



Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship[☆]

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ABSTRACT

The importance of stigma in shaping the experiences of people living with dementia and challenging their social citizenship emerges repeatedly as a powerful and negative force. In a recent participatory action research (PAR) study focused on understanding what people with dementia need to know to live well, this link between stigma, discrimination and social citizenship emerged once again. A group of people living with dementia ($n = 8$) met monthly for 16 months to discuss their experiences and advise on the curriculum of a proposed self-management program. From the first introduction, stigma was identified as a defining feature of the experience of living well with dementia. This paper analyses this group's talk around stigma and discrimination, drawing attention to the critical role that diagnostic disclosure has in both positioning people with dementia in a stigmatizing way and, also, acting as a strategy of resistance that facilitates full social citizenship.

Introduction

There is no question that a diagnosis of dementia—or major neurocognitive disorder as it is now known in the DSM 5—will represent a major life transition. However, it is also important to consider the extent to which difficulties and adjustments caused by the neuropathology are compounded by societal responses to the person with the diagnosis. Specifically, a growing body of research recognizes that at least some of the challenges faced by people with dementia are a result of the way they are treated within their broader socio-relational contexts (O'Connor et al., 2007).

When this broader lens is applied to understanding the dementia experience, stigma as a dominating feature of the experience is highlighted (Batsch & Mittelman, 2012; Milne, 2010; Swaffer, 2014). For example, Katsuno (2005) found that for people living with early onset dementia, subjective life satisfaction was mired not because of the functional declines associated with the dementia, but because of the stigma they encountered as a result of their diagnosis. These findings are, arguably, unsurprising: the dementia experience takes place within the context of an ageist and ableist society, and mental health issues—compared to physical issues—engender particularly strong fear.

Goffman (1963) defines stigma as a sign or mark that designates the possessor as “spoiled” and therefore as less valued than “normal”

people; it is “deeply discrediting” and reduces the bearer “from a whole and usual person to a tainted, discounted one” (p. 3). Benbow and Jolley (2012) extend this description to suggest that stigma includes three aspects: stereotypes (collective judgments about groups of people), prejudice (emotional reactions to a stereotyped person), and discrimination (behaviors that are associated with prejudice, including avoidance, coercion, and segregation). Through processes of labeling, stereotyping, separation, status loss, and discrimination, stigma results in creating an ‘us and them’ mentality that results in “othering” and exclusion of one group of people by another more powerful group (Link & Phelan, 2001, p. 367).

Within the context of dementia, stigma labels people with dementia by their diagnosis, with negative stereotypes of a loss of self and capabilities through the use of metaphors such as “the walking dead,” “zombies” or “empty shells” (Behuniak, 2011; Zimmermann, 2017). At a societal level dementia is portrayed as “a monstrous force that we must fight” (Zeilig, 2014, p. 265). Individual behaviors and actions then become interpreted through these negative stereotypes. Stigma can be externally imposed by others, but importantly, it can also be internalized, with the person feeling a sense of shame or being “less than” (Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu, Riley, Einhorn, Fitzsimmons, Hahn-Swanson, 2015; Burgener & Berger, 2008; Swaffer, 2014). Love (2016)

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referenced this as the “Pygmalion effect” wherein people with dementia may voluntarily begin to limit themselves as they respond to being treated with less respect and as if they were less competent.

As Mitchell, Dupuis, and Kontos (2013) wrote:

Once diagnosed with dementia, persons and their feelings, actions, and expressions become symptoms within a problematized field of possibility. If persons with dementia express feeling healthy and well, they are judged as being in denial. If they are having trouble remembering details but fill in the gaps to save face, they are said to be confabulating. If they get angry with the way in which health care workers are providing care, then they are labeled as aggressive and may end up being restrained and isolated (p. 4).

As a counterpoint to the focus on stigma, growing attention is being paid to the retention of social citizenship within the context of dementia (Bartlett & O'Connor, 2007; O'Connor & Nedlund, 2016). Specifically, stigma challenges the rights of each person with dementia to be accorded and treated as an active agent—or citizen—with rights, history and competencies. A social citizenship lens draws attention to how relationships and practices respond to the entitlement of every person with dementia to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible (Bartlett & O'Connor, 2010). This lens recognizes that social citizenship is both upheld, and challenged, through everyday relational practices.

One such everyday practice revolves around the diagnosis and disclosure of dementia. Over the past decade, there has been growing focus on the importance of earlier diagnosis, and research has examined how—or if—the person with dementia should be told. It is now relatively uncontroversial that, despite continued physician reluctance to disclose (Bamford et al., 2004; Milby, Murphy, & Winthrop, 2017), earlier diagnosis is beneficial to both the person with dementia and his or her family in helping them prepare for the condition (Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006; Prince, Bryce, & Ferri, 2011). Moreover, research suggests that people with the diagnosis generally want to be told the diagnosis (Mitchell, McCollum, & Monaghan, 2013; Waldemar et al., 2007) even though the receipt of the news can be viewed as a traumatic upheaval (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Milby et al., 2017).

To date, research examining diagnostic disclosure has largely been one-way—from the professional to the person with dementia. But what happens with the diagnosis once received? Little research has explored how diagnostic disclosure is used in the day-to-day lives of those living with dementia. In other words, how do people with dementia choose to disclose their diagnosis to others as they move through the dementia experience? The limited work that has examined this issue suggests that at least for some, there may be a tendency to conceal the diagnosis related to fear or experiences of stigma (Hellström & Torres, 2013). For example, Werner and Heinik (2008) found wide-spread concealment of diagnosis by family members because it was their belief that their relative would be treated pejoratively if the diagnosis were revealed to others: they found that 83% of family carers concealed from neighbours, almost half (49%) concealed from friends, and as many as 42% concealed from their children. Disturbingly, over one third did not disclose to their family physician and over two thirds reported concealing the diagnosis from a nurse and a social worker! This reluctance to disclose the diagnosis to others crosses many cultures. For example, examining the attitudes of lay persons for dementia-related stigma in Ethiopia, Adebisi, Fagbola, Olakehinde, and Ogunniyi (2016) found that at least one third of lay people would not disclose a diagnosis of dementia due to perceived stigma and discrimination that would result. This small body of research suggests the importance of better understanding how diagnostic disclosure—as an everyday practice—may be linked to stigma and living well with dementia. In particular, more insight into this process from the perspective of people with dementia is required (Swaffer, 2014).

Only one study was found that explicitly examined the decision to disclose information about diagnosis to others which included the perspective of those with dementia. Hellström and Torres (2013) interviewed 20 couples to better understand what couples living with dementia want to know and tell about the disease. While most wanted to know at least something about the diagnosis, there was more variability amongst the couples in relation to how much they wanted to tell others about the diagnosis. Often decisions to withhold information were based on the preferences of the person with dementia and could cause difficulties for the care partner. While this study recognizes some link between reluctance to tell others and stigma it does not explore this connection.

The purpose of this article is to extend understanding around the diagnostic disclosure process for people with dementia, considering it in relation to stigma, discrimination and social citizenship. Grounded in the experiences of people with dementia, this paper explores the importance of disclosure to others as a day-to-day practice that both facilitates the experience of discrimination and also offers a strategy for naming and resisting stigma.

Methodology

This study draws on data generated in the context of a larger study using participatory action research (PAR) methods to develop a self-management program for people living with dementia in Canada. To develop the self-management program, people with dementia were recruited to assist in the development of the program. Three site-specific advisory hubs consisting of people with dementia and—in two situations—their family members, were formed in different parts of Canada. These individuals were recruited from the research team's connections with various other projects and initiatives, as well as through connections with local organizations who provided services and support for people with dementia. The advisory groups were tasked with providing ongoing input into the content and process of program development. This paper will draw primarily on data from one of these advisory groups—the only group composed entirely of people with dementia.

This group had 8 members volunteer to participate (2 women and 6 men), all with a diagnosis of some type of dementia. Their age range was between 57 and 82 and the time since diagnosis ranged between 4 years to over 11 years. Three members were diagnosed with young onset dementia. Two of the members were unmarried – one lived alone and the other provided care to her aging parents. The remaining six individuals were married (one since his diagnosis) and living with their partners in the community. Several had university degrees or specialized technical training and had held professional positions prior to receiving their diagnosis.

The group met monthly for 16 months for approximately 90 min each session. Initially, group meetings were loosely structured around the question: What do people with dementia need to know to ‘live well’ with dementia? Typically, one of the research team members facilitated the conversation, with a research assistant taking field notes. As the process progressed, meetings became more focused on developing and clarifying emerging topics and themes, and examining how these could be translated into a self-management education program. All meetings were audio-taped with field notes taken immediately following the sessions. Tapes were transcribed verbatim.

Early in the process, the experience of stigma and discrimination emerged as a key experience in this group. Much of the conversation around stigma was initially fluid and spontaneous, but as the group process unfolded, facilitator prompts helped develop, refine and clarify the emerging understanding. All of the advisory group members actively participated in these discussions.

We then drew on the theoretical lens of social citizenship to help structure a focused analysis of the transcripts and field notes. This was done with the understanding that this lens offers a viable approach for

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