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Expanding current understandings of epistemic injustice and dementia: Learning from stigma theory

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ABSTRACT

The current paper addresses the nature of epistemic injustice as it may be experienced by persons with dementia. We describe how theoretical models of stigma align with the current model of epistemic injustice through a consideration of the concepts of ‘stereotype’, ‘prejudice’ and ‘discrimination’, shared by the two models. We draw on current understandings of dementia-related stigma to expand understandings of the epistemic injustice faced by persons with dementia. We discuss how these insights may inform the development of mechanisms to uphold the basic human right to speak, to be heard, and to be believed for persons with dementia.

Introduction

The Convention on the Rights of Persons with Disabilities (The United Nations, 2006) states that all persons, despite disability or difference, have the right to access health and social care that meets their unique needs and expectations. This applies to *all* persons, including persons with dementia (Dementia Alliance International, 2016; Swaffer, 2018). Similarly, the World Health Organization (2017) states that persons with dementia have the right to live in:

> … a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with *dignity*, *respect*, *autonomy* and *equality*. (emphasis added; p. 4).

However, on a global scale, persons with dementia often are denied basic human rights, and equality rarely is achieved (Alzheimer's Disease International, 2017; World Health Organization, 2017). Inequality for persons with dementia is expressed, by example, in health and social care contexts wherein they are positioned as powerless, passive, and dependent recipients of care. In this paper, we explore injustices related to involvement of persons with dementia in the construction of *knowledge*: injustices related to their human rights to speak, to be heard and to be believed. Collectively, these are commonly referred to as ‘epistemic injustices’ (Fricker, 2007).

Epistemic injustice

‘Epistemic injustice’, a concept popularised[1] by philosopher Miranda Fricker (2007), refers to the “wrong done to an individual specifically in their capacity as a *knower*” (emphasis added, p. 1). Epistemic injustice results from partial or full exclusion of selected persons from the construction of knowledge. Of primary relevance is Fricker's concept of ‘testimonial injustice’, a sub-type of epistemic injustice relating to judgements about the credibility of a speaker's testimony. Routinely, when a hearer[2] witnesses a speaker make an assertion, they form judgments both about the credibility of the speaker and of what they said (Goldberg, 2013). A speaker suffers a ‘testimonial injustice’ when a hearer attributes too little credibility to a speaker's testimony, perhaps due to a hearer's prejudice. This kind of harm is *epistemic* in nature: the speaker is harmed in their capacity as a *knower*.

The concept of epistemic injustice has had recent application in health research. These instances include, for example, understanding the experiences of persons with mental illness (Leblanc & Kinsella, 2016), South African women's experiences of menstruation (Paphitis,

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[1] Similar concepts emerged many years ago from the civil rights and feminist movements. Judgements about a speaker's credibility (particularly as they relate to a being a person of colour and/or to being a woman) were said to influence the uptake of knowledge to which they had contributed.

[2] We use the terms ‘hearer’ and ‘speaker’ here for readability and for consistency with the terms used by Fricker. However, these concepts equally apply to judgements about a *writer's* credibility made by a *reader*.

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2018), and patient experiences of drug dependence treatment (Klingemann, 2017), among many others. However, to date, its application to persons with dementia is underexplored.

Epistemic injustice and dementia: existing understandings

A small body of previous work explores how epistemic injustice affects persons with dementia. Collectively, these studies illustrate that Fricker's account of epistemic injustice can be used to understand the lived experiences of persons with dementia. They describe how film can perpetuate (Capstick, Chatwin, & Ludwin, 2015) or challenge (Capstick et al., 2015; Matthews, 2016) negative stereotypes. Further, stereotypes of cognitive unreliability, fuelled by assumptions of severe and global loss (Crichton, Carel, & Kidd, 2016), may inform credibility judgements about persons with dementia (Carel & Kidd, 2014). They suggest that dementia symptoms may justifiably result in a judgment of deflated credibility (Crichton et al., 2016), but that credibility judgements about persons with dementia often are unreasonably deflated (Kidd & Carel, 2017). Finally, epistemic injustice can have widespread consequences for persons with dementia, including discrimination in the form of exclusion from involvement in patient organisations (Jongsma, Spaeth, & Schicktanz, 2017).

Aim

Current understandings of epistemic injustice and dementia are limited to a western perspective (based on research from the UK, Germany, and Australia, cited above), and from disciplinary perspectives of film studies, bioethics, or philosophy, for example. Whilst the studies described above offer important preliminary insights, they do not explicate, with the exception of the assumption of severe and global loss, which stereotypes influence credibility judgments. They do not explore how persons with dementia experience epistemic injustice, nor do they describe the practical outcomes of epistemic injustice.

Given the relative scarcity of literature into the effects of epistemic injustice on the everyday lives and the human rights of persons with dementia, we look to the dementia-related stigma literature for insight. We first introduce stigma theory, then describe how epistemic injustice and contemporary models of stigma relate, through shared consideration of concepts of ‘prejudice’, ‘stereotype’ and ‘discrimination’. We then draw from the dementia-related stigma literature to identify how epistemic injustice may affect persons with dementia.

Stigma theory

Goffman on stigma

In ‘*Stigma: On the management of spoiled identity*’ Goffman (1963) popularised the concept of ‘stigma’: “an attribute [or trait] that is deeply discrediting” (p. 3). Each type of stigma Goffman described (tribal stigma, physical ‘deformities’, or character traits indicating weakness) marks an “undesired differentness” (p. 5) from what we anticipate or accept as ‘normal’ for a group of people. The undesired differentness has its primary impact in social interaction; turning others away from the person assigned a stigmatised identity.

Goffman's conceptualisations rely on testimony from ‘stigmatised persons’ of his time (mid-20th century): e.g., persons with physical deformities, with hearing or vision impairments, with psychiatric illnesses, with drug addictions, who are homosexual, or who perform sex work. Since publication of Goffman's seminal text, new conceptualisations of stigma emerged within both its disciplinary ‘home’ of sociology (focussing on the outcomes of stigma) and in a newly developed field of discursive/social psychology (focussing on how categories of persons are created) (Link & Phelan, 2001).

Theoretical understandings of stigma also have been applied to broader populations, including to the understanding of experiences of persons with dementia. Werner (2014) systematically reviewed the literature exploring the relationships between stigma and Alzheimer's dementia (AD). She identified little consensus about a theoretical understanding of dementia-related stigma. She found that 73% of reports on relationships between stigma and AD (published from 1990 to 2012) do not relate their discussion to any historical or contemporary theoretical model of stigma. The remaining 27% of studies adopted a theoretical framework of stigma: either Modified Labelling Theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) or Attribution Theory (Corrigan, 2000). Both frameworks draw from Goffman yet have distinct foci. Werner concluded that discrepancies between definitions of stigma in this body of work limit its coherence and utility.

More recently, Herrmann et al. (2018) reviewed the dementia-related stigma literature (published from 2004 to 2015). They reported that severity of stigmatising attitudes is shaped by age, gender, personal experience, profession, ethnicity, culture, beliefs, understandings of prognosis, and experience with persons living with dementia. They also noted that there is no published, accepted ‘gold standard’ for assessing or reducing stigma, either in the dementia literature or the broader stigma literature. To this end, Herrmann, Welter, et al.'s (2018) review informed the design and evaluation of evidence-based interventions for reducing dementia-related stigma (see Herrmann et al., 2018).

Together, these reviews (Herrmann, Welter, et al., 2018; Werner, 2014) demonstrate a lack of coherence and inconsistency in the literature about the current conceptualisation, measurement, and reduction of dementia-related stigma. The aim of this paper is to explore, in a preliminary way, relationships between stigma and epistemic injustice associated with the lived experiences of persons with dementia. We do so by describing the conceptualisation of stigma adopted for the purposes of the current exploration, then describe how it relates to current concepts in epistemic injustice.

Current model of stigma: relationship with epistemic injustice

The concept of epistemic injustice is well-defined and consistent across authors, including those who critique it such as Coady (2012) and Hookway (2012). However, there is diversity in the conceptualisations of stigma in dementia-related stigma literature, and in the greater sociological literature.

The current exploration adopts a modified model of public mental illness stigma. The original model (Rüsch, Angermeyer, & Corrigan, 2005), integrates two popular models: Link and Phelan's (2001) sociological model of stigma, and Corrigan's (2000) social psychological ‘attribution theory’. Integrating these two models, Rüsch et al. (2005) assert that:

> …public stigma consists of these three elements—stereotypes, prejudice and discrimination—in the context of power differences and it leads to reactions of the general public towards (sic) the stigmatised group as a result of stigma. (p. 531).

In this context, *stereotypes* are generalised negative beliefs about a specific group; *prejudice* is the alignment or agreement with stereotypes, and negative emotional reactions to them; and *discrimination* is the behavioural response to prejudice. In line with Link and Phelan (2001), the current model posits that stigma occurs under conditions of social, economic, or political power.

To be clear, Rüsch et al.'s (2005) model does not assume an ordinal relationship between these components (i.e., does not assert that stereotypes feed prejudice, which lead to discrimination). Although the current exploration presents each component in this order, the interplay between components is fluid and dynamic. Similarly, although the model requires a convergence of interrelated components, each can reasonably exist independently (e.g., discrimination can occur in the absence of stereotypes; prejudice does not always lead to discrimination). Rüsch et al.'s (2005) conceptualisation of stigma extends Goffman's work, is well-defined, has been adopted by others in dementia research (e.g., Blay & Peluso, 2010; Gove, Small, Downs, & Vernooij-Dassen, 2017) and as we will describe, aligns also with the theoretical concept of epistemic injustice.

Fricker shares with Rüsch et al. (2005) a consideration of stereotype, prejudice, discrimination and power in her conceptualisation of epistemic injustice. Fricker suggests that prejudice arises from stereotype. However, Fricker is concerned with a specific type of prejudice that acts to deflate a hearer's judgment of a speaker's *credibility*. She also describes behaviours, 'discrimination' by Rüsch et al.'s (2005) definition, through which credibility-related prejudice might be expressed, such as discounting, ignoring or failing to seek a speaker's testimony (Fricker, 2007). She considers social power in relation to *epistemic privilege*; the idea that some persons automatically are assigned a high level of credibility (e.g., adults, white people, men), while others are assigned lower levels of credibility (e.g., children, persons of colour, women). Given these shared concepts, the two models align to the extent that permits a careful exploration of how the dementia-related stigma literature might infer epistemic injustice.

Lessons about epistemic injustice from the 'stigma' literature

Three types of stigma are commonly cited: public stigma, self-stigma, and courtesy stigma (Rüsch et al., 2005; Werner, 2014). Public stigma refers to public reactions directed to a group of persons possessing a stigmatising trait. Self-stigma refers to reactions by the person possessing the stigmatising trait, directed inwards. Courtesy stigma refers to the reactions by members of the public who do not possess the trait themselves to family, friends, or healthcare providers who are close to the person possessing the stigmatising trait. The current exploration prioritises the experiences of persons living with dementia by addressing public stigma and self-stigma, and not discussing courtesy stigma further (for discussion, see Abojabel & Werner, 2016; Werner & Hess, 2016). We provide an explication of how the literature relating to 'stereotypes', 'prejudice', and 'discrimination' informs current understanding of epistemic injustice. Henceforth, 'the stigma literature' refers to *dementia-related* stigma literature only, and 'stigma' refers to *dementia-related* stigma only, unless otherwise specified.

Stereotypes

Milne (2010) asserts that persons with dementia may be vulnerable to assuming a stigmatised identity, as dementia:

> …confers a 'master status' on the individual; 'having dementia' not only becomes the most prominent aspect of the person's life but it also serves to subsume all their other attributes and features… (p. 228).

Thus, dementia is constructed as 'identity-consuming'. The prevailing stereotypes of dementia are of hopelessness, dependence, incompetence and "total and irrevocable" loss (Ballenger, 2017, p. 717). According to the stereotypes, persons with dementia are inherently and invariably old, burdensome for family and the healthcare system, and incapable of speaking for themselves (Stites et al., 2018; Werner & Doron, 2017). They are thought to be delirious, unreliable, unable to contribute to society, and unaware of their abilities or limitations (Abojabel & Werner, 2016; Werner, Jabel, Reuveni, & Prilutzki, 2017).

For many, dementia is the worst-case scenario (Avari & Meyers, 2017); a "hopelessly incurable" condition (Ballenger, 2017, p. 715). Assumptions of poor prognosis, such that dementia is seen to be untreatable, degenerative, and leading to inevitable death, pervade to the extent that 'dementia' often is conflated with death itself (Beard, 2017). The assumption, or indeed expectation, of deterioration also affects stigma significantly. One vignette-based study explored the relative contributions of prognosis (improve; static; worsen) and disease label (Alzheimer's disease; traumatic brain injury; no label) to stigmatising attitudes held by members of the US general population (Johnson, Harkins, Cary, Sankar, & Karlawish, 2015). Johnson et al. (2015) reported that poor prognosis (i.e., the expectation that the condition will worsen) contributed to stigma more significantly than did AD labels. This suggests that stigmatising views can arise from views about an individual's current *and* (projected or predicted) future state; stigma may arise from the anticipation of imminent deterioration.

The stigma literature also explores the conditions under which these stereotypes are created and perpetuated, suggesting that the stereotypes noted above: (1) are perpetuated through the language used to talk about persons with dementia, (2) are perpetuated through the prevailing medical model of dementia, (3) compound with other stereotypes, and (4) are culturally mediated. We address each of these issues in turn.

1 Stereotypes are perpetuated through language

Stigma is exacerbated by the language used to talk about dementia and about the persons diagnosed with it. Milne (2010) asserts that the use of negative language is the "face" of public stigma (p. 229). Dementia language guidelines (e.g., Alzheimer's Australia, 2014; Alzheimer's Society Canada, 2012; The Alzheimer's Society of Ireland, 2015) designed to minimise public use of stigmatising language often promote positive, 'person-first' language (e.g., using the term 'living with dementia' in place of 'suffering with dementia'; using the term 'person with dementia' in place of 'demented person'). However, in the academic and lay literature, much of the discussion about language, stigma and dementia revolves around *metaphors.*

Metaphors are powerful tools used to draw similarities between two ideas or concepts. Lakoff and Johnson (1980) assert that, "Since much of our social reality is understood in metaphorical terms, and since our conception of the physical world is partly metaphorical, metaphor plays a significant role in determining what is real for us" (p. 146). Thus, metaphors can hold power, because they can shape current thinking about what it means to have dementia. One of the most pervasive metaphors of dementia is that of the 'return to childhood'. In his best-selling book 'The Forgetting', Shenk (2003) used the metaphor of the slow and steady "reverse childhood" (p. 126):

> …imagine your backwards teenager traversing her way back to infancy, to her very first day of birth, her first breath, and you have a surprisingly good grasp of the unravelling mind, soul, and body that Alzheimer's inflicts on a person. Every skill, feeling, and fact that the patient has learned slowly, satisfyingly, is being steadily erased as if by some sort of cosmic punishment. (p. 126).

Another example is the 'zombie metaphor': the social construction of persons with AD as "the living dead" (Behuniak, 2011; p. 79). Behuniak (2011) identified some associations between zombies and persons with AD. For example, that zombies and persons with dementia both experience a loss of self (in an animated yet 'mindless' body), and that zombies and persons with dementia both can incite feelings of terror and disgust in others. Others report similar stereotypes of persons with dementia as "empty shells" (Van Gorp & Vercruysse, 2012, p. 1277), of dementia as "character stripping, making someone a shadow of themselves" (Reynolds, Poyner, Innes, & Hambidge, 2017, p. 222), and of dementia causing "the slow death of the mind" (Beard & Neary, 2013, p. 140).

Johnstone (2013) exposed a number of additional metaphors, for example, the Alzheimer metaphor (e.g., dementia equates to losing one's mind), the epidemic metaphor (e.g., dementia is an epidemic or plague), the military metaphor (e.g., dementia is an enemy that attacks and destroys) and the predatory thief metaphor (e.g., dementia prowls, sneaks, robs and deprives). Such metaphors often are used without knowledge of the power that they hold. This is evidenced by the use of these metaphors within the literature that aims to identify means to minimise stigma (described by Swaffer, 2014). For example, Avari and Meyers (2017) describe persons with dementia as "on the downward slopes of their life courses" (p. 2). Similarly, Werner and Doron (2017) describe how, "Programs instituted in an increasing number of countries stress the importance of raising awareness and decreasing stigma as the first step in any effort to *battle* the rapidly growing [AD] *epidemic*" (emphasis added, p. 1206), adopting both the military metaphor and the epidemic metaphor (described above; Johnstone, 2013).

Some persons with dementia use such language and metaphor. For example, O'Brien (2014), in his memoir about living with AD, adopts the alien invader metaphor (Johnstone, 2013), when he refers to AD as a 'monster':

> The progression of this disease is unnerving, cutting, and guileful. This *monster* will be *slayed* only when we collectively understand its extensive reach, not just at the end stage of the disease, but at the start of this chaos. (emphasis added; O'Brien, 2014, p. 171).

It is unlikely that these authors (Avari & Meyers, 2017; O'Brien, 2014; Werner & Doron, 2017) intentionally used these terms to perpetuate negative stereotypes of persons with dementia. However, evidence of the use of such language and metaphors both by those who work to minimise stigma (academics in the area) and by those affected by stigma (persons with a diagnosis of dementia) demonstrates the pervasiveness of these concepts in the public collective imagination.

2 Stereotypes are perpetuated by the medical model

In the early 20th century, German psychiatrists Alois Alzheimer and Emil Kraepelin were credited with being the first in the world to identify a link between clinical symptoms of dementia when a person is alive and post-mortem evidence of specific pathological processes, of build-up of amyloid plaques and neurofibrillary tangles, in the brain (Ballenger, 2017).

However, at that time, Alzheimer and Kraepelin limited their diagnostic categorisation of dementia to those presenting with clinical symptoms of dementia and structural brain changes before the age of 65 only. Those with the same presentation after age 65 were thought to be ageing within the realm of 'normal', albeit at the extreme end (Alzheimer, Förstl, & Levy, 1991). Through Alzheimer and Kraepelin's work, 'presenile dementia' gained disease status, but it was not until the 1970s that older adults were included in the diagnostic classification of dementia (Ballenger, 2017). Since then, many researchers (including Kitwood, 1997) have attributed widespread stigma to the dominant biomedical understanding of dementia, regardless of age or ability. With a focus on deficits and impairments, adoption of this model reinforces the representation of all persons with a diagnosis (or label) of dementia as persons who are ill and who require medical 'management'.

3 Stereotypes compound

Stereotypes of dementia compound with other stereotypes, including those associated with ageing (often labelled as 'ageism' or 'gerontophobia'), mental illness, and institutionalisation (Bienvenu & Hanna, 2017; Milne, 2010; Mukadam & Livingston, 2012; Stites et al., 2018). Similarly, persons with pre-existing health conditions (e.g., Down syndrome, Parkinson's disease, etc.) who later develop dementia can experience dementia-related stereotypes, thereby compounding the stereotypes associated with their pre-existing condition. Compounding of stereotypes may multiply their prejudicial and discriminatory effects (Milne, 2010).

4 Stereotypes are culturally mediated

Many dementia-related stereotypes are culturally mediated. Cultural beliefs can fuel the idea persons with dementia are, to a varied extent, responsible for the changes in their cognitive status, symptoms, and/or neuronal degradation. For example, in predominantly individualist Western cultures increasing emphasis is being placed on the potential benefit of modifying individual lifestyle factors to decrease the likelihood of having dementia. Research has shown that modifying factors such as diet, physical activity, social activity, smoking, cognitive stimulation as well as properly managing blood pressure, hearing loss, depression and diabetes may influence the incidence of dementia (Livingston et al., 2017; National Academies of Sciences, 2017). As a result, some may see dementia as somewhat preventable (i.e., can be modified and/or prevented by making consistently 'good' lifestyle choices), and therefore as the responsibility or the fault of the person with dementia.

By contrast, members of some cultures believe that dementia has a religious or moral cause. Under such an assumption, dementia is caused by a supernatural curse, is an 'act of God', represents weakness of character, and/or represents punishment for past sins committed by persons or by their family members (Blay & Peluso, 2010; Woo & Mehta, 2017). For example, Algahtani et al. (2018) report that religious (in this case Islamic) and cultural beliefs contribute significantly to the conceptualisation of dementia by the general public in Jeddah, Saudi Arabia. A small percentage of their sample believed that AD is caused by a punishment from God (5.2%) or by an evil eye or magic (7.0%), and a larger portion (17.5%) reported that AD can be treated by reciting from the Islamic holy book, the Quran.

Similarly, dominant concepts of *familism*, *filial piety* and *family honour* contribute to the conceptualisation of dementia in collectivist cultures, for example in Turkey (Ar & Karanci, 2017), China (Zhang, 2018) and Korea (Casado, Hong, & Lee, 2018), among others. In these cultures, the self is defined primarily through relationship with others, particularly through familial relationships. As a result, occurrence of dementia may be seen to reflect poorly on the family; as something shameful which needs to be hidden from others.

By contrast, a large portion of members in some cultures perceive dementia to be a part of natural ageing, and therefore not an appropriate or necessary target for intervention or rehabilitation. For example, Parra et al. (2018) report that in some Latin American countries, such as Colombia, members of the society believe in determinism (i.e., fatalism). Under such a belief, occurrence of dementia is caused by fate, and results, therefore, in little hope for or confidence in intervention or treatment.

Stereotypes and epistemic injustice

Existing literature in epistemic injustice and dementia predominantly relates to a single stereotype: the assumption of severe and global cognitive and functional losses (Crichton et al., 2016). However, the stigma literature provides additional stereotypes to consider. Given Fricker's concern with 'credibility', we are prompted to consider stereotypes related to a person's position as a credible or reliable reporter. For example, assumptions of dependence, incompetence, untrustworthiness, unreliability, lack of insight into abilities, and inability to speak for oneself (Ballenger, 2017; Stites et al., 2018; Werner & Doron, 2017) may all inform judgements about a person with dementia's credibility as a speaker, regardless of 'actual' ability.

The stigma literature prompts consideration of the influence of future state on credibility judgements. The consideration of future state may account for Kidd and Carel's (2017) observation that credibility judgements about persons with dementia often are deflated beyond what is reasonable. If anticipation of future loss informs credibility judgements (i.e., the imminence of time when credibility necessarily will be poor), it follows that a hearer may judge a speaker with dementia to be less credible than they are currently.

The existing epistemic injustice literature has a distinct focus on the role of film representations of dementia, as noted previously (Capstick et al., 2015; Matthews, 2016), in perpetuating stereotypes that inform credibility judgements. The stigma literature prompts consideration of the additional ways in which stereotypes, and by extension epistemic injustice, may be perpetuated: through language, metaphor, the medical model, compounding stereotypes, and cultural beliefs about the cause of dementia.

Prejudice

Prejudice refers to the agreement with and the internalisation of stereotypes, and to the negative emotional reactions to those stereotypes (Rüsch et al., 2005). Thus, dementia-related prejudice refers to the internalisation of dementia stereotypes. The internalisation of stereotypes is rarely conscious, and therefore their effect (prejudice) may affect children, lay-adults, family members, health care professionals, and persons with dementia alike. For persons other than the person with dementia, these stereotypes may manifest as fear and/or revulsion: a fear of contagion and death, and a desire to be distant from persons with dementia may ensue (Behuniak, 2011; Casado et al., 2018; Johnstone, 2013). They may also evoke ‘positive’ feelings of sympathy and pity (Blay & Peluso, 2010).

(Self-)prejudice

For the person with dementia, with a lifetime of internalisation of ideas about what it means to ‘have dementia’, similar processes of prejudice can occur (Livingston et al., 2017). Stereotypes can manifest as fear of “helplessness, insignificance, uncertainty, and mortality” (Johnstone, 2013, p. 383–384), shame and embarrassment about an “unwanted identity” or changes to self (Jenkins & Feldman, 2018, p. 11). These negative feelings about the self may represent *self-prejudice*.

Both Swaffer (2016) and Bryden (2015), Australian activists who live with dementia and are advocates for persons with dementia, describe how a diagnosis and/or label of dementia incites and exacerbates these emotional responses:

> A diagnosis of dementia exacerbates issues such as social inequality, stigma, isolation, loss of identity and discrimination… It has significant emotional, financial and social cost and impact on the person with dementia, their families, and society. It disempowers, devalues, demeans and lowers self-esteem and very negatively impacts wellbeing and quality of life. (Swaffer, 2016, p. 318).

> Our inner fear at loss of self, of identity, is exacerbated by this outer stripping away of who we once were… we have a stigma of ‘being demented’. (Bryden, 2015, p. 39).

These excerpts demonstrate an awareness of another's reactions to dementia, such that persons with dementia could also be influenced by anticipation that others hold prejudicial views about them and reject them, at least while such awareness is retained.

Prejudice and epistemic injustice

The discussion of prejudice in the existing stigma literature primarily relates to feelings of fear of and/or revulsion by persons *without* dementia, toward persons *with* dementia (Behuniak, 2011; Casado et al., 2018). However, existing literature in epistemic injustice and dementia relates the discussion of prejudice to the internalisation of one specific idea: that persons with dementia are neither credible nor reliable (Carel & Kidd, 2014).

The literature on self-prejudice (e.g., Jenkins & Feldman, 2018) prompts consideration of how judgments about one's own credibility may contribute to epistemic injustice. When a person with dementia internalises stereotypes related to credibility, as described earlier, this may foster negative feelings about the self (deflated self-judgment of credibility) and expectations of prejudice by others (personal expectations that others will judge them as not credible). This, of course, would be dependent on a certain level of insight and awareness of stereotypes, and it remains to be seen whether the effects of these stereotypes are maintained across the progression of cognitive impairment, and to what extent they persist beyond one's conscious awareness of them.

Discrimination

Discrimination, a negative behavioural reaction resulting from prejudice (Rüsch et al., 2005), may be enacted both by persons without dementia (‘others’) and by persons with dementia. ‘Others’ may exhibit behavioural reactions with potentially negative social and/or emotional outcomes for a person with dementia. Similarly, persons with dementia can exhibit behavioural reactions to internalised prejudice (self-prejudice), to similar effect.

Much of the stigma literature on outcomes of discrimination by ‘others’ focusses on clinicians and family members. For example, awareness of stigma can make physicians hesitant to assess, to diagnose, and/or to disclose a diagnosis of dementia, resulting in delayed diagnosis and, if offered, delayed treatment and support (Mukadam & Livingston, 2012). Once diagnosed with dementia, stigma contributes to the exclusion of persons with dementia from health and social care decisions, and to poor provision of services or treatment (Herrmann, Welter, et al., 2018). Dementia advocacy pioneer Richard Taylor (2007) clearly describes an additional tension between diagnosis and self-stigma, acknowledging a practical imperative of timely diagnoses for allocation and receipt of formal supports, whilst suggesting that a delay of diagnosis may postpone the pre-emptive sadness often associated with impending decline.

Stigma also influences interactions, social roles, and relationships with family and friends (Jenkins & Feldman, 2018; Johnson et al., 2015). Bryden (2015) describes the impact of her dementia diagnosis on interaction:

> Diagnosis has changed our world forever. Our lives become limited by the stigma we face in the world around us. It's like we have a target painted on our foreheads shouting out ‘dementing’ for all the world to see. *People become awkward in our presence, are unsure of our behaviour*, and our world becomes circumscribed by the stigma of our illness (emphasis added; p. 40).

Similarly, Sakamoto, Moore, and Johnson (2017) quoted one participant with a diagnosis of ‘earlier onset dementia’, Simon, saying:

> When you have that dementia, people seem to treat you differently…. It's sad that you can be talking to somebody and once you mention the D word — dementia — you can tell the conversation is going to end or change. (p. 15).

Diagnostic labels may also have consequences for a person with dementia in a legal context (Werner & Doron, 2017). In this context, a label of dementia can assist in accessing benefits (e.g., programs of support), yet may also lead to a denial of autonomy; a denial of *all* legal rights. In Werner and Doron's (2017) study, an experienced social worker recounts an example of the latter:

> … I asked a judge whether he would be willing to invite the person with dementia [to the court room] before deciding to grant guardianship. He responded vehemently: No way! He didn't even understand what I was asking him … He said: It is a one-way street; once he/she'd been diagnosed with AD there was no way he could make decisions, so why invite him/her to appear in court? It is crystal clear that there is a need to appoint a guardian. (p. 1209).

In this instance, the dementia label was so stigmatising that the person with dementia was excluded from involvement their own legal guardianship case.

Stereotypes internalised by persons with dementia (i.e., self-prejudice) may also have practical outcomes. For individuals with dementia, fear of diagnosis and concerns about stigma cause delays in recognition of everyday challenges, reluctance to seek help (Garand, Lingler, Conner, & Dew, 2009; Stites et al., 2018), late presentation to health services, and late diagnosis of dementia (Livingston et al., 2017). In more extreme instances, stigma may result in complete avoidance of help or diagnosis, or disbelief in diagnosis.

Stigma also may cause social isolation (Ashworth, 2017). Social isolation may result from the person with dementia's actions, such as avoidance of group social situations, reliance on familiar communication partners, or total withdrawal from social interaction (Riley, Burgener, & Buckwalter, 2014). Social isolation may also arise from anticipations of others' negative reactions, described earlier. Stigma also acts to discourage participation in dementia-related research (Garand et al., 2009; Stites et al., 2018).

Ultimately, these forms of discrimination accumulate to decrease quality of life (Stites et al., 2018), as described by Swaffer (2016):

> A diagnosis of dementia … has significant emotional, financial and social cost and impact on the person with dementia, their families, and society. It disempowers, devalues, demeans and lowers self-esteem and very negatively impacts wellbeing and quality of life. (p. 318).

Discrimination and epistemic injustice

Existing literature in epistemic injustice and dementia relates discrimination to the involvement in (or, indeed, exclusion from) contributing to knowledge (Carel & Kidd, 2014; Crichton et al., 2016; Kidd & Carel, 2017). We propose that the stigma literature prompts consideration of four distinct types of epistemic injustice. Types 1 and 2 relate to discrimination by ‘others’ toward persons with dementia. These types align with Fricker's concepts of testimonial injustice (type 1) and pre-emptive testimonial injustice (type 2). Types 3 and 4 relate to discrimination that originates from the person with dementia, from internalised ideas about one's own credibility (on the assumption of retained awareness and insight into one's own condition, and/or ability to predict other's perceptions). Informed by Fricker's concepts and by the stigma literature, we propose two new types of epistemic injustice: testimonial withdrawal (type 3) and pre-emptive testimonial withdrawal (type 4).

Types 1 & 2: testimonial injustice and pre-emptive testimonial injustice

As noted earlier, the literature describes how epistemic injustice may affect involvement of persons with dementia in patient/political organisations (Jongsma et al., 2017) and in healthcare settings (Carel & Kidd, 2014; Crichton et al., 2016; Kidd & Carel, 2017). The stigma literature suggests that, along with political and healthcare settings, discrimination may also occur in social and legal settings. These settings may be targets for future research.

Rüsch et al.'s (2005) model provides a useful framework for considering how epistemic injustice may manifest as discrimination of persons with dementia. For example, the distinction between stereotype, prejudice and discrimination is useful when considering Fricker's ‘testimonial injustice’ (defined earlier; See Fig. 1). In this scenario, a hearer internalises a stereotype about the credibility of a person with dementia (‘June’, a hypothetical woman with dementia), it influences their judgment about June's credibility, and manifests behaviourally as exclusion from epistemic practices (type 1).

June has dementia
→ Persons with dementia are not credible reporters of their own experience **(stereotype)**
→ June is not a credible reporter of her own experience **(prejudice)**
→ I will listen, but I won’t believe and/or act on what she says **(discrimination)**

Fig. 1. Discrimination in the form of testimonial injustice (type 1).

June has dementia
→ Persons with dementia are not credible reporters of their own experience **(stereotype)**
→ June is not a credible reporter of her own experience **(prejudice)**
→ I will not seek June’s testimony **(discrimination)**

Fig. 2. Discrimination in the form of pre-emptive testimonial injustice (type 2).

Similarly, pre-emptive testimonial injustice (type 2) is a special type of testimonial injustice, arising from the same stereotypes and prejudices as type 1, with a different behavioural manifestation but same outcome (See Fig. 2). In the case of ‘pre-emptive testimonial injustice’ the credibility of an individual “is already sufficiently in prejudicial deficit that their potential testimony is never solicited; so the speaker is silenced by the identity prejudice that undermines her (sic) credibility in advance” (Fricker, 2007, p. 130).

In this example, a stereotype about the credibility of persons with dementia again is internalised by a hearer, influences the hearer's judgment about their credibility, and manifests as explicit exclusion from epistemic practices.

The stigma literature provides a clear example of pre-emptive testimonial injustice in Werner and Doron's (2017) legal scenario, in which a judge interpreted a diagnosis of dementia as a marker of complete inability to make decisions and led to exclusion from invitation to offer testimony in a courtroom (see earlier discussion).

Types 3 & 4: testimonial withdrawal and pre-emptive testimonial withdrawal

As stated earlier, internalised stereotypes may affect, and may be reflected in, the ways persons with dementia position *themselves* in epistemic practices (See Fig. 3).

This scenario demonstrates how internalised stereotypes can cause self-prejudice, leading persons with dementia to withdraw *themselves* from involvement in epistemic practices. We refer to this as ‘testimonial withdrawal’ (type 3).

Similarly, the internalisation of stereotypes, and the awareness that others are likely to have internalised them too, may lead to ‘pre-emptive testimonial withdrawal’ (type 4; See Fig. 4).

In this scenario, stereotypes are internalised to the extent that persons with dementia pre-emptively think that their testimonies will be given lower credibility than deserved so they do not offer up their testimonies. All four types of injustice can conceivably lead to social withdrawal.

I have dementia
→ Persons with dementia are not credible reporters of their own experience **(stereotype)**
→ I am not a credible reporter of my own experience **(self-prejudice)**
→ I don’t know what I’m talking about, so I won’t say anything **(discrimination)**

Fig. 3. Discrimination in the form of testimonial withdrawal (type 3).

I have dementia
→ Persons with dementia are not credible reporters of their own experience **(stereotype)**
  → Others will think I am not a credible reporter of my own experience **(predict other's prejudice)**
    → Others will think I don't know what I'm talking about, won't believe and/or act on what I say, so I won't say anything **(discrimination)**

Fig. 4. Discrimination in the form of pre-emptive testimonial withdrawal (type 4).

Power

According to Rüsch et al.'s (2005) model, stigma is dependent on power. Given a societal preference for 'normality', social power often is held by persons presenting (and/or passing) as 'normal' (Link & Phelan, 2001). The stigma literature reports that discriminatory effects may differ depending on who holds the power. For example, Avari and Meyers (2017) explored how geriatric psychiatrists contribute to stigma. The authors assert that physicians, who are widely-accepted to hold considerable social power, must be aware of power differences implicit in the care of persons with dementia, particularly as they relate to diagnosis. Physicians not only mediate access to health and social care for persons with dementia, but they hold the power to mark differences, through diagnosis, between persons with dementia and persons without dementia.

The same conditions of power appear to hold for epistemic injustice. Like stigma, epistemic injustice commonly occurs at the hands of persons in a position of epistemic privilege. Jongsma et al. (2017) offer a prime example of epistemic privilege when describing how persons with dementia are excluded from developing policy that shapes their care. Instead, the voices of physicians or family members, who in these contexts hold epistemic privilege, are given primary rights and opportunity to influence policy and practice relating to dementia care.

The stigma literature prompts consideration of additional groups of persons who may hold social power (e.g., physicians, health service providers and family members). Thus, we might expect that these groups of persons hold epistemic privilege over persons with dementia (i.e., their testimonies are likely to be taken more seriously).

Summary and implications

The current paper offers insights into the nature of knowledge-related injustice, *epistemic injustices*, with the intent that these insights might inform mechanisms to uphold for persons with dementia their basic human right to speak, to be heard and to be believed.

The current paper identifies that:

1. Epistemic injustice occurs when stereotypes of the deflated credibility of persons with dementia are internalised (by anyone; physicians, family members, friends, persons with dementia, judges, etc.);
2. Stereotypes of deflated credibility take many forms (beyond the assumption of severe and global loss), and are perpetuated in various ways (through language, metaphor, the medical model, compounding stereotypes, cultural beliefs);
3. Credibility judgements may be affected by assumptions about future state (namely, by the assumption of deflated credibility with the progression of cognitive impairment);
4. Internalisation of stereotypes can cause 'others' to exclude persons with dementia from epistemic practices (types 1 and 2); and
5. Internalisation of stereotypes (self-prejudice) can cause persons with dementia to withdraw themselves from epistemic practices (types 3 and 4).

The implications of these insights outlined herein are relevant across several themes. Our treatise considers the role of persons with dementia in their own epistemic practices. This exploration identifies the source of epistemic injustice as residing both with 'others' and with individuals with dementia. Thus, interventions or approaches to minimise epistemic injustice for persons with dementia need to bring together persons with dementia, those who care for them, and the general public, as well as those who hold evident epistemic privilege (authority in individual cases and authority to affect processes and practices), as identified in the literature (i.e., judges, physicians, healthcare practitioners). Social contact between persons with dementia and 'others' reduces stigma to some extent (Herrmann, Welter, et al., 2018). Providing education sessions in this way may have a double benefit: of both imparting knowledge and facilitating contact between persons with dementia and others.

There is a role for persons with dementia, family members, physicians, and others to play in challenging (credibility-related) stereotypes. There is a measurable implication for health education since researchers identify education and training as one promising means of reducing dementia-related stigma (Herrmann, Welter, et al., 2018; Milne, 2010; Stites et al., 2018). Education designed to minimise epistemic injustice may target content toward challenging stereotypes that fuel epistemic injustice in dementia (e.g., those stereotypes that represent persons with dementia as not credible) and increasing awareness of the ways these are perpetuated (see point 2 above). Education, information and training should raise awareness of the impact of internalised assumptions (namely, the assumptions that persons with dementia are not credible, or that others see them as not credible) on epistemic practices involving persons with dementia. Similarly, education and training programs should be provided to assist in moderation of credibility judgments (e.g., by 'reorienting epistemic sensibilities', as suggested by Matthews, 2016) and to encourage moderation of behavioural enactment of prejudices.

Limitations and future research

This paper raises several areas for future research. Firstly, there is a tension, also raised by Kidd and Carel (2017), that has not been addressed to date, between knowledge of a particular person and 'reasonable' credibility deflation, and credibility deflation resulting from stereotypes. The current discussion assumes some degree of epistemic reliability of persons with dementia. However, this might not be accurate, especially for those in the later stages of dementia. Future research should explore this tension further.

Secondly, this paper provides preliminary evidence that, by virtue of a shared relationship to stereotype, prejudice and discrimination, the stigma literature might inform understandings of the types of epistemic injustice a person with dementia can experience. Researchers in fields where the concept of epistemic injustice has not been adopted may explore the utility of this relationship further. Finally, it remains to be seen the extent to which both dementia-related stigma and dementia-related epistemic injustice may be self-perpetuating.

Conclusion

This paper explored how epistemic injustice for persons with dementia occur and might be addressed. The challenge for the future is to implement these suggestions to change perspectives and behaviours, to improve the quality of life of persons with dementia. We place ourselves in a better position to uphold the basic human rights of persons with dementia in our global community by adopting mechanisms to overcome the epistemic injustice they may experience.

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Declarations of interest

none.

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