

# The Social Construction of Dementia: Implications for Healthcare Experiences of Caregivers and People Living with Dementia

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## Abstract

Globally, systems have invested in a variety of dementia care programs in response to the aging population and those who have been diagnosed with dementia. This study is a qualitative secondary analysis of interview data from a larger study investigating stakeholder perceptions of programs that support caregivers and people living with an Alzheimer's Disease or Alzheimer's Disease-related dementia (AD/ADRD) in five North American jurisdictions. This study analyzed interviews with individuals living with an AD/ADRD and caregivers of individuals living with an AD/ADRD (n = 11). Thematic analysis was conducted to understand how the perception of dementia may have shaped their engagement and experience with healthcare systems. Our analysis resulted in three main themes of care users' experience: (i) undesirable experience owing to the overarching negative shared understanding and stereotyping of dementia; (ii) dismissal throughout disease progression when seeking health and social care support; and (iii) dehumanization during care interactions. The findings carry critical social and clinical implications, for example, in informing person-centered approaches to care, and communication tools clinicians can use to enhance provider, patient, and caregiver well-being.

## Keywords

access to care, clinician-Patient relationship, healthcare planning or policy, qualitative methods, patient expectations, dementia

## Introduction

A considerable body of literature seeks to understand how, where, and by whom the meaning of dementia is constructed.<sup>1-5</sup> Historically, dementia has been understood to mean imbecility associated with aging, divine punishment, evil possessions, and senility.<sup>3</sup> In fact, the term “dementia” originated from the Latin word “demens” or “madness” which speaks to its etymology and the misconceptions of dementia that persist today.<sup>6</sup> The construction of its meaning and how it is perceived by both persons living with dementia and society at large is mainly informed by misconceptions, negative stereotypes, and stigma.<sup>1-5,7,8</sup> Some misconceptions endured in society are also enacted in clinical practice. Clinicians can harbor stigma and often dismiss symptoms of dementia.<sup>9</sup> There are patterns of discrimination in acute care settings, with people who present with confusion receiving less contact time, infantilization by hospital staff, and inappropriate discharge.<sup>10</sup> Misconceptions about dementia also shaped healthcare training. With the exception

of geriatricians, few healthcare workers are explicitly trained in dementia care.<sup>10</sup> This contributes to a cascade of negative events among people living with Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD), including emergency room visits, institutionalization, and premature death.<sup>10</sup>

The internalization of discriminatory practices in healthcare can impact the everyday experiences of people living

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with an AD/ADRD and caregivers. For example, they may feel self-doubt about attending social events, thereby contributing to chronic isolation which can further exacerbate symptoms of dementia and comorbidities.<sup>3,10,11</sup> Moreover, earlier work suggests that society's perception of age-related illnesses, like dementia, can impact how people living with an age-related illness perceive themselves, recognize their own needs, access care systems, and experience health systems.<sup>1,12,13</sup>

This study is secondary analysis of a larger study investigating dementia interventions in North America, findings from which have been published elsewhere.<sup>14</sup> During the early stages of the inductive analysis of the larger study, it became evident, through the stories of the participants, that how dementia is perceived was playing a role in shaping care experiences, which inspired a qualitative secondary analysis (QSA) on a subset of the data, the purpose of this study. Using QSA, this study investigates how the social construction of dementia impacts the experiences of caregivers and people living with AD/ADRD when interacting with health and social care services.

We applied a social constructionist lens to the interpretation of semi-structured interviews with individuals who have lived experience with the disease (people living with an AD/ADRD and caregivers). The social constructionism theory posits that knowledge is created from socially communal processes with reality being a function of shared social conventions and discourse.<sup>15</sup> Social constructionism, a branch of sociology, has been applied to understand how social and cultural aspects influence diagnostic processes, mental health care experiences, and how experiences of disability vary across time and cultures.<sup>16-18</sup> This study is specifically situated in the health services research discipline exploring health system experiences and influence on caregivers and individuals living with an AD/ADRD. Accordingly, we discuss how the social construction of dementia shapes the health and social care interactions and experiences of people living with an AD/ADRD and their caregivers.

## Materials and Methods

This research uses QSA<sup>19</sup> of data from a larger project funded by Canadian Institutes of Health Research (150705) and Alzheimer Society of Canada (17D) that looked to examine

policy programs in five North American jurisdictions (British Columbia (BC), Ontario (ON), and Newfoundland and Labrador (NL), New York (NY) and Vermont (VT)). Ethics approval was obtained from the Office of Research Ethics at the University of Toronto.

For the larger project, there was a total of 40 interview participants, including decision makers, program administrators, people living with an AD/ADRD, and caregivers. In this secondary analysis, we relied only on participant responses of individuals living with an AD/ADRD or a caregiver of an individual living with an AD/ADRD and included three people living with an AD/ADRD (one each in ON, BC, and NY) and eight caregivers (ON = 1; BC = 1; NL = 3; NY = 1; VT = 2) (Table 1). The researchers engaged in the parent study were also involved in this secondary analysis that is presented here. The lead author was not engaged in the conceptualization of the parent study and, as such, was not influenced by the objectives of the parent study during the familiarization stage. This allowed for a nuanced and fresh perspective that was not influenced by the parent study.

Caregivers recruited for this study were all caregivers of individuals living with an AD/ADRD diagnosis. In an attempt to diversify experiences, we did not recruit dyads and rather invited persons living with an AD/ADRD and any caregiver of an individual with an AD/ADRD diagnosis to participate. Participants were identified using snowball sampling through program administrators. Potential participants first consented to be contacted by program administrators and then the research team contacted them through e-mail to determine their willingness to participate and arrange a time for an interview. All possible participants who reached out to the research team or who provided contact information to the research team were contacted to arrange a call at a time of their convenience.

All participants provided oral informed consent prior to participating. Most interviews were conducted over the phone and lasted from 60 to 90 min, and all occurred between 2019 and 2020. The interview guide (attached as supplementary file) asked participants about their individual context (diagnosis, how long they have been a caregiver or been diagnosed), the types of support they received, if they paid for support out of pocket, the degree to which supports were meeting their needs, and referral experiences. Interviews were transcribed verbatim and reviewed for accuracy. Further details about the parent study have been previously published.<sup>14</sup>

Three authors (authors #1, 2, & 3) were involved in the data analysis process. Consistent with Braun and Clark's framework, reflexive thematic analysis (RTA) was used to derive findings from the interview transcripts.<sup>20</sup> First, the authors familiarized themselves with the data. During data familiarization and through conversations with the research team, it became clear that there were consistencies across the transcripts in highlighting similarities in experiences and potential attributes to the social construction of the disease. Accordingly, social constructionism theory was

**Table 1.** Participant Characteristics.

Participant group included in this sub-study (n = 11)	Jurisdiction				
	BC	ON	NL	NY	VT
Caregiver of an individual living with an AD/ADRD (n = 8)	1	1	3	1	2
Individuals living with an AD/ADRD (n = 3)	1	1	-	1	-

AD/ADRD, Alzheimer's Disease or Alzheimer's Disease-related dementia. BC, British Columbia; ON, Ontario; NL, Newfoundland and Labrador; NY, New York; VT, Vermont.

chosen to inform a meaningful interpretation of the data. In line with Braun & Clark's RTA approach, the focus was on meaning generation through interpretation, rather than striving to reach saturation or securing a certain sample size in advance to ensure study quality.<sup>21</sup>

Second, two of the authors (authors #1 & 3) discussed potential approaches to coding and began to construct codes, using an inductive approach. For phase three, we began coding three transcripts to identify data examples of experiences where the social construction of dementia seemingly affected experiences. Rounds of discussions resolved any discrepancy between coders (authors #1 & 3). Phase four and five involved reviewing, revising, and re-conceptualizing how associated extracts could be collated into thematic groupings, which resulted in four primary themes. Phase six involved the solidification of themes and was further refined (authors #1, 2, & 4) and resulted in three main themes that depict how the perspectives of dementia influence the experiences of people living with an AD/ADRD and caregivers.

## Results

The three themes illustrate how largely negative stereotypes toward the disease result in undesirable experiences for people living with an AD/ADRD when accessing health and social care.

### Theme 1: Experience Negative Stereotyping

Various interactions, such as with the public, healthcare professionals, friends, and family shape experiences of dementia and related care.

Participants mentioned the prevalence of negative images of dementia—that people living with an AD/ADRD have limited capacity—are problematic and inaccurate. For example, a caregiver participant shares:

*I'm not a fan when it's in the news when people write stories and they kind of just put that adjective or descriptor saying, 'A person suffering with dementia is missing downtown.'*  
[ON Caregiver 1]

Another participant stated that people “jump right to the end stage in their mind” [NY participant with an AD/ADRD diagnosis 1], constructing a skewed picture of what it means to be living with dementia. Negative preconceptions of dementia have consequences for how health providers interact with people living with an AD/ADRD and potentially diagnose someone experiencing symptoms of dementia. For example, a participant with an AD/ADRD diagnosis who was a keynote speaker at a conference described a physician audience member who stood up and questioned her dementia diagnosis based on her presenting abilities.

The perception that individuals with an AD/ADRD diagnosis have limited capacity is an example of a negative stereotype that may influence whether those living with an

AD/ADRD are included and engaged with for decision-making. For example, a repeated concern among participants was the lack of representation of people living with an AD/ADRDs' input in system strategies. One of the participants wondered, “why there's been nobody on the board of directors for Alzheimer's that has dementia” [BC participant with an AD/ADRD diagnosis 1]. The same participant shared that their lived experience is not adequately incorporated in dementia-related decision-making, noting they must “almost beg because many organizations don't want someone with a dementia to talk to” [BC participant with an AD/ADRD diagnosis 1].

While many participants did make use of their local Alzheimer's Society to access social services, there was often misunderstanding among healthcare providers about the role of community-based supports for individuals living with AD/ADRD. This limited some participants from seeking community-based care, as shared by one participant:

*Interviewer: But nobody connected you with the Alzheimer's Society?*

*Respondent: No. [...] again it's probably one of the other hardest things I did was to swallow your pride to go to them and talk to them. [...] because... I was raised with that 'You keep it in the family'. [NY participant with an AD/ADRD diagnosis 1]*

Theme 1 serves as a foundation for the remaining themes that highlight how these experiences impact people living with an AD/ADRD and caregivers' health and social care experiences.

### Theme 2: Experience of Dismissal Throughout Disease Progression

The second theme highlights the dismissal that people living with an AD/ADRD and caregivers experience when seeking health and social care support. For example, multiple participants reported that physicians dismissed their concerns about early symptoms, which resulted in delayed diagnosis. As one participant highlighted:

*I started to see symptoms. When I went to the doctors...well it's this, it's that, everything else but deep down inside I knew what it was but nobody would listen to me. ... So, I finally told a white lie to get into a neurologist ... I had to tell her I lied.*  
[ON participant with an AD/ADRD diagnosis 1]

Another participant with an AD/ADRD diagnosis shared that their physician “just always brushed it off” [NY participant with an AD/ADRD diagnosis 1]. The issue of timely diagnosis was thought to be worse for younger individuals since physicians may be particularly hesitant to “hang that label on them” [ON participant with an AD/ADRD diagnosis 1].

People living with an AD/ADRD and caregivers also felt that they did not receive adequate help when seeking care after diagnosis. One caregiver described feeling alone in

their caregiving journey: “I felt for a while like I was being abandoned or stuck with my father’s healthcare” [NL Caregiver 1]. Another caregiver described the lack of attention or focus they received when seeking care at a hospital:

*Like you take your person to the hospital living with dementia, and they don’t really help you. They’re like, “Oh, we’ve checked everything. She seems fine. It’s the dementia.”...they don’t want to deal with it. [BC Caregiver 1]*

A caregiver also talked about physicians “rolling their eyes” at their mother who lives with dementia [BC Caregiver 1]. This participant connected the difficult nature of the disease to why healthcare professionals may not address dementia care appropriately. Another participant reported that people living with an AD/ADRD receive different care than individuals with other diagnoses, including rehabilitation:

*As soon as you have a stroke, you’ve got speech and language, OT [occupational therapy], physio [physiotherapy], all those guys there helping you rehabilitate... why not start that early to keep us up, keep us moving, keep us engaged. [ON participant with an AD/ADRD diagnosis 1]*

Another participant highlighted that once diagnosed with dementia, the quality of healthcare received seems to be limited: “your healthcare isn’t as great as it used to be because they figure well you know... “She’s got dementia” [ON participant with an AD/ADRD diagnosis 1].

### Theme 3: Experience of Dehumanization

The third theme conveys that people living with an AD/ADRD and caregivers often feel that their psychosocial needs and well-being are insufficiently considered during care interactions. For example, a participant with an AD/ADRD diagnosis described that upon diagnosis, the doctor told their husband: “Yes, your wife has Alzheimer’s but she’s doing fairly well. Bring her back when she can’t dress herself” [ON participant with an AD/ADRD diagnosis 1]. This interaction signifies infantilization of the participant and a lack of sensitivity.

Another participant described the interaction with their doctor upon diagnosis, presented below. The interaction signifies the disconnect between the psychological state of the person living with an AD/ADRD upon diagnosis and the clinician’s matter-of-fact approach that does not attend to the emotional or holistic needs of the individual:

*We immediately went to an attorney and got all the paperwork done, ... thinking that I had just a matter of mere years. When my doctor ... said, “Do you have any questions?” I said no. But I was shocked. And he said, “Go get your affairs in order.” [BC participant with an AD/ADRD diagnosis 1]*

A participant attempted to understand the disconnect from clinicians. As described below, clinicians may be more

focused on the disease outcome and factual processes or ‘tasks’ to be completed, including those associated with end of life. The focus may be less on emotional experience with the disease progression:

*Respondent: Ok, because their [physicians] linkage is pretty much, “Here’s the facts ... and here are the things you should focus on in life. The power of attorney’s, ...who’s going to pay that...” ...*

*Yeah task...versus “Well what’s the emotional journey. ... how’s life going to be shifting? ...the various relationships?” that can come not from the doctor but that linkage to possibly the Alzheimer’s Society. [ON Caregiver 1]*

Physicians were also reported to lack sensitivity and respect when treating people living with an AD/ADRD. Physicians appeared to perceive that people living with an AD/ADRD may not be able to make their own decisions. For instance, referring to their interaction with their physician, a participant diagnosed with an AD/ADRD shared:

*...that’s against my human rights to privacy because never once was I asked if they could talk to my family. [...] left me with a disabled impression of my being. That I know nothing, I can’t even make decisions...I can’t do anything. [ON people living with an AD/ADRD 1]*

In the excerpt below, a caregiver describes how their experience with the healthcare system makes them feel about dementia and highlighted the lack of personhood involved with care:

*This person’s got dementia, they’re not an active participant in society. They’re, ..., not really paying taxes anymore. ... let’s just let them die as fast as possible...that’s what it really seems like. It seems like let’s get this person living with dementia in a home, let’s chemically lobotomize them. That gives them a year or two tops. The family pays for them to be in a home. And then they’re gone. Next. Like that is the short answer of what it feels like. [BC Caregiver 1]*

These interactions describe the dehumanizing experience of people living with an AD/ADRD upon the diagnosis of dementia and during treatment. Care providers failed to include people living with AD/ADRD in conversations and recognize their agency. They also seemed to reduce people living with an AD/ADRD to a mere collection of outward physical symptoms that need to be treated rather than appreciate the person holistically.

## Discussion

This study identified how the perception of dementia influences the experiences of people living with an AD/ADRD and their caregivers. The findings suggest poor experiences (ie, dismissal and dehumanization during clinical

experiences) during healthcare interactions are likely shaped by the societal perceptions of dementia. Of significance, participants were recruited from programs deemed innovative to meet the complex needs of individuals living with dementia and their caregivers.<sup>14</sup> This research offers a unique opportunity to highlight the experiences of these individuals and has identified that despite accessing programs aiming to improve care experiences for these individuals, there remains systematically embedded cultural climate impacting care experiences. Exploring these nuances from a health service research perspective is innovative and offers an opportunity for future research that drives quality improvement and policy reform efforts. Despite advances of dementia care and person-centered care models, people with dementia and their caregivers continue to report experiences that result in devaluing the self. The interactions and experiences presented in this study identify areas for clinical improvements including person-centered communication techniques that are balanced with clinical education and efforts to support clinician resilience and well-being. For example, engaging in co-production and relying on personhood models of care may result in increased dignity, quality of care, and social reciprocity—a key function of personhood.<sup>22</sup>

This study confirms that pre-conceived ideas of dementia (eg, low competence) and cultural depictions of dementia (eg, suffering, or having no voice) may create a sense of fear, and stigma.<sup>23,24</sup> Earlier literature highlights that clinicians perpetuate stigma against people living with an AD/ADRD by using infantilizing language and dehumanizing practices.<sup>25</sup> It is possible, in an effort to cope through challenging situations, that clinicians detach which may lead to experiences of dehumanization.<sup>26,27</sup> Consistent with the literature that suggests provider perceptions of the disease impact timely diagnosis and diagnoses of other comorbidities,<sup>28,29</sup> which may result from providers attributing other ailments to the dementia.<sup>29</sup> These experiences can lead individuals to feel dismissed and that their clinical experiences were not holistic, similar to literature on therapeutic nihilism.<sup>13</sup>

There are opportunities to engage in co-production efforts at both the clinical and organizational level. Building in personhood models of care encourages agency in care planning. Such processes could be facilitated through the meaningful engagement of people with dementia and their caregivers in the socio-political life of the community or organization. Such actions would facilitate efforts of understanding and a horizontal view of knowledge dissemination.<sup>3</sup> Professional training needs to address therapeutic nihilism and dehumanization, reinforce a person-centered approach, and uphold quality of life regardless of disease prognoses. Training also needs to address dementia-related stigma and incorporate empathy while remaining clinically skillful.<sup>25,30,31</sup>

## Limitations

Although inter-jurisdictional comparative analysis was not conducted in this study, the issues noted by participants were common regardless of jurisdiction. Inclusion of

multiple jurisdictions strengthened this study by increasing the diversity of perspectives. However, it remains plausible that experiences of accessing health and social care may be considerably different in other settings, where health education, perception of mental health, cognition, and aging are significantly different.<sup>32,33</sup> Future research should also consider the perspectives of healthcare professionals.

The QSA methodology allowed us to explore the data corpus through a lens that was different from the original objective of the parent study. While the research questions were not directly asking about pre-conceived notions of dementia and the associated implications of that on experiences, following a familiarization stage with the data, there was a clear undertone of participants describing how these pre-conceived notions of what it means to live with or have dementia impacted their experiences. Therefore, while there may not be a direct link between the interview guide and the findings, we consider this a strength of the inductive iterative thematic analysis process, where we identify interpretations of these experiences, despite participants not being directly asked about these connections.

## Conclusion

This study identifies a connection between how dementia is perceived and the experience of caregivers and people living with an AD/ADRD within health and social settings. Interestingly, despite longstanding understanding of these issues, we continue to encounter poor experiences within clinical and social settings. This study creates further impetus to redesign support systems for people living with an AD/ADRD. The implications that emerge as a result of the social construction of dementia expand into increasingly complex, yet important care settings. For example, palliative care, timely advanced care planning, and conversations with respect to medical assistance with death and dying.<sup>34</sup> As the need for palliative care increases, this research supports the critical nature of these conversations in developing and understanding clinical and social interventions.<sup>35</sup> Additionally, patient-centered care offers holistic approaches to care extending beyond symptom-based approaches and considers people in their context. It is with patient-centered approaches that bring about positive experiences and patient and caregiver well-being. Despite this being a desired approach to AD/ADRD care, there are potential implications for providers that must first be considered. If providers engage in distancing as a coping mechanism, how can we create additional and different tools for them to rely on that will simultaneously allow for person-centered care and provider well-being. Without education, additional clinical toolkits for well-being, and negative framing and language use, these negative experiences will continue to persist.

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### Data Sharing

Research analysis process can be made available. However, raw data cannot be shared due to the condition of anonymity.

### Declaration of conflict of interest

The authors have no conflict of interest with the study findings.


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### Supplemental Material

Supplemental material for this article is available online.

### References

- Sabat SR, Harré R. The construction and deconstruction of self in Alzheimer's disease. *Ageing Soc.* 1992;12(4):443-61.
- Biggs S, Carr A, Haapala I. Dementia as a source of social disadvantage and exclusion. *Australas J Ageing.* 2019;38(S2):26-33. doi:10.1111/ajag.12654
- Bosco A, Schneider J, Coleston-Shields DM, Higgs P, Orrell M. The social construction of dementia: systematic review and metacognitive model of enculturation. *Maturitas.* 2019;120:12-22. doi:10.1016/j.maturitas.2018.11.009
- Riley RJ, Burgener S, Buckwalter KC. Anxiety and stigma in dementia: a threat to aging in place. *Nurs Clin North Am.* 2014;49(2):213-31. doi:10.1016/j.cnur.2014.02.008
- Parker J, Cutler C, Heaslip V. Dementia as *Zeitgeist*: social problem construction and the role of a contemporary distraction. *Sociol Res Online.* 2021;26(2):309-25. doi:10.1177/1360780420929033
- Jellinger KA. Should the word 'dementia' be forgotten? *J Cell Mol Med.* 2010;14(10):2415-6. doi:10.1111/j.1582-4934.2010.01159.x
- Singer M. The social origins and expressions of illness. *Br Med Bull.* 2004;69(1):9-16. doi:10.1093/bmb/ldh016
- Tyler I, Slater T. Rethinking the sociology of stigma. *Sociol Rev.* 2018;66(4):721-43. doi:10.1177/0038026118777425
- Sarmento ALR. Stigma of Alzheimer's disease in healthcare professionals: numbers that still surprise: dementia care research (research projects; nonpharmacological) / behavioral interventions. *Alzheimer's & Dementia.* 2020;16(S7). doi:10.1002/alz.042146
- George J, Long S, Vincent C. How can we keep patients with dementia safe in our acute hospitals? A review of challenges and solutions. *J R Soc Med.* 2013;106(9):355-61. doi:10.1177/0141076813476497
- Evans SC. Ageism and dementia. In: Ayalon L, Tesch-Römer C, eds. *Contemporary perspectives on ageism.* International Perspectives on Aging. Springer International Publishing; 2018:263-75. doi:10.1007/978-3-319-73820-8\_16
- Werner P, Goldstein D, Karpas DS, Chan L, Lai C. Help-seeking for dementia: a systematic review of the literature. *Alzheimer Dis Assoc Disord.* 2014;28(4):299-310. doi:10.1097/WAD.000000000000065
- Callisaya ML, Purvis T, Lawler K, Brodtmann A, Cadilhac DA, Kilkenny MF. Dementia is associated with poorer quality of care and outcomes after stroke: an observational study. *J Gerontol A Biol Sci Med Sci.* 2021;76(5):851-8. doi:10.1093/gerona/glaa139
- King M, Peckham A, Marani H, Roerig M, Yung S, Mcgrail K, Young Y, Shaw J, Marchildon G. Gaps in the system: supporting people living with dementia. *Journal of Aging and Social Policy.* 2023;13:1-21. doi:10.1080/08959420.2023.2226341
- Slater JR. Social constructionism. In: *The SAGE encyclopedia of communication research methods.* Sage Publications, Inc; 2017:1623-8. doi:10.4135/9781483381411.n572
- Horwitz AV. Creating an age of depression: the social construction and consequences of the major depression diagnosis. *Soc Ment Health.* 2011;1(1):41-54. doi:10.1177/2156869310393986
- O'Reilly M, Lester JN. *Examining mental health through social constructionism: the language of mental health.* Springer International Publishing; 2017. doi:10.1007/978-3-319-60095-6
- Dawn R. Role of culture and media in disability studies: a medium of social construction of disability. *J Disability Religion.* 2023;27(1):1-22. doi:10.1080/23312521.2019.1673872
- Ruggiano N, Perry TE. Conducting secondary analysis of qualitative data: should we, can we, and how? *Qual Soc Work.* 2019;18(1):81-97. doi:10.1177/1473325017700701
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
- Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual Res Sport Exerc Health.* 2021;13(2):201-16. doi:10.1080/2159676X.2019.1704846
- Bosco A, Schneider J, Coleston-Shields DM, Orrell M. Dementia care model: promoting personhood through co-production. *Arch Gerontol Geriatr.* 2019;81:59-73. doi:10.1016/j.archger.2018.11.003
- Fletcher JR. Discovering deviance: the visibility mechanisms through which one becomes a person with dementia in interaction. *J Aging Stud.* 2019;48:33-9. doi:10.1016/j.jaging.2018.12.003
- Low LF, Purwaningrum F. Negative stereotypes, fear and social distance: a systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatr.* 2020;20(1):477. doi:10.1186/s12877-020-01754-x
- Bacsu J, Mateen FJ, Johnson S, Viger MD, Hackett P. Improving dementia care among family physicians: from

- stigma to evidence-informed knowledge. *Can Geriatr J.* 2020; 23(4):340-3. doi:10.5770/cgj.23.426
26. Capozza D, Falvo R, Boin J, Colledani D. Dehumanization in medical contexts: an expanding research field. *TPM: Testing Psycho Methodol Appl Psychol.* 2016;23(4):545-59. doi:10.4473/TPM23.4.8
  27. Halpern J. *From detached concern to empathy: humanizing medical practice.* Oxford University Press; 2001.
  28. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Dis Assoc Disord.* 2009;23(4):306-14. doi:10.1097/WAD.0b013e3181a6bebc
  29. Bunn F, Burn AM, Goodman C, et al. Comorbidity and dementia: a scoping review of the literature. *BMC Med.* 2014;12:192. doi:10.1186/s12916-014-0192-4
  30. Patel S, Pelletier-Bui A, Smith S, et al. Curricula for empathy and compassion training in medical education: a systematic review. *PLoS One.* 2019;14(8):e0221412. doi:10.1371/journal.pone.0221412
  31. Kim S, Werner P, Richardson A, Anstey KJ. Dementia stigma reduction (DESeRvE): study protocol for a randomized controlled trial of an online intervention program to reduce dementia-related public stigma. *Contemp Clin Trials Commun.* 2019;14:100351. doi:10.1016/j.conctc.2019.100351
  32. Uwakwe R. Knowledge of religious organizations about dementia and their role in care. *Int J Geriatr Psychiatry.* 2000;15(12):1152-3. doi:10.1002/1099-1166(200012)15:12<1152::aid-gps247>3.0.co;2-m
  33. Brooke J, Ojo O. Contemporary views on dementia as witchcraft in sub-Saharan Africa: a systematic literature review. *J Clin Nurs.* 2020;29(1-2):20-30.
  34. Eisenmann Y, Golla H, Schmidt H, Voltz R, Perrar KM. Palliative care in advanced dementia. *Front Psychiatry.* 2020;11:699. doi:10.3389/fpsy.2020.00699
  35. Bravo G, Trottier L, Arcand M. Physicians' characteristics and attitudes towards medically assisted dying for non-competent patients with dementia. *Can J Aging / La Revue Canadienne du Vieillessement.* 2022;41(1):135-42. doi:10.1017/S0714980821000088