Reimagining Dementia Care Beyond the Academy: A Reflexive Doctoral Journey in Nursing Scholarship

By Dr. Jasmine Jihye Hwang[1] (Ph.D. graduate), Faculty of Nursing, University of Calgary, Calgary, Alberta, Canada

[1] This work is based on the author's reflexive journaling during doctoral research on access to dementia care. Her PhD in Nursing at the University of Calgary was completed in August 2025.

Corresponding Author: Dr. Jasmine Jihye Hwang, Email: jasmine.hwang@ucalgary.ca

Abstract

Dementia continues to be framed widely through narratives of inevitable decline, loss, and social death, contributing to persistent stigma and constraining how care is imagined and delivered. This reflective article draws on my doctoral journey as a nurse scholar to examine how dominant dementia narratives shape assumptions, knowledge production, and engagement with care beyond diagnosis. Rather than reporting empirical findings, I explore how sustained encounters with diverse stories of living with dementia challenged my deficit-oriented assumptions and revealed marginalization of alternative narratives that emphasize continuity, adaptation, and meaning. Drawing on the concept of epistemic injustice, I argue that stigma operates as a narrative system that privileges certain forms of knowledge while silencing others, with implications for nursing practice, education, and community engagement. I conclude by positioning narrative change as a legitimate form of scholarly and ethical intervention and by calling on nurses to engage publicly in expanding the lived stories that shape dementia care, equity, and possibility.

Keywords: dementia care, dementia stigma, epistemic injustice, narrative change, community engagement, nursing scholarship

Dementia is widely recognized as one of the most pressing public health challenges associated with population aging (World Health Organization, 2017, 2025). In Canada, the number of people living with dementia continues to rise, accompanied by growing concern about the adequacy, accessibility, and equity of care (Alzheimer Society of Canada [ASC], 2022; Government of Alberta [GoA], 2017; Public Health Agency of Canada, 2019, 2024). Despite decades of clinical research, policy initiatives, and advocacy, dementia remains heavily stigmatized in public, professional, and institutional discourse (Kontos et al., 2021). It is frequently framed through narratives of inevitable decline, loss of self, and social death (Putland

& Brookes, 2024), narratives that shape expectations, interactions, and care pathways long before individuals encounter formal diagnosis and services.

This article offers a reflective account of how my doctoral journey reshaped my understanding of dementia stigma and the role of narrative in shaping care. Rather than presenting empirical findings, I focus on sense-making of my doctoral research journey as an intellectual and ethical process. It foregrounds positionality, reflexivity, and learning by examining how my clinical background, early expectations, and encounters with diverse narratives of dementia influenced the questions I asked, the gaps I noticed, and the responsibilities I came to recognize as an emerging nurse scholar. This reflective journey prompts a shift from viewing stigma as an individual attitude to understanding it as a narrative system that structures knowledge, practice, and access to care. This reflection traces how these insights led me to consider the ethical accountability of nurses, grounded in nursing's commitments to optimal health, well-being, dignity, high-quality care, and human rights, to engage beyond academic spaces through public-facing, community-engaged initiatives that aim to reshape how dementia is understood within communities.

Reflexive Journey

The following sections delineate how my assumptions about dementia are shaped, challenged, and ultimately transformed through my doctoral journey. By making this process visible, I aim to illuminate how knowledge about dementia is produced not only through research but also through assumptions we bring to it and languages we use to describe it.

Assumptions and Motivations Grounding My Doctoral Work

Before beginning my doctoral studies, I worked as a geriatric nurse consultant in primary and community care settings, supporting older adults and families navigating complex care needs. Dementia was a familiar presence in this work as most of my clients lived with dementia. Yet, what struck me most was not the progressive cognitive or functional changes associated with the condition, but how little meaningful support was visible, available, or accessible after diagnosis – a reality often accompanied by profound denial, resignation, and isolation. Conversations with families frequently revolved around what had been lost or what could no longer be expected. Support options beyond medication, behavioural symptom management, generic lifestyle advice, or institutional care often felt invisible or inaccessible.

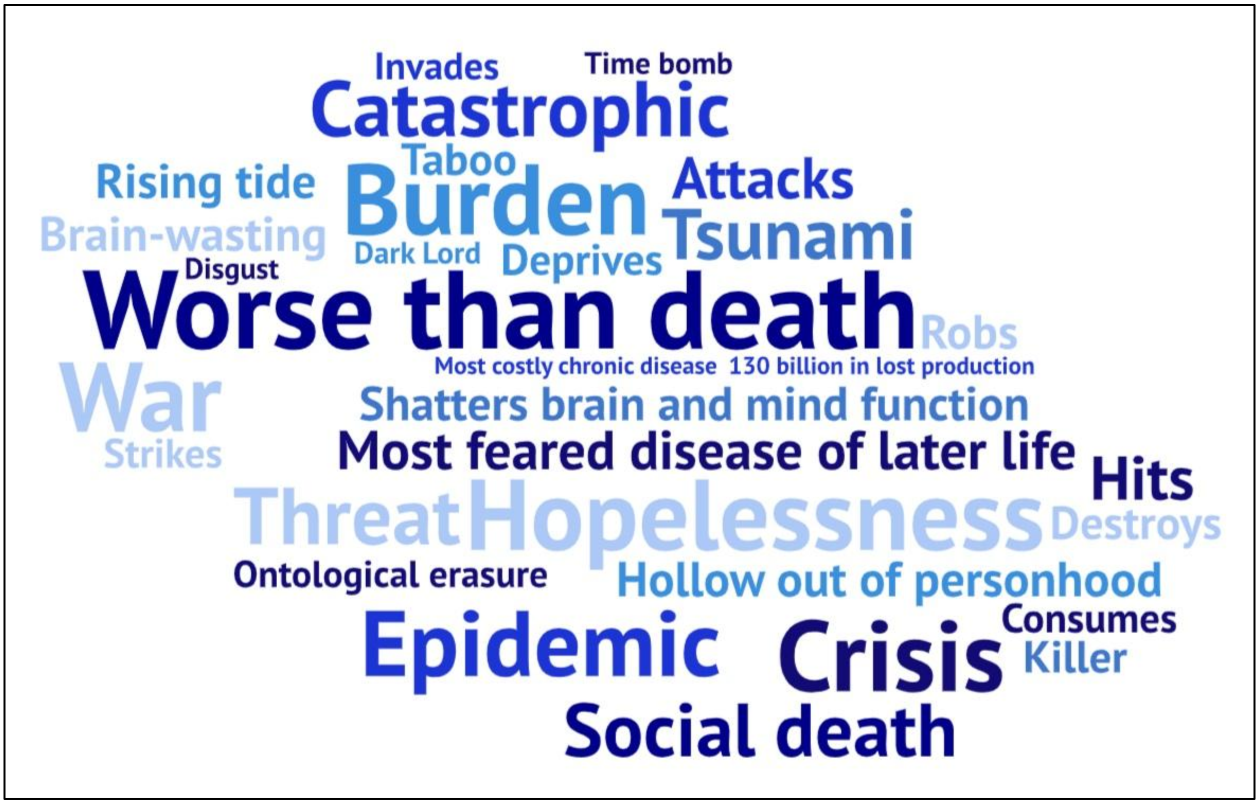
At that time, my own assumptions were not immune to these narratives. Like many clinicians trained within biomedical systems, I had internalized a largely deficit-oriented understanding of dementia, one that emphasized multiple losses, increasing dependency, and inexorable decline. While I recognized the importance of nonpharmacological approaches, these supports often appeared peripheral rather than central to dementia care, as they were not well understood as rehabilitative or therapeutic interventions (often seen as resources for families or something extra) or readily accessible (due to long wait times, transportation, variable family involvement and support, and language and cultural barriers). Moreover, the absence of a pharmaceutical cure seemed to reinforce a quiet nihilism, a sense that meaningful intervention was limited and that formal diagnosis and intervention could be delayed.

These experiences motivated my doctoral work (Hwang et al., 2023; Hwang, 2025). I wanted to better understand why supportive, health-promoting interventions remained so difficult to access after a dementia diagnosis, and how systems of care might be reorganized to better support people earlier in their journey. Initially, my focus was pragmatic and structural, centred on tangible barriers such as service availability, referral pathways, eligibility criteria, wait times, and coordination of care across sectors. I was primarily concerned with how health systems were designed and where, in practice, people were falling through the cracks. However, as the doctoral research unfolded, it became increasingly clear that barriers to care were not only material or organizational. Access was also shaped by how dementia was talked about, understood, and anticipated in clinical encounters and everyday social interactions. Assumptions embedded in language, expectations of an unstoppable decline, and beliefs about what could or could not help after diagnosis quietly influenced decisions about whether care was sought, offered, or deferred.

Encountering Competing Narratives of Dementia

As I engaged more deeply with stories surrounding dementia through research activities, professional dialogues, conference presentations, and community conversations, I became increasingly aware of the coexistence of competing narratives. Dominant cultural stories portrayed dementia as a catastrophic rupture, a condition associated with fear, loss of self, erasure of identity, caregiver distress, economic burden, and an inevitable downward trajectory (Canadian Centre for Economic Analysis, 2023; Kontos et al., 2020; Putland & Brookes, 2024; Richardson, 2023). See Figure 1 for a word cloud illustrating tragedy narratives represented in the literature and media. These narratives circulated widely in clinical language, policy discourses, media portrayals, and even casual conversations. They shaped expectations about what dementia means and what kinds of futures are imaginable for people living with dementia.

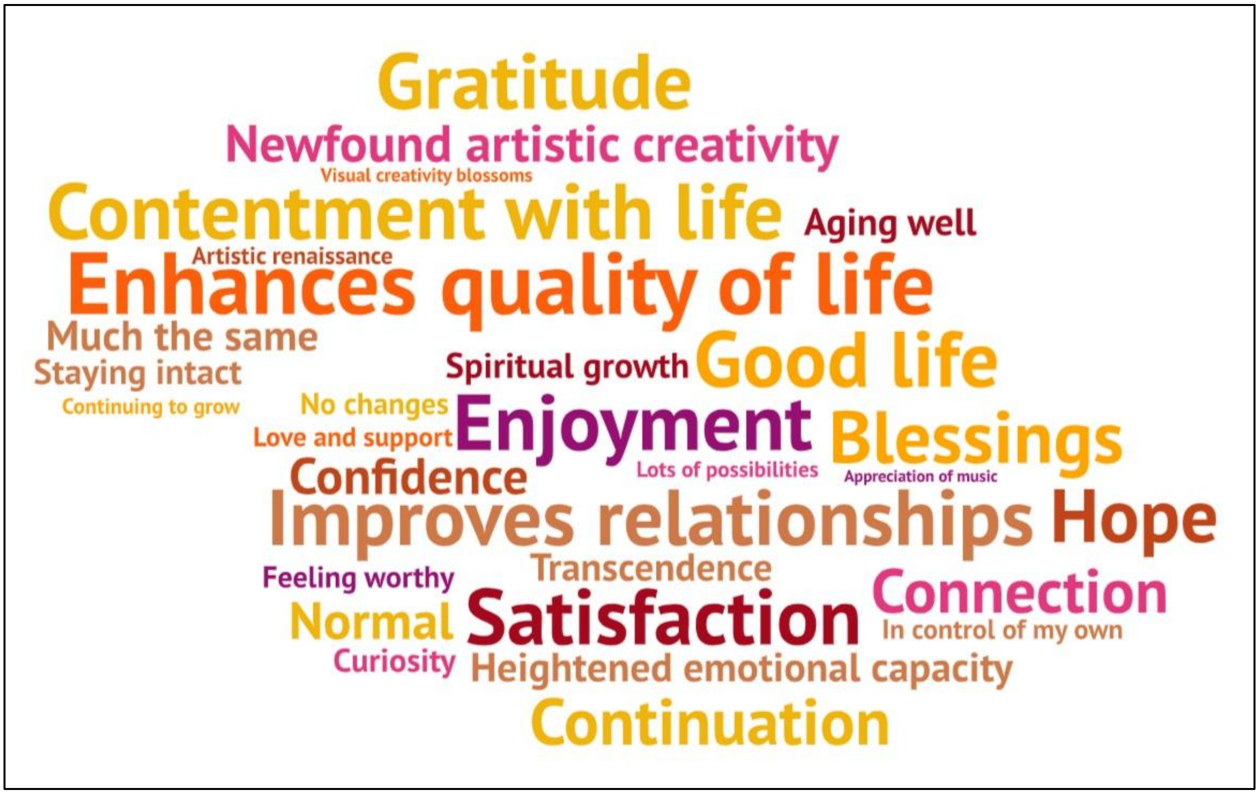
Figure 1
A Word Cloud Illustrating Tragedy Narratives in Media and Literature



Note. Word cloud content was derived from published literature and media sources (ASC, 2010; Ayalon & Tesch-Römer, 2018; Centers for Disease Control and Prevention, 2022; Dewing, 2008; GoA, 2017; Latimer, 2018; Putland & Brookes, 2024; Wolverson et al., 2016).

At the same time, quieter, less visible narratives also surfaced. See Figure 2 for a word cloud depicting alternative narratives drawn from the literature and media. These stories did not deny difficulty or loss, but they emphasized continuity, adaptation, connection, moments of meaning, as well as new possibilities. Dementia was not always described solely as an endpoint, but as a condition that coexisted with scaffolded agency, interdependent relationships, shared bodily realities, and an ongoing subjective sense of normalcy, wellness, and enjoyment in life. Such perspectives resonate with longstanding calls within nursing scholarship to expand understandings of care beyond biomedical and task-oriented approaches, emphasizing creative, relational, and embodied dimensions of well-being that are often overlooked in conventional practice (Kontos et al., 2020; Le Navenec & Bridges, 2005). In turn, these narratives complicate the assumption that the quality, or even meaning, of life disappears after diagnosis.

Figure 2
A Word Cloud Illustrating Alternative Narratives in Media and Literature



Note. Word cloud content was derived from published literature and media sources (Britt et al., 2023; Dalby et al., 2011; Erkkinen et al., 2019; Leigh, 2023; Le Navenec & Bridges, 2005; Miller & Miller, 2013; Odell-Miller, 2021; Wolverson et al., 2016).

As part of my reflexive research practice through field notes after interviews, analytic memos, and reflective journaling, I became increasingly aware of an implicit assumption I had carried into the field: I did not expect to encounter anything optimistic about living with dementia. However, as I was exposed to a growing range of accounts that unsettled this expectation, I began to recognize a disjuncture between lived experience and dominant ways dementia is typically imagined, talked, and understood. This realization marked a moment of deep learning and recalibration. In my subsequent reflection on my own research protocols, I noticed that my interview guide at the outset of the study did not include questions about strengths, moments of celebration, joy, creativity, or other less-debilitating aspects of living with dementia, a serious omission that revealed an unexamined bias I had brought into the work.

What struck me even more was not simply the existence of these alternative narratives but their marginal status. They were rarely foregrounded in formal knowledge production, service design, or care decision-making. Rather, they were often dismissed as personal anecdotes, hopeful illusions, forgetfulness, denial, or lack of insight, instead of being recognized as legitimate ways of understanding dementia. Over time, I came to see how the dominance of tragedy narratives narrowed the range of imaginable responses to dementia, shaping clinical language, family expectations, and care models. This narrowing reflects what Fridley (2026) describes as the emotional dominance of tragedy narratives, which, while grounded in real experience of loss, can obscure relational and meaningful aspects of living with dementia. This realization marked a turning point in my thinking about how knowledge about dementia is produced and legitimized. Dementia stigma was no longer simply about negative attitudes or misconceptions but about which stories are recognized, valued, and taken up as knowledge.

Stigma, Narrative, and Epistemic Injustice

To make sense of these tensions, I turned to the concept of *epistemic injustice*, which describes harms that occur when individuals or groups are unfairly excluded from participating as knowers and from shaping shared understandings (Fricker, 2007; Smith & Archer, 2020). In the context of dementia, epistemic injustice can be understood as the systematic privileging of certain narratives, particularly those emphasizing loss and incapacity, while simultaneously sidelining lived experiences that challenge these assumptions.

Within dominant discourse, dementia is often framed as a condition that undermines agency, personhood, or capacity, thereby diminishing the epistemic credibility of those living with it (Matthews & Kennett, 2022; Smith & Archer, 2020; van der Byl Williams & Zeilig, 2023). As cognitive impairment becomes foregrounded, the voices of people living with dementia are frequently treated as unreliable, irrelevant, or even bizarre. Importantly, this marginalization does not occur only at the level of interpersonal interaction. It penetrates broader systems of knowledge production, shaping research funding and priorities, educational curricula, clinical guidelines, health services, and policy decisions (Canadian Academy of Health Sciences, 2019; see also Hwang, 2025). When certain stories dominate attention and legitimacy, they come to define what is thinkable, fundable, and actionable in dementia care. In this sense, dominant dementia narratives contribute to what Kontos and colleagues (2020) describe as a constrained "cultural imaginary" (p. 91) that narrows how dementia, agency, and care are collectively envisioned.

Drawing on Smith and Archer's (2020) extension of epistemic injustice, this exclusion can be further understood as *epistemic attention deficit* (Smith & Archer, 2020), a systemic failure to attend to certain experiences initially, rather than merely a failure to believe them. In the context of dementia, alternative narratives are often not actively contested or refuted; instead, they are quietly bypassed, ignored, or treated as irrelevant to decision-making. Consequently, these experiences rarely enter a shared epistemic common ground that informs policy, professional practice, and service delivery.

Reflecting on my doctoral journey, I came to see stigma not merely as a social attitude but as a narrative and linguistic infrastructure that organizes sociocultural knowledge (e.g., what counts as knowledge). It operates across personal, relational, organizational, and policy domains, reinforcing a skewed, deficit-oriented understanding of dementia and constraining imagination of what care might involve. Importantly, this narrative infrastructure is self-perpetuating. When tragedy-oriented stories govern public understanding, they can justify absent or delayed intervention, minimal investment in services and the care workforce, and fragmented care pathways (Hwang, 2025). These conditions of care, in turn, reinforce the perception that dementia is a condition for which little can be done beyond respite, assistance with daily functioning, or end-of-life care (Du Preez et al., 2018; Symonds-Brown et al., 2021; Tretteteig et al., 2017). Exclusions from knowledge and meaning-making undermine not only care practices but also recognition of persons living with dementia as full agentic participants in social life.

Because nursing practice is embedded in everyday encounters, nurses are often among the first to witness how epistemic exclusion unfolds in real time. For nursing, this realization raises pressing ethical and epistemic questions. Nursing has long emphasized relational practice, holistic care, and attentiveness to lived and embodied experiences (Le Navenec & Bridges, 2005). Yet, nurses also practice within socio-cultural-historical health systems shaped by dominant narratives. Recognizing epistemic injustice and the nurse's role as a moral and epistemic agent invites critical reflection: How do we know what we know? Whose knowledge is amplified, and whose remains unheard or even silenced? How might care change if alternative narratives were viewed not as anomalies but as legitimate and necessary sources of profound insight for practice, education, and policy? Taken together, these questions highlight that attending seriously to alternative narratives is neither an optional interpretive exercise nor a romanticization of dementia, but a necessary condition for more just, responsive, and relational forms of dementia care.

Moving Insight to Responsibility Beyond the Academy

As these reflections deepened, I became increasingly uneasy with the idea that narrative change should remain confined to academic spaces. Conferences and journals play a critical role in knowledge dissemination, but they reach limited audiences. Meanwhile, stigma is produced and reproduced in everyday interactions on the streets, in community centers, in clinical spaces, in the media, in families, and in public discourses. If dominant narratives are sustained socially, then narrative change must also occur socially.

This realization prompted a shift in how I understood my role as a scholar. Rather than viewing public engagement as optional or merely a requirement for knowledge translation, I began to see community engagement as an ethical extension of the work itself. Initiatives such as *Taking It to the Streets*, a global campaign developed through the Reimagining Dementia movement (reimaginingdementia.com), exemplify this orientation. By bringing conversations about dementia into public spaces through art, dialogue, and lived experience (KITE Research Institute University Health Network, 2025; Kontos et al., 2020; Kontos & Grigorovich, 2018; Lockwood, 2023), such initiatives aim to disrupt stigma where it is most deeply embedded. Importantly, these efforts do not seek to replace one narrative with another but to expand the range of stories that are heard and valued.

For me, involvement in this kind of public-facing work represents a continuation of doctoral learning rather than a departure from it. Those interested in learning more or engaging with this initiative may explore related activities through #ReimaginingDementia and #TakingItToTheStreetsYYC. This shift reflects an evolving understanding that scholarship carries responsibilities not only to generate knowledge but also to participate in reshaping the conditions under which knowledge is recognized, accessed, and used.

Implications for Nursing Practice, Education, and Community Engagement

Reflecting on this journey has several implications for nursing. It underscores the importance of attending to narrative as a determinant of care. How dementia is talked about in classrooms, clinics, and communities shapes expectations, relationships, and care pathways from diagnosis through treatment. Nurses are uniquely positioned to notice and challenge deficit-oriented narratives both through everyday interactions (in our conversations with patients, families, and other healthcare practitioners) and through individual and collective advocacy (through our participation in social campaigns, collective discussions, and position papers).

Nursing education offers a critical site for narrative change. Preparing future nurses to engage with dementia requires more than technical knowledge; it requires cultivating the capacity to hold complexity and compassion, resist reductive stories, and remain open to multiple ways of knowing. Integrating lived experience, reflective practice, up-to-date evidence, and strengths-based perspectives into curricula can help counter therapeutic nihilism and foster more equitable and empathetic care.

Community engagement should be understood as central to nursing's scholarly and professional engagement. Public-facing initiatives and community partnerships that invite dialogue, creativity, and connection can help reduce fear and isolation not only for those living with dementia but also for society more broadly. Such efforts align closely with nursing's social mandates to health equity, social justice, and relational care (Canadian Nurses Association, 2025), echoing Nightingale's (1860) emphasis on the care environment conducive to optimal health. For nurse scholars, narrative change invites reimagination of the real-world impact of their work, which values relational ethics in enhancing one another's agency, epistemic justice as the fair recognition and inclusion of individuals as knowers in knowledge production, and knowledge mobilization alongside traditional academic outputs.

Conclusion: From Reflection to Collective Responsibility

This doctoral reflection traces a shift in how I came to understand dementia stigma, not as a matter of individual prejudice or misconception but as a narrative system that shapes whose voices are heard, whose knowledge is valued, and which forms of care are considered possible. Along this journey, it became clear that dominant stories of tragedy, loss, and decline do more than describe dementia. They can actively structure practice, expectations, and access to support, thereby confining the moral and practical imagination of care when left unchallenged. For nursing, this realization carries an important call to action. Grounded in relational ethics, equity, and attentiveness to lived experience, nursing is uniquely positioned to question deficit-oriented narratives and to amplify those that have been muted or marginalized. This work does not deny loss, pain, or difficulty but resists one-dimensional stories in favour of holding space for diversity, continuity, and possibility. Responding to dementia stigma, therefore, requires more than producing evidence or refining service models. It also demands deliberate engagement with the narratives circulating in classrooms, clinics, communities, and public spaces. This article invites readers, as clinicians, educators, scholars, advocates, and community members, to participate in expanding those narratives, fostering conversations that move beyond fear and finality and toward more inclusive, ethical, and hopeful approaches to living well with dementia.

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