Ageing & Society **39**, 2019, 1436–1458. © Cambridge University Press 2018
doi:10.1017/S0144686X18000089

The narrative self in rural dementia: a case study from eastern Nova Scotia

RILEY CHISHOLM* and KATHERINE BISCHOPING†

ABSTRACT
This analysis examines how the narrative self of a person with dementia is maintained by family members in a small rural Nova Scotian community. In the literature, the expectation is often that rurality is a condition of isolation, distance from family and limited health resources. However, drawing on three years of ethnographic and interviewing research with a large extended family whose patriarch, Alexander, is a person with dementia, we demonstrate how a community's rurality influences interpretations of dementia. In Alexander's rurality, of particular import are local definitions of belonging, which privilege intimate knowledge of local history, working as a farmer to shape the land, and being of Scottish descent and male. As family members find Alexander's belonging to come into question in their community, we show them to employ narratives in which he is valorised for continuing to uphold local values – of 'usefulness' and of 'being the land'. We show how the family members must also revisit and revise these narratives when Alexander's belonging is further called into question outside the family setting and, specifically, at the local farmer's market, where Alexander is often no longer greeted by other marketgoers. The men and women of the family arrive at different interpretations of this development, with the women considering marketgoers to demean and dehumanise Alexander, while the men feel that the marketgoers are avoiding interactions that would embarrass him. Such disagreements reveal the ongoing emotional labour of creating narratives that lack closure, certainty and consensus, as well as ways in which gender and rurality operate intersectionally in the process of meaning-making.

KEY WORDS – dementia, identity, rural, family, narrative.

Introduction

Our inquiry is set in a close-knit extended family, living in seven households near a small community in the forest and farmland of eastern Nova Scotia, Canada. Our research is motivated by the diagnosis of dementia that one of

* Department of Sociology, St. Francis Xavier University, Antigonish, Nova Scotia, Canada.
† Department of Sociology, York University, Toronto, Canada.

this family's older members, a man whom we will call Alexander, had received two years before we write. Alexander's family members, like so many others discussed in the dementia literature (Adams 2000; Dunham and Cannon 2008; Eustache *et al.* 2013; Goldsteen *et al.* 2007; Harris and Keady 2009; Hinton and Levkoff 1999; Orona 1990), dread that, as his memory loss progresses, he will lose his sense of self. Indeed, Alexander, who no longer communicates verbally, has already had to relinquish many of the identities that had formerly mattered to his sense of self, *e.g.* he can no longer hold paid employment. Our analysis closely examines the narratives that family members produce in response to the encroachments of Alexander's memory loss. Our thesis is that the rural setting is no mere backdrop to these narratives, but is instead intrinsic to the ways in which Alexander's self, especially including his gender identity, is reproduced by family members, post-diagnosis.

To make this claim, we situate our project in relation to literatures on the social and narrative character of the self, on illness narratives, and on the significance of rurality to dementia. We draw, first, on the legacy of social theorists who maintain that the self, however bounded and individual it may seem, is socially constructed. These theorists include Mead (1934: 172), who defined self-consciousness as a state of seeing oneself as an object through relations with others, and Goffman ([1955] 2010, 1963), who alerts us to how particular identities are possible only within social contexts and are grounded in intersubjective processes of recognition. We also draw on a conception of everyday storytelling as a key means of socially constructing, sustaining and revising the self on an ongoing basis (Bamberg and Georgakopoulou 2008; Berger and Luckmann 1966; Chandler, Lalonde and Sokol 2000; Ezzy 1998). Illness, as Bury (1982: 167) observes, is a powerful form of 'biographical disruption'. Scholars from Frank (1995) onward have demonstrated how powerfully narratives work to construct the meanings of illness and new identities associated with it; narratives not only explain the past development of an illness, but also agentically project the self into a future whose emplotment may variously be hopeful, questing, desperate, absurdist, ambivalent and more (*e.g.* Ezzy 2000; Kelly and Dickinson 1997; Whitehead 2006).

Many forms of dementia are challenging not only because they are chronic, progressive and presently irreversible, but also because of how they specifically alter an individual's capacities to use language, to formulate narrative and to recollect the past. Because one's control of memory is commonly understood to demonstrate and legitimise one's autonomy (Post 1995), it in turn is increasingly, and problematically, used as a measure of personhood (Kitwood 1997). To the insights of social theorists who have established the fundamentally social nature of the self, we thus add

Baldwin's (2008) recognition that the very notion of the self also has a political dimension. As he explains, selfhood is 'dependent upon, social relationships and everyday activities [through which the self is] inextricably linked to the concept and practice of citizenship' (Baldwin 2008: 224). Baldwin's (2008) narrative citizenship approach foregrounds issues such as social inclusion, power and justice for those living with dementia, challenging the dominant discourse which holds that their selfhoods are diminished or non-existent. Relatedly, narratives are expressions of people's *relationality* – the specific ways that individuals narrate their connections and give meaning to the people and places around them (Herron and Rosenberg 2017). In this conception, what matters is how the members of the family we studied are agentively involved in making their particular rural life meaningful.

With this in mind, we also point to how the biographical disruption (Bury 1982) particular to dementia means that those experiencing dementia come to rely on the narrative work of *others* in order to define, strengthen or weaken their social identities (Sabat, Napolitano and Fath 2004). In this respect, meaningful others and particularly family members become importantly involved in discursively locating the person with dementia, as a valued subject with the associated rights, protections and social connections of full personhood. Accordingly, households, families, professional care-givers and communities become all the more implicated in doing – by commission or omission – social and political identity work associated with dementia. For instance, studying how people experiencing dementia write autobiographies (*i.e.* craft extended stories of their selves), Basting (2003) showed that for people living with dementia, their social networks maintain the integrity of their selves and narratives by carrying out work such as editing, co-authoring and even chapter-writing. Meanwhile, fine-grained linguistic analyses have pointed to ways in which care-givers could better detect and support the traces of self-narration capacity in persons whose dementia is quite advanced (Hamilton 2008; Hydén and Örulv 2009).

The socially constructed meanings of spaces also play an essential part in scaffolding the narrative citizenship and sense of belonging of people experiencing dementia (Clarke and Bailey 2016). However, when dementia and dementia care-giving are studied in rural contexts, the focus has largely been on the challenges of providing specialised health-care services to widely dispersed populations (*e.g.* Damme and Ray-Degges 2016; Kaufman *et al.* 2010; Keefover *et al.* 1996; Morgan *et al.* 2002; Orpin *et al.* 2014). In such work, rurality risks becoming reduced to a quantitative measure of population density and, as Blackstock *et al.* (2006) point out, associated either with deficits, such as remoteness, isolation and poverty,

https://doi.org/10.1017/S0144686X18000089 Published online by Cambridge University Press

or with romantic ideals about nature. The effects are to reproduce rural stereotypes, and to overlook the multiple, intensely localised meanings that rurality may have, the ways in which rural life and the meanings of rural spaces can be textured by history, economy and culture (Philo, Parr and Burns 2003). For instance, we can contrast the rurality of the Arkansas Delta (Gerdner, Tripp-Reimer and Simpson 2002) to that of rural people living with dementia and care-givers in the rural Scottish Highlands (Blackstock *et al.* 2006) or in rural or urban countryside settings of Ontario (Herron and Rosenberg 2017). In the first of these settings, important influences on dementia care-giving and the meaning-making surrounding it include the legacy of slavery, poverty and the associated outmigration of youth, and the centrality of the church (Gerdner, Tripp-Reimer and Simpson 2002). In the second, clan-based kin networks and a cultural ethic of self-reliance play key roles (Blackstock *et al.* 2006). In the third, it was found that staunchly gendered rural identities can cause gender-neutral services to seem irrelevant or distasteful (Herron and Rosenberg 2017).

In the case study that we offer, we will show none of the assumptions common about dementia in rural settings to hold: while Alexander is working class, we would not describe him as poor, he is not isolated from his family, he was diagnosed swiftly and he has reasonable access to specialised health care. Instead, as we will show, in the versions of rurality we were offered by our study participants, a core antagonism of dementia is that it poses a moral (Durkheim [1895] 1982) threat to the community's sense of belonging, which is reckoned in our research setting in relation to the capacity to locate one's self within generations of kin. Second, we will demonstrate that, in response, Alexander's family members produce narratives about his dementia identity that seek to establish him as continuing to uphold values important in his rural context, and these values are often grounded in locally endorsed gendered identities. Finally, we will show how the family interprets the challenges to these gendered narratives that arise during Alexander's visits to the local market, a key site of rural publicity.

Methods

Our data come from a three-year period of fieldwork set in Gillisburn,[1] a village-like community in eastern Nova Scotia, an Atlantic province that boasts a distinct history of fishing, forestry, coal mining and agriculture. Nova Scotia is also one of the most rural provinces in Canada, with one of the highest proportions of older adults in the country and a per capita

https://doi.org/10.1017/S0144686X18000089 Published online by Cambridge University Press

prevalence of dementia that is also comparatively high. Currently, an estimated 15,275 Nova Scotians have Alzheimer's disease or another dementia, and many of them reside in rural and remote locations (Government of Nova Scotia, Department of Health and Wellness 2014). Population ageing and youth out-migration are significant demographic trends in comparison to other provinces (Harling Stalker and Phyne 2014). Finally, within Canada, the Atlantic region has the highest reported sense of community belonging (Shields 2008), although youth, single people and parents there tend to report lower levels (Kitchen, Williams and Chowhan 2012: 122).

Located some 20 kilometres from the town we will call Pictou (population 4,700), Gillisburn is inhabited by descendants of Gladys and Johnny Gillis, whose ancestors are traceable to the 14th-century residents of the Isle of Skye, Scotland. The approximately 1,000-acre farm holds seven households, with a total of 13 adult residents and 12 children, almost all related by birth or marriage. The exceptions were co-author Chisholm and her daughter: during the fieldwork, Chisholm was the domestic partner of a Gillis son, and she and her daughter were living with him and his two children.

This research, comprising both interviewing and ethnography, was approved by the ethics board of St. Francis Xavier University. Chisholm conducted semi-structured interviews with ten individual adult family members, and with three groups of adult family members. Each of the interviews were digitally recorded and then transcribed, verbatim. However, in several instances, follow-up questions were taken up over the phone and during family gatherings, or even incidental moments such as at the communal garbage bin. Interviews were conducted in the living rooms and kitchens of homes on the farm, including Chisholm's home. The length of interviews ranged from 40 minutes to 3 hours and 30 minutes.

The person at the centre of this analysis, Alexander himself, was unable to be interviewed. We take seriously that people living with dementia are too often disenfranchised in dementia research, in part because they are regarded as unlikely participants (Beard and Fox 2008). Some dementia researchers have successfully employed participatory methods such as Photovoice and TalkingMats to read 'the body as a generative source of agency', or what Kontos (2012) has referred to as 'embodied selfhood', in contexts where participants' verbal and/or written communication options are limited. In our own study, Alexander's diagnosis of Frontal Temporal Dementia with Primary Progressive Aphasia is distinguished from other types of dementia in terms of the way it affects the ability to speak and conduct other executive functions. At the start of our study, we were not able to ascertain whether Alexander would give informed consent to be interviewed because he no longer spoke, wrote or gestured. His wife, Judy, granted consent to perform observational research, but

declined consenting to an interview. She explains, 'It would be really unlike him, whether before or after he got dementia, to talk about himself like that. He's spent his whole life making this farm. That's his expression. He's a farmer. Go look at his farm and that's *his* way of telling people about himself' (Judy). Such reflections and observations about the farm as standing in for Alexander's self came to be very significant to our analysis.

Although interviews were an important part of the data, the project is more fully described as an ethnography, a method capable of illuminating how human behaviours and attitudes, meaning-making and narratives are produced in relation to their context and culture (*e.g.* Hinder and Greenhalgh 2012; Schoenberg *et al.* 2005). Chisholm took part in the everyday life of the family in Gillisburn, being in direct, daily contact with other households there, and participating in family functions, regular Friday night dinners, family photos, birthday parties, visits to hospitalised family members, funerals and wakes. She also took part in public events in Pictou, most significantly, the weekly farmer's market. These experiences were recorded in a field diary and augmented with examination of photographs, maps, genealogies and census reports. As will become plain, our analysis was underpinned by the ways in which the narratives coming forward in the interviews were associated with the broader social context.

Although 'intimate insider' (Taylor 2011) researchers can sometimes become the objects of suspicion and distrust (*e.g.* DeLyser 2001; Irwin 2006), Chisholm found her experiences to be more like those of Foster (2009): during several interviews, participants indicated that they had shared more with her because they regarded her as a 'trusted researcher'. Because Chisholm had been participating in the everyday life on the farm before the research began, we were concerned that study participants, despite having given informed consent, would not always be mindful of the fact that Chisholm was conducting research. Therefore, following Parker's (2007: 248–9) advice, in the first few weeks of conducting ethnography and when sensitive topics came up thereafter, Chisholm made sure to raise ethics issues with the participants.

At the same time as Chisholm felt accepted as a family member-researcher, that she had lived in Nova Scotia for only seven years meant that, in the language of eastern Canadian provinces, she was irrevocably marked as a 'Come-from-Away' (CFA), a term our analysis will discuss. For Chisholm, to have come from away was to be seen as urban, not oriented to tradition and perhaps even a touch exotic. The rurality she experienced in Gillisburn and its surrounds contrasted not only with the largely urban settings of her adulthood, but also with the more affluent and comparatively transient rural setting in which she had passed much of her childhood in British Columbia. Chisholm's ongoing interest in familiarising herself with local

practices, networks and histories meant that she was attuned to how these might shape her participants' senses of self and identity. This, in turn, would become a central theme of the analysis.

As ethnographers develop theory in their capacities as both insider and outsider, Chisholm moved between the roles of privileged in-group member and naïve stranger. Her intimacy with the research participants and her immersion in Gillis family life initially led her to give more weight to her 'emic' or insider perspective; as Forsythe (1999: 138) explains, 'insider ethnography takes local meanings at face value overlooking tacit assumptions rather than questioning them'. In particular, although Chisholm is ordinarily an ardent social constructionist, she initially tended to interpret some of the interview data as 'real', as opposed to 'constructed'.

Bischoping, on the other hand, lives in Toronto, has visited Pictou only four times, has never seen Gillisburn and has met only one of the Gillises; she brought unambiguously etic or outsider perspective to the study, one that could permit her to 'maximise the position of strangeness and not to take for granted what a member of the community would consider unremarkable' (Morgan-Trimmer and Wood 2016: 8). In the tradition of researchers concerned with how acts of narration can aid those struggling to make sense of hard circumstances (*e.g.* Frank 1995; Sinding and Aronson 2003), she read the interview data with an eye to the emotion work that they entailed and to their affective consequences. This, too, would become central to the analysis. Finally, Bischoping's role included conducting an 11th individual interview with Chisholm as a participant. This meant, first, that in Wilkinson and Kitzinger's (2013: 253) terms, Chisholm's insider experience as a family member could be 'incorporated' into the research. Responding to Wilkinson and Kitzinger's (2013) caution that a researcher who is incorporated as a research participant risks overprivileging her own perspective in the analysis, Bischoping served as a counterbalance to that possibility.

The meaning and regulation of belonging in the Pictou area

The very existence of Gillisburn is a remarkable thing, when considered in the face of demographic trends towards regional unemployment, increased rural depopulation, a decrease in family size and greater spatial distance between family members, all of which mean that fewer people are living proximate to and therefore are less able to share resources, skills and support with kin (Commachio 1999: 32–47). The Gillises are unusual inasmuch as they have resisted these trends, capably maintaining an operational farm for over six generations. Through daily life on the farm and in

conversations and interviews with family members, it immediately became apparent that they value the abiding connection to the farmland and surrounding lands upon which they have lived. Indeed, the land was one of the most powerful elements of the dementia narratives that we collected.

Our exploration begins, as family members generally would, on the steps of the original farmhouse where Alexander's mother, Gladys, raised him and his 11 siblings. Although the house is quiet these days – only Alexander's brother lives there now – at one time it spilled over with people and activity, and it continues to be considered the centre of the farm. Two of Alexander's siblings live on the farm with their families while several others have homes just minutes away. All of Alexander's children have family homes on the farm and his 12 grandchildren, of ages 1–16 years, are often found cycling back and forth on the dirt road in front of the barns or playing in the brook that runs past their homes. For most of the year, a herd of Black Angus cows rotationally graze the 15 pastures across the farmland; or in extreme weather, are tucked into one of the two barns at the foot of Alexander's driveway. As in most of the Scottish farmsteads in the region, Alexander's house is perched far off the road. Set in the middle of a large pasture that is now mowed as lawn, it overlooks the impressive barnyard.

That this farmstead is understood to be 'Scottish' is no trivial matter. The Scots are but one of several groups that have figured in the history of Nova Scotia (*i.e.* New Scotland): Indigenous peoples, the descendants of French and English colonisers and of African slaves, and subsequent waves of immigrants also continue to shape the province. However, as McKay (1992) shows, through a cultural politics of tartanism emerging in the 1930s, the province is most often presented as Scottish in essence. Although the name of Pictou is Mi'kmaq in origin, Scottish culture is visible in Pictou in local Highland Games, Gaelic signage, step-dancing, kilt-wearing and ceremonial bagpiping. In the town of Pictou, Gillises, MacDonalds, MacNeils, MacGillivrays and a host of other 'Mac's take up the lion's share of the phone directory. Moreover, the local park is called Gillis Park, a Gillis cairn (a large pile of stones) in the middle of the town marks the existence of a clan in the area and the mayor of the town, at the time of writing, is also a Gillis, albeit of a different clan. The abundant ways in which the surname Gillis and other Scottish names are ensconced in the area indicates the degree to which the Gillises are understood to self-evidently 'belong' here.

The Gillis family's place here is symbolically coded as natural and their status as *from here* is never questioned. The query commonly posed by locals, 'Who's your father?', also manages the boundary between 'us and them' by privileging insider knowledge of such things as family names, kin networks and the intimate details of everyday social relations in the

area. It also locates the patriarchy as significant to understanding the local value system, in which tradition, masculinity, family and community are paramount. In the Pictou area, it is the identity of 'the Scottish farmer' that has come to capture these values.

In Chisholm's ethnographic work, she spoke with several family members who endorsed the idea that it takes 'several generations' for a family to be thought of as truly local. To be a Scottish farmer is to be deemed the most authentically local figure, surpassing others with local ties of similar duration. For example, although substantial numbers of Dutch farmers immigrated to the area in the 1920s, not long after the Scots, Dutchness continues to be exotified or suspect in the area. As a Gillis son explained, 'My great-grandfather hauled the milk every morning for the only two Dutch farmers in the area but for sure, he was the exception. Still today you get a lot of people saying, you know, "those fucking Dutch". I'm glad to say our family was never like that.' At the farthest extreme of the continuum of belonging is the 'Come-from-Away', a designation so commonly used that even its acronym, CFA, is readily intelligible to community members. The use of this term suggests a highly regulated border organised around notions of belonging and authenticity (*see* Baldacchino 2012). For instance, Chisholm's daughter complained one day that she did not want her surname, which is of Portuguese origin, to be used in public because she was being teased as a CFA at school. Her resistance to the label reflects her understanding, even at a young age, of how it locates her undesirably on the periphery of local social networks.

Dementia as a threat to rural belonging

As noted in our introduction, Alexander's family members were haunted by the commonly observed dread of dementia as a progressive loss of self, because they tacitly understood that identity categories do moral work (Durkheim [1895] 1982). For instance, Bob, a Gillis son, said of his father's participation in family interactions: 'It's not the same. There's less conversation. We all just sit together and there's not much conversation but he's not there.' In this rural context, one in which social relations are so highly regulated around notions of authenticity and belonging, signalling one's relationship among a network of names and places has an important moral function (Durkheim [1895] 1982). Recognising this, we can see the degree to which, in this rurality, dementia's effects on memory and language exceeds the threat to the individual self, and poses a broader, profoundly *moral* threat.

This is especially clear in relation to the following interview passage, in which Judy, Alexander's wife, gives insight into the heightened significance placed on memory of names and places in this locale:

> Yes, people here take places and names pretty seriously. Some people are more particular than others but everyone around knows people and families and you know, where events happened (pause) life is remembered like that. Like naming a baby. Here we name our kids after their ancestors. Daniel [one of her sons] is named after his uncle Daniel that died in a car crash and same with his middle name … Names and even places: they help us to know where we came from. And what's the saying, 'You don't know where you're going unless you know where you've come from?' Well here that's especially so, you know.

The capacity to recollect, to claim a status, to know your way around and to have intimate knowledge of the area is, as Judy suggests, 'serious'. To her and to other participants, names are not simply arbitrary but daily enact temporal links to ancestors, while geography is similarly sedimented with history. Together, they are part of knowing 'where you've come from', determining the capacity to know 'where you're going'. Although Judy is not speaking directly of Alexander's dementia in this passage, we can see from it how memory and recollection is relevant to how one signals a moral status in the community.

In this light, the way in which family members speak of the event that precipitated Alexander's diagnosis is especially telling. One winter afternoon, Alexander was doing his regular job of grading the back roads (*i.e.* using a heavy vehicle that levels out the potholes in gravel roads). The grader went off the road. Although Alexander was uninjured, when he used his mobile phone to call his colleagues at the dispatch at the Department of Transportation, he was unable to indicate his location. He was found because his colleagues were familiar with his usual route. Alexander's licence was taken away shortly after. In family members' emplotment of this event, the emphasis was not on any risk to Alexander of hypothermia or of using heavy machinery while not fully competent; even his going off the road was treated as a routine eventuality, given that local roads can easily lie beneath a foot or more of drifting snow. Rather, as Judy tells it, Alexander had been someone who 'knows the back roads like nobody else because he plowed them for what, now, 17 years'. The crisis was that 'he couldn't tell them where he was. And that just broke my heart. *He couldn't say where he was*' (Judy). In a Durkheimian reading of these comments (Durkheim [1895] 1982), Alexander's confusion, which signals a loss in his capacity to know 'where he has come from and where he is going', threatens the privileged, intimate relationship with 'people and places' that is the basis of moral currency in the area.

Narratives of belonging via the persistence of local values

The literature also offers many examples of persons living with dementia, family members, professional care-givers and academics who struggle to combat the dread of dementia, to construct narratives that are more hopeful and that emphasise the personal dignity and personhood of people living with dementia. Often, these narratives employ personal registers: for instance, we see this effort explicitly voiced in the statement of his daughter, Holly, that, 'As far as I'm concerned the mourning is over, like [it occurred in] the first four months [after the diagnosis] until we smartened up and learned to enjoy the time we have left with Dad.' At other times, these narratives underscore the resilience of certain social identities. For instance, Calasanti and Bowen (2006) found husbands caring for wives with dementia to speak of learning to apply cosmetics to their wives so as to sustain the gender identity they understood their wives to have held dear.

In response to the local significance accorded to memory and its association with community identity, we found members of the Gillis family to be working to co-produce narratives in which Alexander, despite his diagnosis, is positioned as continuing to be a morally upstanding member of his community, enduringly upholding local community values, norms and practices. Such narratives dominated the way in which family members spoke of Alexander. Of the several variants, we hone in on two that were most commonly referenced, and which show in two distinct ways the work of narration, of adapting to different circumstances and making meaning within them.

The 'usefulness' narrative

He never did housework but it's funny. He tries to do it now. But that's his sense of feeling useful. (Judy)

Before the diagnosis, as one of Alexander's sons-in-law recalled, 'Just like, he'd be The Guy up in Pictou East and any questions about things, he'd be the one to go see. He was the elder. You know, aside from his mother.' Alexander's disease has affected his capacity to contribute his leadership and knowhow – as 'The Guy' – to the local community, as well as to do the paid work of maintaining local roads. Within Gillisburn, he has ceased to participate in many of the activities that had formerly been habitual for him. He has lost interest in the machinery that he used to repair with ease, he no longer cuts wood or works in the potato garden, and, as one of his sons recounted in tears, he no longer seems to care about the cow barn. In narrating such developments, family members took pains to emphasise that Alexander had begun to contribute to family life in new ways. For

instance, his daughter spoke of how Alexander had taken to pulling her sunglasses from her face in order to clean them, setting out an end-of-workday beer for her husband and trying to do the laundry.

Gillisburn is not unusual among farm communities in having a division of labour in which men typically do more of the outdoor farm work, while women do more of the indoor work (*e.g.* Saugeres 2002). This division of labour has been linked to hegemonic masculinity, for example, by Morgan (1992) who points to how rural men's demonstrations of physical strength and manual skill are valued for enacting the overcoming of nature to make a living upon which *all* depend.

Thus, it would be quite possible for family members to emplot these developments in a way that emphasises solely that Alexander has *changed*. It would be in keeping with other research to find that family members and the people living with dementia alike notice that occupational identities decline in importance as the disease progresses (Cohen-Mansfield, Parpura-Gill and Golander 2006). However, the Gillis family members' narratives also emphasise that something has nonetheless *persisted* about Alexander: his adherence to a value spoken of as 'usefulness'.

To our research participants, usefulness is not simply a personal trait, but a social attribute with community-wide moral consequences. The ignominy of uselessness was expressed quite bluntly by a Gillis son, Daniel, as he spoke with Chisholm a week after he had been kicked in the knee by a cow, sustaining a serious injury:

Chisholm: You sure get upset when you can't work.

Daniel: Well, around here if you aren't being useful, what good are you? Papa always used to give us a hard time if we were leaning up against the barn waiting for the milkers to be finished on the cows. 'You don't need to hold that wall up, it's been up since 1969', he'd say. We'd lean against the concrete wall behind the cows but that's the most you could get away with. You'd never sit (pause). Yeah, I hate this. I hate sitting here and being useless.

As the Gillises articulate it, to be 'useful' is associated with belonging. It is positioned as such through contrasts to other values that might appear superficially similar, such as having an overruling work ethic or seeking to acquire wealth. We see this in Daniel's explanation that, 'It's not just about making money or you know, working all the time. For people around here, we have always worked *together* so it's about contributing and being seen to be, you know, helping out and not just sitting here being a plug.' Daniel thus aligns usefulness with the valued local culture of 'people around here'. His younger brother, Jacob, goes further in aligning it with the category with the most privileged claim to belonging, that of the male Scottish farmer:

Dad's always worked hard and well, he's a farmer and a Scotsman so he's like the rest around here. Work hard, drink hard, then work some more (laughs). But seriously, we were never rich or anything but everybody pitches in. Dad was you know, the leader in directing how things would be done. He was handy and knew how things worked and he was the one who steered the ship and got things done.

By this logic, the family narratives of Alexander's continued striving to be useful position him as persisting in being valued by his community, as belonging in the most favourable terms possible.

However, the 'usefulness' narrative can be seen to have a provisional element. Daniel speaks frankly of his concern that his father 'feels useful and can still do this because I know that is really important to him to feel, you know, *useful*. I think as long as he knows he can do things, he'll feel like he's still okay'. However, as Judy observes, Alexander's efforts to do housework are waning: 'He does laundry and he puts a sock and towel and stuff in and empties the dishwasher once in a dog's age. It's almost like he was trying to do things but now it's stopping. He felt things needed to be done but he's kind of losing it.'

The 'he is this land' narrative

If you want to know who Papa is, look all around you. He is this place. (Holly)

In the face of this uncertainty, one of the most powerful narratives the Gillises have constructed asserts that Alexander possesses an essential self that transcends any impact of dementia. Family members employ local cultural, geographic and historical cues to affirm this self, saying, for example, 'this land is him' and 'he is this place'. They point to innumerable examples, for instance to 'Papa's barns', or to the deck in which 'there must be a thousand screws now down there … you know, that he's put in'.

This emplotment works, in part, by positioning concrete evidence of Alexander's essence as a valued alternative to the ordinary use of ephemeral conversation as a means of expressing identity. Further, as our participants uniformly interpreted it, that Alexander is increasingly silent is not a symptom of his dementia identity, but naturalised: as Holly explains, it's 'ordinary because he's, he's never been a big talker'. As she proceeds, Holly transforms this comparative silence from an individual and ordinary personality trait to a social and even desirable one, saying

and I guess you could say that's the Scottish way about him. You know, you persevere and (pause) there's a stoicism there. So, he doesn't *need* to speak for us to know that he's all around us and more than anybody *he is this land* (pause). Nothing, nobody needs to say that, it just is.

Along with our own study, Parr, Philo and Burns (2004) have also found that stoicism is gendered in rural contexts, suggesting it is broadly understood as an expression of valued rural masculinity. (Later in our findings, however, we will show that this narrative, in which Alexander's silence is normalised, falters when it is taken from the family setting of Gillisburn into the farmer's market of Pictou.)

A narrative of Alexander's connection to the land responds to the ways in which Alexander's belonging in the community is threatened by his silence. For instance, Daniel explains:

> Scottishness is totally about land. They came over and they farmed, you know, and that's how they lived was working the land. If you are Scottish and live here, you come from an agricultural family for sure and it's likely your father was some kind of farmer. Dad is pretty much a purebred. If you have grown up out in the County, who you are (pause) – well, it's all about the land. I mean we've been farming for six generations so the land, yeah, it's *everything*.

Here, Daniel establishes the uncontroversial nature of the claim that his father persists in having a culturally valued identity, and in fact embodies a cultural ideal. He does this most notably through an 'earth and blood' (Saugeres 2002: 373) discourse, structuring Alexander's 'purebred' Scottish essence as synonymous with, and 'all about the land', which holds deep cultural value to anyone who has 'grown up out in [Pictou] County'. References to Scottishness, local geography and historical kin connections again establish and protect Alexander's membership in a privileged category, in implicit contrast to the peripheral, landless, ahistorical CFAs and others along the local continuum of belonging.

Finally, the narrative of Alexander's deep ties to the land projects his self and its present-day, concrete manifestations into a future in which he can be abidingly and positively remembered. As Daniel continues, he explains that 'the land' is a significant local memory resource: 'Working the land and having a relationship with it: over time a family gets known for that, that connection to their land. And that's why it's, you know, O'Hare's Mountain and Isabel's[2] and (pause) those people are remembered in the land.' Although collective memory scholarship has made much of monuments and museums as sites of remembrance, landscapes have newly been garnering attention for the role they play (*e.g.* Giles-Vernick 2001; Green and Green 2009; Krupnik *et al.* 2010).

The fragility of belonging narratives in the face of rural publicity

The narratives that we have seen thus far provide family members with bases for belief in the continuity of Alexander's self and dignified personhood,

https://doi.org/10.1017/S0144686X18000089 Published online by Cambridge University Press

and for hope that Alexander will continue to be held in warm regard for his contiguity with local values. We have also seen that these bases do not come automatically. The narrators are aware of anomalies that they must account for, such as Alexander's new housework activities, the wane in these activities and his silence. They struggle with the uncertainties of how the disease will progress. However, the greatest threat to the family members' work of sustaining Alexander's self arises when he leaves the farm, and enters public rural settings, specifically, say Angela (a daughter-in-law) and Judy, 'when we go in to town, you know, to the [farmer's] market or Tim Hortons.'[3]

To understand why, we will concentrate on the market setting and its local functions. For 17 years, Judy Gillis has been working at the Pictou farmer's market, selling her home-baked oatcakes, blueberry pies and her sister-in-law's brown sugar fudge. Every Saturday, from eight in the morning to one in the afternoon, she and other community members congregate in the barn belonging to the 4-H, a global network of youth organisations that aim to connect education to rural life through hands-on learning. Although Alexander has long played an integral role in helping his wife load, transport and sell her goods, following his dementia diagnosis, he decreasingly helps to sell at the market. Concerned about the possibility of his wandering, Judy arranges for another family member to pick him up about an hour after the market opens.

Having both spent time at the market as customers, and in co-author Chisholm's case, as a vendor of seasonal vegetables and handmade chocolate truffles, we both have a sense of this context's social intensity and concentrated publicity. To co-author Bischoping's touristic eyes, the market first appeared as a site in which to sigh over quilts that would be too big for her suitcase or to assess seaweed-infused salt as a curiosity for her Toronto 'foodie' friends. However, through conversation with Chisholm, it quickly became apparent that market goods were suffused with local meanings. For instance, the quilt that Bischoping succumbed to buying turned out to have been made by Chisholm's new partner's ex-wife's mother; to locals, it would be self-evident that such a purchase would be awkward. The seaweed-infused salt was from a Buddhist farm, started by Vietnam draft-dodgers from the United States of America, in other words, by CFAs of a particular provenance. In sum, the flow of goods through the market is not solely an economic activity, but part of the currency of affects and knowledges of the local social network. Ordinary use objects become *aide-mémoires*, embodying the social network in its absence (*see* Radley 1990); food from the network's land is incorporated into the bodies of the network's members. Accordingly, the market has an important

role in a day-to-day sedimentation of land, bodies, memories and values in Pictou and its surrounds.

Finally, the market is where the state of relationships becomes public knowledge. Thus, for example, Bischoping noticed Chisholm become endearingly anxious about going to the market after she had been on a few dates with a Gillis son, knowing that his family would be forming their first impressions of her there. Because the community is so closely knit, most of the people at the market tend know one another, meaning that interactions – or deliberate non-interactions – are acutely visible. As several family members mentioned, marketgoers sometimes do not greet Alexander, though they greet others in the Gillis family. Because the meaning of this non-interaction differed considerably between women and men in the family, we will discuss each in turn.

Each of the women in the family – Judy, Holly, Angela, Megan, Veronica and Chisholm herself – echoed the view that it was important that people be 'talking to [Alexander] and not ignoring him or treating him like, like he's not there or something' (Holly). For Angela, 'what gets me the most' is 'when people who know Alexander, just, they just see him and they turn away like he's not even a person anymore'. As Judy explained:

> I can see people are mostly good but sometimes you know, I can see and everyone can see when they ignore Alexander and (crying) I don't know why they do that to him. I, just, it hurts me so much. It breaks me, my heart.

In the women's view, these marketgoers are adding insult to the injury of ignoring Alexander by so publicly announcing that he lacks the personhood to warrant being addressed. Their view is like that of social scientists who would speak of Alexander, at these junctures, as being shunned (Williams 2007) or treated as 'socially dead' (Basting 2003; Bauman 1992; Sudnow 1967; Sweeting and Gilhooly 1997). In this interpretation, such incidents tear at the fabric of the family's comforting and familiar narratives of Alexander as a moral figure who upholds the values of his community. Thus, although the women might value the association of silence with hegemonic masculinity, they were not willing to defend this gendered narrative in the face of what they perceived was a more profound threat to his identity – the fact of his basic personhood. For the women, that Alexander is shunned in public especially disturbs the narrative that projects his presence in the land into the future in an enduringly positive way: if people turn away from Alexander, they are rejecting the claim that he is a contributor to their community, and imagining for him a different narrative, one that has already reached an irrevocably harsh finality.

The Gillis men interviewed – Bob, Daniel, Jacob, Josh and Andrew – also were concerned that Alexander was at times ignored in public settings.

However, what disturbed them most was the risk they felt Alexander ran when he was being publicly greeted. For example, Bob said:

> It doesn't make me happy to think people are doing that [ignoring Alexander] but the thing that actually gets me is why people talk to him and you know, make him feel uncomfortable because, he can't, he doesn't have the ability to communicate like he used to. And *that* I don't like. I wish people would actually leave the guy alone and not make him feel like he has to struggle to say things, you know, and embarrassing him … He can't show people he's still got it, you know, [is still] competent or whatever and that can't feel good to a guy. This is a guy who ran the whole show so, how's that going to feel if you can't even, um, carry on a simple conversation?

Both Jacob and Daniel likewise regard efforts by others to engage publicly as potentially difficult for Alexander. As Jacob puts it, 'I like it when people say hi but, they don't need to make a big thing of it because I don't think he really can do that stuff anymore.' Daniel, too, narrates a view that sees public communication as a possible threat to Alexander's already fragile 'presentation of self' (Goffman [1955] 2010). As he explains:

> Yeah, I know it bugs Holly and Mom but I think Dad really finds it hard to communicate with people in town (pause) if everyone came up to him who saw him and tried to engage him, that would be hard for him. If Dad wants to talk to somebody, he will. He likes to say hi and keep going and that's it. People should just leave him alone and let him be.

The men's interpretations of interaction echo those of conversation analysts from Sacks (1995) onward, who have observed that the adjacency pair structures of ordinary conversation render accountable a person who does not respond to a greeting with a greeting or a question with an answer. When other marketgoers initiate conversation with Alexander, they risk making his dementia identity salient as the account for why he may not reply. The Gillis men are proposing that it should be incumbent on community members to discern what Alexander can competently accomplish, and to permit him to take the interactional lead, to 'say hi and keep going'. Although we have shown the discourse of hegemonic masculinity to generally inform both the women's and the men's narratives about Alexander's persistent embodiment of local values, such as silence, when market interactions are in question, this discourse appears more salient to the men. That is, they seem more alert to the risk that interpersonal interaction will threaten Alexander's reputation for competence and his status as 'a guy who ran the whole show', whereas the women of the family are more concerned about the harms of social disconnection.[4]

Finally, we observe that the men's answers at times show that they are aware that their understandings of Alexander's market experience differ from those of women in the family; Daniel, for instance, contrasts his views to those of his sister, Holly, and his mother, Judy. The women are

likewise painfully aware that their narratives of Alexander's personhood differ from those of some other marketgoers. Here, as elsewhere, following from Ayres' (2000) and Pals' (2006) reasoning, the family members' awareness that their narratives are not certainties, so much as provisional interpretations that may not reach consensus or closure, itself contributes to the emotional labour of ongoingly narrating Alexander's self.

Conclusion

As we are not interested in reproducing a *general* theory of the rural, we were fascinated to explore what this setting could tell us about the intersections among rurality, gender and dementia in the construction of selfhood. One of the contributions of this paper is to further those of works such as Gerdner, Tripp-Reimer and Simpson (2002) and Blackstock *et al.* (2006), which show how the rural contexts in which dementia and dementia caregiving may be experienced are far from uniform, and far from reducible to 'low population density' and the concomitant challenges of specialised service provision. The rural, for instance, cannot simply be conceived of as a discrete space but, ever-increasingly, may be experienced in connection to other rural or even urban settings (Herron and Rosenberg 2017: 82). Accounting for these different scales and sites of rurality allows for a focus on how dementia narratives express socially organised relations, shaped particularly in accordance with the gendered social identities considered valuable to a certain people and place. Specifically, we have shown that how the rurality of the Pictou region shapes the experience of dementia is inflected with significantly gendered meanings. In the context of our study, the identity of a male, white Scottish farmer is constructed as privileged, in contradistinction to women, CFAs and other Others.

But this position is not without its contradictions: most apparently, the men and women do not hold on to this narrative in the same way. Alexander's diminished ability to participate in the local memory culture, as well as his silence, are viewed particularly by women family members as a threat to his narrative self, these identities and the extent to which he is understood to belong to his community.[5] In response, Alexander's family members draw on discursive resources specific to their rurality, producing narratives about how he continues to subscribe to the value of 'usefulness' and about how his essential self persists through the marks he has left upon the land. The women position Alexander's silence as underscoring an identity related to his privileged pre-dementia status, but also as threatening to his essential personhood.

Our claims about the specificity of narrative meaning-making in the Pictou region, and about the rarity of Alexander's village-like family setting, have

https://doi.org/10.1017/S0144686X18000089 Published online by Cambridge University Press

been our entryway into discovering the significance of gender to the experience of dementia and the challenges to personhood it presents, in this context. From this, we imagine that other people living in other social contexts might also engage heavily with their own regional and cultural gender scripts – or that social class, age or sexuality might equally surface as relevant in their construction of dementia narratives. Alexander's family struggles with how dementia has toppled him from a position of privilege within a community where he had been 'The Guy', employing gender narratives as a social and political resource, to attribute dignity, citizenship and personhood to him. How then do other, more marginalised families, those of CFAs, of Indigenous peoples, non-farmers or those in other locales accomplish this identity work? What are the discursive resources on which they draw?

Acknowledgements

We wish to thank our interview participants, as well as the two anonymous referees for their thoughtful comments and suggestions on the paper. We also thank the Faculty of Liberal Arts and Professional Studies, York University, and the Social Sciences and Humanities Research Council of Canada for conference travel support to KB. Ethical approval for interviews was granted by the St. Francis University's Research Ethics Board. All participants gave informed consent. Both RC and KB contributed equally to the research, with the division of labour as described in the body of the paper. There are no conflicts of interest.

NOTES

1 The names of people, communities and towns have been altered.
2 'Isabel's' is the name given to a pasture nearest the old farmstead. Notably, it is the only woman's name used to reference place on the farm.
3 This is a national coffee chain and the only significant one in the region. Although our focus is on the farmer's market, as it is most related to the particularities of belonging in this rurality, Cormack (2008) has shown that Tim Hortons is remarkably powerfully associated with a national sense of belonging.
4 Our earlier study of men and women with panic disorder analogously found men to consider threats to their place in social hierarchies to incite panic attacks, while women considered a sense of detachment from others to incite their attacks (Olstead (now Chisholm) and Bischoping 2012).
5 It is possible that the stigma of dementia or lack of information about it in this context may have delayed Alexander's diagnosis. Although family members recalled changes in Alexander's behaviour pre-diagnosis, such as his taking all of his sick days or refusing to work in foul weather, they described mentally summing these changes up as 'strange for him' and did not recall speculating about the possibility of dementia. His status within his family and within the local community may have made such speculation threatening.

References

Adams, T. 2000. The discursive construction of identity by community psychiatric nurses and family members caring for people with dementia. *Journal of Advanced Nursing*, **32**, 4, 791–8.

Ayres, L. 2000. Narratives of family caregiving: four story types. *Research in Nursing & Health*, **23**, 6, 359–71.

Baldacchino, G. 2012. Come visit, but don't overstay: critiquing a welcoming society. *International Journal of Culture, Tourism and Hospitality Research*, **6**, 2, 145–53.

Baldwin, C. 2008. Narrative, citizenship and dementia: the personal and the political. *Journal of Aging Studies*, **22**, 3, 222–8.

Bamberg, M. and Georgakopoulou, A. 2008. Small stories as a new perspective in narrative and identity analysis. *Text & Talk*, **28**, 3, 377–96.

Basting, A. D. 2003. *Forget Memory: Creating Better Lives for People with Dementia*. Johns Hopkins University Press, Baltimore, Maryland.

Bauman, Z. 1992. *Morality, Immorality and Other Life Strategies*. Stanford University Press, Stanford, California.

Beard, R. L. and Fox, P. J. 2008. Resisting social disenfranchisement: negotiating collective identities and everyday life with memory loss. *Social Science & Medicine*, **66**, 7, 1509–20.

Berger, P. and Luckmann, T. 1966. *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Anchor Books, New York.

Blackstock, K. L., Innes, A., Cox, S., Smith, A. and Mason, A. 2006. Living with dementia in rural and remote Scotland: diverse experiences of people with dementia and their carers. *Journal of Rural Studies*, **22**, 2, 161–76.

Bury, M. 1982. Chronic illness as biographical disruption. *Sociology of Health & Illness*, **4**, 2, 167–82.

Calasanti, T. and Bowen, M. E. 2006. Spousal caregiving and crossing gender boundaries: maintaining gendered identities. *Journal of Aging Studies*, **20**, 3, 253–63.

Chandler, M., Lalonde, C. and Sokol, B. W. 2000. Continuities of selfhood in the face of radical developmental and cultural change. In Nucci, L., Sax, G. and Turiel, E. (eds), *Culture, Thought and Development*. Lawrence Erlbaum, Mahwah, New Jersey, 65–84.

Clarke, C. L. and Bailey, C. 2016. Narrative citizenship, resilience and inclusion with dementia: on the inside or on the outside of physical and social places. *Dementia*, **15**, 3, 434–52.

Cohen-Mansfield, J., Parpura-Gill, A. and Golander, H. 2006. Salience of self-identity roles in persons with dementia: differences in perceptions among elderly persons, family members and caregivers. *Social Science & Medicine*, **62**, 3, 745–57.

Commachio, C. 1999. *The Infinite Bonds of Family: Domesticity in Canada. 1850–1940*. University of Toronto Press, Toronto

Cormack, P. 2008. 'True stories' of Canada: Tim Hortons and the branding of national identity. *Cultural Sociology*, **2**, 3, 369–84.

Damme, M. J. and Ray-Degges, S. 2016. A qualitative study on home modification of rural caregivers for people with dementia. *Journal of Housing for the Elderly*, **30**, 1, 88–105.

DeLyser, D. 2001. 'Do you really live here?' Thoughts on insider research. *Geographical Review*, **91**, 12, 441–53.

Dunham, C. C. and Cannon, J. H. 2008. 'They're still in control enough to be in control': paradox of power in dementia caregiving. *Journal of Aging Studies*, **22**, 1, 43–53.

Durkheim, É. [1895] 1982. *The Rules of Sociological Method and Selected Texts on Sociology and its Method*. Lukes, S. (ed.), Halls, W. D. (trans.). Free Press, New York.
Eustache, M., Laisney, M., Juskenaite, A., Letortu, O., Platel, H., Eustache, F. and Desgranges, B. 2013. Sense of identity in advanced Alzheimer's dementia: a cognitive dissociation between sameness and selfhood? *Conscious Cognition*, **22**, 4, 1456–67.
Ezzy, D. 1998. Theorizing narrative identity. *The Sociological Quarterly*, **39**, 2, 239–52.
Ezzy, D. 2000. Illness narratives: time, hope and HIV. *Social Science & Medicine*, **50**, 5, 605–17.
Forsythe, D. 1999. 'It's just a matter of Common Sense': ethnography as invisible work'. *Computer Supported Cooperative Work (CSCW)*, **8**, 1/2, 127–45.
Foster, J. 2009. Insider research with family members who have a member living with rare cancer. *International Journal of Qualitative Methods*, **8**, 4, 16–26.
Frank, A. W. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. University of Chicago Press, Chicago.
Giles-Vernick, T. 2001. Lives, histories and sites of recollection. In White, L., Miescher, S. and Cohen, D. W. (eds), *African Words, African Voices: Critical Practices in Oral History*. Indiana University Press, Indianapolis, 194–213.
Goffman, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster, New York.
Goffman, E. [1955] 2010. On face-work. In Lemert, C. (ed.), *Social Theory: The Multicultural Readings*. Westview Press, Philadelphia, 338–43.
Goldsteen, M., Abma, T., Oeseburg, B., Verkerk, M., Verhey, F. and Widdershoven, G. 2007. What is it to be a daughter? Identities under pressure in dementia care. *Bioethics*, **21**, 1, 1–12.
Government of Nova Scotia, Department of Health and Wellness 2014. *Toward Understanding – Informing Nova Scotia Dementia Strategy*. Available online at http://novascotia.ca/dhw/dementia/Towards-Understanding-Informing-Nova-Scotias-Dementia-Strategy.pdf. Accessed January 23, 2017.
Green, L. J. and Green, D. R. 2009. Space, time, and story tracks: contemporary practices of topographic memory in the Palikur Territory of Arukwa, Amapá, Brazil. *Ethnohistory*, **56**, 1, 163–85.
Hamilton, H. 2008. Narrative as snapshot: glimpses into the past in Alzheimer's discourse. *Narrative Inquiry*, **18**, 1, 53–82.
Harling Stalker, L. and Phyne, J. 2014. The social impact of out-migration: a case study from rural and small town Nova Scotia, Canada. *Journal of Rural and Community Development*, **9**, 3, 203–26.
Harris, P. and Keady, J. 2009. Selfhood in younger onset dementia: transitions and testimonies. *Aging and Mental Health*, **13**, 3, 437–44.
Herron, R. V. and Rosenberg, M. W. 2017. 'Not there yet:' examining community support from the perspective of people with dementia and their partners in care. *Social Science & Medicine*, **173**, 81–7.
Hinder, S. and Greenhalgh, T. 2012. 'This does my head in': ethnographic study of self-management by people with diabetes. *BMC Health Services Research*, **12**, 83, 1–16.
Hinton, W. L. and Levkoff, S. 1999. Constructing Alzheimer's: narratives of lost identities, confusion and loneliness in old age. *Culture, Medicine and Psychiatry*, **23**, 4, 453–75.
Hydén, L.-C. and Örulv, L. 2009. Narrative and identity in Alzheimer's disease: a case study. *Journal of Aging Studies*, **23**, 4, 205–14.
Irwin, K. 2006. Into the dark heart of ethnography: the lived ethics and inequality of intimate field relationships. *Qualitative Sociology*, **29**, 2, 155–75.

Kaufman, A., Kosberg, J., Leeper, J. and Tang, M. 2010. Social support, caregiver burden, and life satisfaction in a sample of rural African American and white caregivers of older persons with dementia. *Journal of Gerontological Social Work*, **53**, 3, 251–69.
Keefover, R., Rankin, E., Keyl, P., Wells, J., Martin, J. and Shaw, J. 1996. Dementing illnesses in rural populations: the need for research and challenges confronting investigators. *Journal of Rural Research*, **12**, 3, 176–81.
Kelly, M. P. and Dickinson, H. 1997. The narrative self in autobiographical accounts of illness. *The Sociological Review*, **45**, 2, 254–78.
Kitchen, P., Williams, A. and Chowhan, J. 2012. Sense of community belonging and health in Canada: a regional analysis. *Social Indicators Research*, **107**, 1, 103–26.
Kitwood, T. 1997. *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham, UK.
Krupnik, I., Aporta, C., Gearheard, S., Laidler, G. J. and Holm, L. K. (eds) 2010. *SIKU: Knowing Our Ice*. Springer, Dordrecht, The Netherlands.
McKay, I. 1992. Tartanism triumphant: the construction of Scottishness in Nova Scotia, 1933–1954. *Acadiensis*, **21**, 2, 5–47.
Mead, G. 1934. *Mind, Self, and Society*. Morris, C. (ed.). University of Chicago Press, Chicago.
Morgan, D. 1992. *Discovering Men*. Routledge, London.
Morgan, D., Semchuck, K., Stewart, N. and D'Arcy, C. 2002. Rural families caring for a relative with dementia: barriers to use of formal services. *Social Science and Medicine*, **55**, 7, 1129–42.
Morgan-Trimmer, S. and Wood, F. 2016. Ethnographic methods for process evaluations of complex behaviour interventions. *Trials*, **17**, 232, 1–11.
Olstead (now Chisholm), R. and Bischoping, K. 2012. Men, masculinities and constructions of self in panic discourse. *Journal of Men's Studies*, **20**, 3, 274–86.
Orona, C. 1990. Temporality and identity loss due to Alzheimer's disease. *Social Science & Medicine*, **30**, 11, 1247–56.
Orpin, P., Stirling, C., Hetherington, S. and Robinson, A. 2014. Rural dementia carers: formal and informal sources of support. *Ageing & Society*, **34**, 2, 185–208.
Pals, J. L. 2006. Authoring a second chance in life: emotion and transformational processing within narrative identity. *Research in Human Development*, **3**, 2/3, 101–20.
Parker, M. 2007. Ethnography/ethics. *Social Science & Medicine*, **65**, 11, 2248–59.
Parr, H., Philo, C. and Burns, N. 2004. Social geographies of rural mental health: experiencing inclusions and exclusions. *Transactions of the Institute of British Geographers*, **29**, 4, 401–19.
Philo, C. Parr, H. and Burns, N. 2003. Rural madness: a geographical reading and critique of the rural mental health literature. *Journal of Rural Studies*, **19**, 3, 259–81.
Post, S. 1995. Alzheimer's disease and the 'then' self. *Kennedy Institute of Ethics Journal*, **5**, 4, 307–21.
Radley, A. 1990. Artefacts, memory and a sense of the past. In Middleton, D. and Edward, D. (eds), *Collective Remembering*. Sage, London, 46–59.
Sabat, S., Napolitano, L. and Fath, H. 2004. Barriers to the construction of a valued social identity: a case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, **19**, 3, 177–85.
Sacks, H. 1995. *Lectures on Conversation*. Volume 2, Jefferson, G. (ed.). Wiley-Blackwell, New York.
Saugeres, L. 2002. The cultural representation of the farming landscape: masculinity, power and nature. *Journal of Rural Studies*, **18**, 4, 373–84.
Schoenberg, N., Drew, E., Stoller, E. and Kart, C. 2005. Situating stress: lessons from lay discourses on diabetes. *Medical Anthropology Quarterly*, **19**, 2, 171–93.

Shields, M. 2008. Community belonging and self-perceived health. *Health Reports*, **19**, 2, 51–60.
Sinding, C. and Aronson, J. 2003. Exposing failures, unsettling accommodations: Tensions in interview practice. *Qualitative Research*, **3**, 1, 95–117.
Sudnow, D. 1967. *Passing On: The Social Organization of Dying*. Prentice-Hall, Upper Saddle River, New Jersey.
Sweeting, H. and Gilhooly, M. 1997. Dementia and the phenomenon of social death. *Sociology of Health & Illness*, **19**, 1, 93–117.
Taylor, J. 2011. The intimate insider: negotiating the ethics of friendship when doing insider research. *Qualitative Research*, **11**, 1, 3–22.
Whitehead, L. C. 2006. Quest, chaos and restitution: living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine*, **62**, 9, 2236–45.
Wilkinson, S. and Kitzinger, C. 2013. Representing our own experience: issues in 'insider' research. *Psychology of Women Quarterly*, **37**, 2, 251–5.
Williams, K. 2007. Ostracism: the kiss of social death. *Social and Personality Psychology Compass*, **1**, 1, 236–7.

Accepted 5 January 2018; first published online 6 March 2018

Address for correspondence:
Riley Chisholm,
Department of Sociology,
110C Annex Building, PO Box 5000,
St. Francis Xavier University,
Antigonish, Nova Scotia, B2 G 2W5, Canada

E-mail: Rchishol@stfx.ca