda** is informed by the needs of an aging society and to promote public discourse on how higher education can better respond to the varied interests and needs of older adults.
7. To increase the understanding of students of the **longevity dividend** and the increasing complexity and richness that aging brings to our society.
8. To enhance access for older adults to the university's range of **health and wellness** programs and its **arts** and **cultural activities**.
9. To engage actively with the university's own **retired community**.
10. To ensure regular **dialogue** with organizations representing the interests of the aging population.

Courses in gerontology and dementia-focused service projects have also been shown to impact positively the knowledge and attitudes of gerontology majors (e.g., Yamashita, Kinney, & Lokon, 2013). Other studies have demonstrated the efficacy of novel curricular efforts, such as the potential for arts-based interventions and creative storytelling interventions to improve medical students' attitudes toward persons with dementia (e.g., George, Stuckey, & Whitehead, 2013, 2014).

Although existing research points to the value of curricular efforts in higher education, more research is warranted to assess the need for programs directed at undergraduate students more generally. Such research is especially pressing given indications that students' knowledge about Alzheimer's disease (AD) falls well below individuals working in the aging field, dementia caregivers, senior center staff, and older adults in general (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011). Moreover, studies showing a lack of D/AD knowledge in high school students reinforce the likelihood that undergraduate students will move in and out of higher education with negligible knowledge unless dementia-friendly educational opportunities are made available to them (Farina, Hughes, Griffiths, & Parveen, 2019; Isaac, Isaac, Farina, & Tabet, 2017). Understanding better the nature of students' D/AD experience and knowledge can help guide AFU institutions toward age-friendly educational efforts to increase awareness and improve support services.

The present study sought to provide AFU institutions with guidance about how they can more fully address the complexities of aging with dementia-friendly educational efforts. To this end, the study was designed around three research questions. First, what is the nature of students' experience with individuals with D/AD? Second, what is their level of knowledge about D/AD and their concern about developing D/AD when they are older? Third, what is their interest in educational programs geared toward providing information and support about D/AD? A survey format was used to explore these questions among undergraduate students at an AFU partner institution.

Method

Sample

Undergraduate students at Lasell University, a US institution that became a member of the AFU initiative in 2015, comprised the study sample. Lasell University is a New England institution established in 1851 that enrolls approximately 1700 undergraduate students (93% 18–22 years, 65% female) pursuing professional majors within a liberal arts curriculum. The study sample consisted of 106 respondents (M age = 20.12 years, range 18–35), with 69% identified as female, 29% male, or 2% other; and, 88% identified as White, and 12% as Black, Hispanic, Asian, or other. Four class levels (32% 1st year, 21% 2nd year, 32% 3rd year, 21% 4th year) were represented, and respondents indicated that they were pursuing diverse majors (e.g., education, athletic training, communications, criminal justice, fashion, psychology, journalism, sports management).

Procedures

Surveys were created and administered using SurveyMonkey. Following approval of the study goals and methods by the Committee for the Protection of Human Subjects (CPHS),

the surveys were distributed in a range of classes across the curriculum via e-mail invitations. In total, 106 students responded to the survey which was an estimated 30% response rate. In the invitations to participate, respondents were informed that the study explored students' experience and knowledge of D/AD, along with assessing what they thought would be useful education and support opportunities on campus. While it could be argued that the explicit description of the survey made for a biased recruitment strategy because of its potential to attract the interest of students who had more experience with dementia and were motivated to participate, the alternative of using a general description ran the risk of not adequately capturing these students' attention and resulting in a narrow and limited view of the issues. As well, it was felt that the focus could be a sensitive topic for some students and it was therefore prudent to be clear about the specific aims of the study. Informed consent to participate was obtained by asking respondents to indicate if they did or did not agree to volunteer to participate in the study following a description of the goals of the study and the general design of the survey. This was the only required response in the survey. No special incentives were offered for participation.

Measures

Demographics and experience with D/AD

In the surveys, students first responded to demographic questions and then completed questions about their experience with D/AD. To this end, they were asked if they had known anyone diagnosed with dementia or Alzheimer's disease (the person could be living or deceased.). If so, they were then asked to identify the nature of their relationship with the person. Next, they were asked how often they participated in various activities using 5-point Likert scales that ranged from 1 (never) to 5 (always). As described in Table 2, activities included spending time with the person, assisting with home help, helping with personal care, transportation, and technology, along with engaging in leisure, physical, religious, and community activities.

Knowledge of D/AD

Using a 5-point Likert scale that ranged from 1 (not at all) to 5 (a great deal), respondents indicated if they thought they had accurate knowledge about D/AD. Using the same scale, their concern was assessed by a question asking how concerned they were about personally developing dementia or Alzheimer's disease when they are older. Next, they completed the Alzheimer's Disease Knowledge Scale (ADKS, Carpenter, Balsis, Otilingam, Hanson, &

Table 2. Experience with D/AD survey questions.

Question
How often do you spend time with this person?
How often do you help this person with home activities (e.g., shopping, cleaning)?
How often do you help this person with personal care (e.g., dressing, hair, nails)?
How often do you help this person with hygiene needs (e.g., bathing)?
How often do you help this person with transportation (e.g., driving to appointments)?
How often do you do leisure activities with this person (e.g., tv, movies, games)?
How often do you do physical activities with this person (e.g., walking, exercise)?
How often do you help this person with technology (e.g., computers, phones, television)?
How often do you attend religious activities with this person (e.g., going to church, praying)?
How often do you attend community programs with this person (e.g., senior centers, bingo, library)?

Gatz, 2009) which calls for true/false responses to 30-items about AD risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management. Scores on the ADKS can range from 0 to 30. Previous analysis of the scale's psychometric properties by Carpenter, Balsis, Otilingam, Hanson, and Gatz (2009) demonstrated its overall reliability (test – retest correlation =.81; internal consistency reliability = .71) and validity (content, predictive, concurrent, and convergent), with undergraduate samples showing lower reliability in comparison to other subgroups owing to their discrepant knowledge (Cronbach's alpha = .55). The scale statistic for the present sample was consistent with previous findings (Cronbach's alpha = .60).

Interest in D/AD education

Finally, using 5-point Likert scales that ranged from 1 (very unlikely) to 5 (very likely), respondents indicated the likelihood they would participate in a series of educational and support programs on campus (i.e., attend a one-time information session about dementia and Alzheimer's disease, use online information about dementia and Alzheimer's disease, meet with an expert on dementia and Alzheimer's disease, attend a guest speaker series about issues related to dementia and Alzheimer's disease, take a course about aging issues, go to a program about dementia and Alzheimer's disease offered by the counseling center, participate in a peer (student) support group, participate in an intergenerational support group). When these questions were completed, respondents were given the opportunity to suggest other ways support could be provided to students.

Analysis

Descriptive statistics were calculated for the sample to assess students' relationship and experience with someone diagnosed with D/AD. Relationships among ADKS scores, measures of dementia concern, perceived dementia knowledge, and experience were explored using Pearson product moment correlations. Several surveys (n = 5) had extensive missing data and were excluded from the final sample. All analyses were conducted using SPSS statistical software.

Results

With respect to the research question of students' experience with individuals with D/AD, descriptive analyses revealed that over 50% of students reported experience with someone diagnosed with D/AD. These individuals mainly included grandparents, as well as aunts or uncles, family friends, and even parents (see Table 3). Approximately 4% reported that they had experience with several individuals with D/AD. Table 4 shows the patterns of activity students reported. Approximately 60% of students who knew someone with D/AD indicated that they spent time with them sometimes, usually, or always, whereas fewer students (40%) indicated that they rarely or never spent time with them. The most common activities students engaged in with adults with D/AD were doing leisure activities and helping the person with home activities and transportation. About 1 in 5 students (21–25%) engaged in physical activity (like walking), assisting with technology, and attending religious activities. Fewer students (11–17%) reported engaging in assisting

Table 3. Nature of students' D/AD relationships.

Relationship	Percent
(Great) Grandmother or Grandfather	33%
Aunt or Uncle	10%
Family Friend	8%
Parent	2%
Professional Contact	1%
No Contact	46%

the person with hygiene needs and attending community programs (although some did engage in these activities).

With respect to the research question of students' knowledge and concern, a majority of students (62%) expressed a moderate to great deal of concern about developing D/AD when they were older. Moreover, their concern about developing D/AD was not associated with their experience with having known someone with D/AD, r (104) = .06, $p > .05$. Using students' overall scores on the Alzheimer's Disease Knowledge Scale (ADKS) as an index, it was found that their level of understanding was relatively low (M = 19.82 out of a possible score of 30, sd = 3.77) and consistent with the relatively low levels of student knowledge reported by Carpenter and colleagues (M = 20.19, 2009; M = 20.21, 2011). Those who had experience with someone with D/AD believed they had more accurate knowledge (r (104) = .37, $p < .01$), and had higher ADKS scores (r (104) = .24, $p < .01$) than those without experience. Those who thought they had actual knowledge also had higher ADKS scores (r (104) = .31, $p < .01$). As well, students who expressed greater concern about developing dementia also believed they had more accurate knowledge about dementia, r(104) = .29, $p < .01$, and their ADKS scores tended to be somewhat higher than students who reported less concern (although not significantly so), r (104) = .12, $p < .20$).

Finally, with respect to the research question of students' interest in educational opportunities, students expressed an interest in participating in several activities geared toward D/AD knowledge and support (see Table 5). Accessing online information, attending an

Table 4. Students' activities with adults with D/AD.

Activity	Mean Time Spent	Percent Sometimes or More	Percent Rarely or Never
How often do you spend time with this person?	2.80	60%	40%
How often do you help this person with home activities (e.g. shopping, cleaning)?	2.15	34%	66%
How often do you help this person with personal care (e.g. dressing, hair, nails)?	1.64	21%	79%
How often do you help this person with hygiene needs (e.g. bathing)?	1.42	11%	89%
How often do you help this person with transportation (e.g. driving to appointments)?	1.93	26%	74%
How often do you do leisure activities with this person (e.g. TV, movies, games)?	2.58	58%	42%
How often do you do physical activities with this person (e.g. walking, exercise)?	1.89	24%	76%
How often do you help this person with technology (e.g. computers, phones, television)?	1.78	22%	78%
How often do you attend religious activities with this person (e.g. going to church, praying)?	1.80	25%	75%
How often do you attend community programs with this person (e.g., senior centers, bingo, library)?	1.64	17%	83%

Table 5. Students' interest in D/AD educational activities.

Activity	Mean Rating
Attend a one-time information session about dementia and Alzheimer's disease	3.10
Use online information about dementia and Alzheimer's disease	3.28
Meet with an expert on dementia and Alzheimer's disease	2.80
Attend a guest speaker series about issues related to dementia and Alzheimer's disease	3.18
Take a course about aging issues	3.17
Go to a program about dementia and Alzheimer's disease offered by the counseling center	2.85
Participate in a peer (student) support group	2.65
Participate in an intergenerational support group at Lasell Village	3.07

Lasell Village is the institution's university-based retirement community housed on its campus.

information session or a guest speaker series, taking a course, and participating in an intergenerational support group were the most popular activities. Meeting with an expert, attending a counseling program, and participating in a peer support program were relatively less appealing. Several students offered additional suggestions including providing dementia workshops for students and their families, and inviting adults with D/AD to talk about their experiences and needs.

A final set of exploratory analyses were undertaken to examine if students' experience was associated with any particular educational interests. To this end, a mean index of overall engagement was computed by averaging across responses to the D/AD activity measures and correlated with interest reported in the various activities. None of the associations were significant (all ps > .05). Correlations were also computed with responses to knowing versus not knowing someone with D/AD and interest in educational activities. None of the correlations were significant (all ps > .05).

Discussion

The present study revealed that dementia and Alzheimer's disease are factual aspects of many undergraduate students' personal lives, which AFU institutions should be mindful to address by expanding their age-friendly efforts to include more dementia-friendly activities. Not surprisingly, students' experience was most often with their grandparents who had D/AD, the prevalence of which can be expected to increase given forecasts of extended generational longevity and the rise in D/AD onset in older life stages. Some students had experience with parents, which may pose particular challenges that call for student support. Students' engagement with adults with D/AD was varied. While a majority spent time interacting with these adults, engaging in leisure activities and helping with home activities and transportation, others spent relatively little time, if at all. Some students engaged in what may be considered challenging care activities such as assisting the person with hygiene needs, although at lower rates than other activities.

Variations in students' activity may reflect a number of factors that would be of interest to explore in more detail. For example, students' living arrangements may be one factor (e.g., if they live close to home and visit frequently). To inform future AFU efforts, it would be useful to examine the extent to which students' experience and engagement may be associated with their age and life stage demands. Exploratory analyses of associations between student age and their D/AD experience, activities, and knowledge in the present study did not reveal any significant trends. However, research looking at patterns in student

samples from AFU institutions that enroll a more age diverse student body would be of interest to pursue. It may also be the case that students spend little time with adults they know who have D/AD because of stigma, communication challenges, and related barriers. If so, developing educational opportunities that address these issues in AFU efforts would also be of great value.

Although many students had experience with individuals in their lives who have D/AD, their factual knowledge was clearly lacking. Moreover, the lower level of understanding of students in the present study was consistent with students' levels documented by other researchers (Carpenter et al., 2009, 2011). This suggests that the present findings do not reflect a special case or select sample. Interestingly, students' greater concern of developing dementia was associated with their belief that they had more accurate knowledge and a somewhat higher level of actual knowledge. While these data are consistent with other research exploring the relationship between students' dementia concern and knowledge (Montepare & Pendergast, 2016), they contrast with research showing that knowledge about aging is associated with fewer concerns of aging (Levy, 2018; Palmore, 1999). These trends suggest that dementia-friendly educational efforts may call for attention to broader issues beyond providing factual knowledge. Deficits in students' knowledge, coupled with their concern or fear, confirm a distinctive gap in students' understanding of aging issues, calling for AFU institutions to consider how they can expand educational opportunities to address students' dementia-related needs.

Beyond offering special programs tailored to students in particular majors or those pursuing particular career paths, the present research suggests that there are a number of ways AFU institutions can be more dementia-friendly to students in general. Moreover, in contrast to programs that require specialized expertise, costly resources, and unique demands, these programs may be more easily mounted and made accessible to a broad range of students. For example, AFU advocates may work with various classes, programs, and student groups to identify speakers and create information sessions to raise students' awareness and enhance their knowledge about dementia. Excellent online resources are available through organizations such as the Alzheimer's Association, the Dementia Action Alliance USA, the Administration for Community Living, as well as professional organizations such as the Gerontological Society of America and its education unit the Academy for Gerontology in Higher Education, that could be used to develop support services for students. Although the present study did not find strong associations between students' experience and particular educational interests, future age-friendly dementia programming efforts may wish to revisit this issue so that educational efforts are best tailored to meet students' individual needs.

Other curricular-focused efforts are also possible for AFU institutions looking to be more dementia-friendly. For example, the present authors' AFU institution developed the course, *Living and Learning with Dementia*, which was open to students across the curriculum. In addition to gaining an understanding of D/AD issues, students engaged with residents with D/AD living in our affiliated senior housing community. Activities such as interactive collaborative storytelling that extended across multiple class sessions allowed residents the opportunity to participate in educational efforts at their level. Indeed, one of the motivations behind the development of the course was to extend educational accessibility (a core AFU principle) to older adults experiencing cognitive changes to complement age-friendly educational opportunities afforded other older adults on campus. As other AFU

institutions open their doors to age diverse learners, they should be mindful to consider if their efforts offer opportunities to the diversity of older learners. In addition to curricular efforts, community efforts are also possible. For example, AFU campuses offer prime meeting space for Memory Cafes (a recurring program where individuals with D/AD and their care partners gather to share in music, art, dance, and other creative activities). Such efforts also offer opportunities for student engagement and intergenerational interaction (another core AFU principle).

The Age-Friendly University (AFU) initiative was conceived as a way for higher education to respond to shifting age demographics that are reshaping societies through new approaches to age-related programs, practices, and partnerships (Montepare, 2019; O'Kelly, 2015; Talmage, Mark, Slowey, & Knopf, 2016). Institutions in the emerging AFU network have been exploring innovative ways to rise to this challenge to fulfill the AFU principles (Montepare, Farah, Bloom, Tauriac, 2020). As they navigate this new educational terrain, gaps and opportunities are being identified (Silverstein, Hendricksen, Bowen, Weaver, & Whitbourne, 2019). It is hoped that the present study will draw attention to the need for AFU institutions to integrate their age-friendly efforts with ones that are also dementia-friendly, such as developing educational opportunities to increase students' knowledge, reduce their concerns, and enhance their experiences with family members and friends with D/AD. In the long run, addressing aging concerns such as these with educational interventions in higher education has the great capacity to benefit students' own healthy aging and longevity (Levy, 2003, 2009, 2018; Whitbourne & Montepare, 2017). Such educational efforts that involve older adults with D/AD likewise have beneficial capacity for their well-being (e.g., Fritsch et al., 2009). With new educational developments there is the need for research geared toward formative and summative evaluation to address the impact on students as well as older adults with D/AD. In addition to providing information about the efficacy of educational efforts, such research would provide needed evidence to support the value of a more age-friendly model of higher education. In short, while the present work aimed to raise awareness about the value of incorporating dementia-friendly efforts within the AFU initiative, the importance of recognizing the need for dementia education should be a goal for all colleges and universities.

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