

I'M JUST STRAIGHT-UP DEMENTED: AN EXPLORATION OF DEMENTIA IN FICTION

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INTRODUCTION

Whether known as 'medical humanities,' 'arts and health' or 'arts and medicine,' these terms all refer to a collaborative relationship between an art form (such as poetry, fiction, dance, theatre, or visual arts) and health, in its broadest sense. Much has been written on the benefits of the arts in the education of health professionals and on the value of the humanities to gerontology (Falcus, 2014). Such an approach encourages nurses, doctors, allied health professionals and others to view the world and, more specifically, the world of their patients, from a wider and more holistic perspective than the one which is more evident and accessible in everyday life. The critical thinking associated with examining fictional narratives can challenge assumptions (Zeilig, 2011). This paper presents the results of a broad study of fiction and ageing and examines how people with dementia are represented in two selected works of fiction, where one of the main characters has a dementia.

LITERATURE REVIEW

One of the purposes of studying older people, ageing and old age in fiction and, specifically in this paper, the portrayal of dementia in literature, is to introduce these concepts to nurses from a different perspective to the usual health science-based perspectives on assessment, diagnosis and treatment, and to encourage their engagement with the works. How do writers portray characters with a dementia? What are they saying about them and the context they are placing them in? What do they want the readers' response to be? How does their portrayal fit with your experience of dementia? Zeilig (2011) writes that 'narrative, literary and critical gerontology all share an ability to confront (rather than shirk) the ambiguities and complexities of age, ageing and later life and an interest in quizzing the cultural norms of ageing via non-scientific forms of knowing' (p. 9).

For a long time, nursing has been considered as both a science *and* an art, a concept that Carper (1978) examined in her pivotal work on 'ways of knowing.' Her thesis acknowledges that no one approach to learning or knowledge is superior to another; but that multiple forms of knowledge are necessary to provide holistic care. Zeilig (2011, p. 9) adds that narrative and the literary gerontology of ageing 'quiz the cultural norms of ageing via non-scientific forms of knowing.' Nurses and other health professionals who are exposed to stories or fictional narratives gain the opportunity to learn of other ways of being, seeing old people as humans outside of the health system encounter.

Care of older people and people with dementia is not a popular field of study or work for New Zealand health workers – and yet most have contact with older people, a reality which will be increasingly the case into the future. Ethical reflection, aesthetic and empathetic factors are the rationale most often given by scholars for studying literature and medicine. Health professionals often encounter challenging clinical situations which require ethical debriefing and reflection. Macnaughton (2011, p. 938) believes that 'there is a sign that research in medical humanities has the potential to mount a persuasive challenge to medicine's ways of teaching, working and finding out.'

METHODS

Rationale for selecting fiction for analysis

It is now well recognised, in New Zealand and globally, that as the population ages, so does the incidence of dementia. In response to this, a growing body of literature, both fiction and non-fiction, is being published. In New Zealand in the last two years alone, at least three significant books have been published on the topic: a collection of poetry about a grandmother with dementia (Breslin, 2017); a self-help book giving advice to both professional and family carers on how to communicate with someone with dementia (Caughey, 2018); and a daughter's memoir of her mother with dementia (Desmond, 2018). Memoirs, essays, blogs, journalism, children's literature, thrillers, fiction, poetry and plays on the subject are proliferating, commenting on and perhaps helping to make sense of events and responses when someone the authors know or have observed has dementia. These writings come from a variety of sources: adult children, carers, professional writers, journalists and people who have dementia themselves; and they address a wide range of subject matter including communication, grief, strategies for coping and 'management' of dementia, early-onset dementia and institutionalised care.

A key criterion for the wider study I undertook was to examine selected works of fiction and poetry only; non-fiction was excluded. Material was sourced from book reviews, by word of mouth from a network of readers, and the researcher's own reading. Various databases were searched (Medicine and Literature, CINAHL, Google Search) to inform the background literature review. Although the wider study examined ten literary works, for the purposes of this paper, only two novels are investigated.

It may be asked what is the rationale for exploring fiction, as opposed to other forms of writing on dementia. The characters in the novels chosen for analysis constitute a creative response to people who are living with dementia, experiencing everyday life with their families and others in their personal worlds and communities; they are simply getting through their days and, as readers, we walk alongside them. Good fiction does not judge, preach or tell the reader how to think about the narrative situation – rather, it leaves the thinking, reflection and interpretation up to the readers themselves. Fictional characters may seek answers from science, as non-fiction sources often do, but it is not the role of fiction to preach or explain, but rather to leave readers to make up their own minds and perhaps leave them with a range of thoughts, questions and emotions ripe for discussion and with the satisfaction of having listened to a skilled, authentic voice. As Hepworth (2000, p. 1) wrote of his own studies on fiction and ageing, 'readers explore fiction as an imaginative resource for understanding variations in the meaning of the experience of ageing in society.' He wrote of the value of 'spaces being opened up by creative licence' (p. 5). Fiction writers have a different impetus for choosing their subject matter. In the novel *Elizabeth is Missing* (Healey, 2014), for example, the protagonist Maud, who has dementia, is loosely based on the author's grandmothers. The combination of creative distance and keen observation works well as Healey employs the literary device of having Maud narrate her own story, from her own perspective.

The two novels to be examined in this paper are *We are not Ourselves* by Matthew Thomas (2014) and *Goodbye, Vitamin* by Rachel Khong (2017), utilising the theoretical framework outlined below. Both novels are by American authors and were published within the last five years. They have many parallels in terms of plot: the characters with dementia are male, in their 50s, university professors in mid-career, living with spouses and children. Despite my wider study being focussed on older people and fiction, the two key characters examined in this paper have early-onset dementia.

Theoretical framework

According to O'Connor and Nedlund (2016), the way in which dementia is viewed by society has passed through four distinct stages (see Table 1): firstly, as a sign of natural ageing; secondly, as primarily a biomedical condition; thirdly, there has been a shift to seeing the person beyond the medical condition; and, most recently, embedding

the dementia discourse within socio-political discourses and practice. This fourth step introduces the language of citizenship and a move away from the individual experience of dementia to an emphasis on how people's experiences are shaped by socio-cultural practices and assumptions. In examining this new lens through which to view dementia, O'Connor and Nedlund state that 'the personal is political' (p. 285) and argue that new possibilities of people living well with dementia are being opened up through 'inclusionary practices' (ibid).

| THE FOUR DISTINCT STAGES OF DEMENTIA: |
|---|
| 1. A sign of natural ageing |
| 2. Seen primarily as a biomedical condition, disease focus |
| 3. A shift to seeing the person beyond the medical condition; person-centered care |
| 4. Embedding the dementia discourse within socio-political discourses and practice; citizenship focus |

Table 1: *The Four Stages of Dementia*, O'Connor and Nedlund, 2016, p.285

Analysis

A combination of content and literary analysis is employed in this study to identify key themes in the two fictional works under consideration. Content analysis, as utilised in qualitative research, refers to the analysis of the themes and patterns that emerge in the narrative content, an approach often used when the study claims no particular methodological or disciplinary roots, as in the current study (Polit and Beck, 2017). Literary analysis investigates authors' creative approach to their narratives – how they formulate plot, characters and chronology, and the devices they use to render their work interesting, readable and believable.

One aim of my research is to examine how the selected novels align with O'Connor and Nedlund's (2016) framework, which outlines the ways in which dementia has been thought about, made sense of, and researched over recent years in both the health setting and in the wider society. A second aim is to argue the case for utilising fiction in the teaching or professional development of health professionals – how fiction can be made accessible and relevant to their clinical practice and ongoing learning.

Synopsis and literary approach of the novels

The first novel to be examined, Matthew Thomas's *We are not Ourselves*, is narrated in the third person, and primarily tells the story of Eileen, who is married to Ed, a 51-year-old American college professor. As the novel progresses, the reader learns that all is not well, and it is eventually revealed that Ed has dementia. From the time of their marriage, Eileen, a nurse and mother of one son, has been an ambitious person; she wants more for the family – a new house, a new neighbourhood, status, social recognition. As the reality of Ed's dementia unfolds and changes in his behaviour and cognition become more and more apparent, Eileen's feelings for Ed and the situation they find themselves in fluctuate wildly. One day – moment even – she wants one thing, and then a moment later, another. Her thoughts and feelings constantly swirl in a contradictory, ambivalent, shifting pattern. She is by turns frustrated, appalled, compassionate and loving. Her former ambitions fade as she and her son spend more and more time attending to Ed's needs.

Goodbye, Vitamin, by Rachel Khong, is narrated in the first person by Ruth, the 30-year-old daughter of middle-aged parents. She has come home for Christmas, fresh from a relationship break-up, to spend time with her parents, and ends up staying for a year at her mother's behest. Her help is needed to care for her father, Howard, who has dementia, and whose unpredictable behaviour and actions require someone to be near him all day. Her mother is still working and is no longer prepared to stay home, as she needs a break from Howard. Ruth's story-telling point of view is often very funny and, although her dry and witty sense of humour is due partly to her age and personality, it is also a way of coping with the situation she finds herself in. The use of humour in her narrative does not mean that the novel shrinks from showing the underlying sadness and pathos of the family's situation.

Although the two novels have similar premises – a family in turmoil as they care for a loved one with a dementia – the authors have adopted very different styles and tones to impart their story to the reader. At 620 pages, *We are not Ourselves* is epic in both length and time span (1951-2011), in the events covered and the characters' gradual life changes. It captures the subtleties and confusions of living with someone whose personality and behaviour is very different from their former selves (hence the title), and the family's gradual realisation of these changes which grow increasingly harder to bear and come to terms with. The narrative does not gloss over the challenges and dramatic incidents experienced, and the reader is drawn into the family's decline, which is chronicled day by day.

In contrast, *Goodbye, Vitamin* is relatively short (198 pages) and covers a single year (Christmas to Christmas) in the life of the Young family. It is written in the form of a diary (kept by daughter Ruth) and thus appears more piecemeal, random and spontaneous on the page than a 'standard' plot-driven novel. The adoption of the diary form is enhanced by the age and preoccupations of its young protagonist – her friendships, romances, ex-lovers and preoccupations are equally covered alongside her almost daily accounts of her father's life. A delightful writerly technique is the inclusion in the narrative of her father's diary, kept when Ruth was a little girl. He puts up small excerpts on post-it notes around the house, in a kind of reciprocity to her contemporary diary-keeping of him.

RESULTS

Thematic analysis of the two novels resulted in the identification of three major themes: naming or not naming (diagnosis); conflict and ambivalence; and the adoption of coping strategies and ways of keeping the dementia sufferer occupied. The explication of these themes, with supporting quotes, is presented in this section. I then explore these themes in relation to the dementia framework set out in Table 1 and discuss the relevance of these fictional themes for health professionals.

A. Naming ... or not naming (diagnosis).

The act of giving a name to an unexplained set of symptoms could be seen to be contributing to the pathologising or medicalising of a person's health situation. Much has been written on the complex issue of receiving a diagnosis (Jutel & Nettleton, 2011), and reactions vary from individual to individual and context to context. While a diagnosis may be spelled out by a medical practitioner, it is not always overtly acknowledged by name by the recipient of the diagnosis and their family or carers in precisely the same way – if at all. This is the case for both wife and carers in the two novels examined in this paper:

The dawning came all at once, though it felt as if it had been heading her way for a while, like a train she'd heard whistle from miles off that was now flying past and kicking up a terrible wind. Still, she couldn't pronounce the sentence in her head, Ed has ... because it was impossible that he had it. He had a demanding job that kept him stimulated. Until recently, he had read constantly, done the crossword puzzle almost every day, exercised four times a week ... maybe it was a tumour ... a glandular problem, a dietary deficiency, a failing organ. Whatever it was she would get it checked out ... She needed to find out if something was wrong with him. (*We are not Ourselves*, p. 309-10).

"Well, I have good news and bad news," Dr Khalifa said. "The good news is, physically, you're as healthy as a horse. A great specimen." She felt a jolt of excitement, then one of fear: "What about the bad news?" He turned to her: "The bad news is your husband likely has Alzheimer's." She gasped; Ed's hand in hers seized into a fist . . . "Are you sure?" she asked. "There's little doubt," the doctor said, with all the detached finality of one of those enormous computers in old movies that spat out answers on punch cards. "I knew it," Ed said grimly. She realized in an instant that he probably had known it, that he might have known it for years. "How can this be? He's barely 51." "It's early, but it happens," Dr Khalifa said. "I'm sorry." . . . It was so obvious now that he had Alzheimer's. The news felt old already somehow. (*We are not Ourselves*, p. 322-323)

These excerpts from *We are not Ourselves* reflect the gruelling process of learning a diagnosis. The novelist reveals that the diagnosis had been on Ed's mind and, unconsciously, on Eileen's too for some time ("The news already felt old somehow"). As often with disclosure of diagnoses, shock, disbelief and an extreme reaction set in, but this response can also be coupled with an innate, instinctive knowing, so that the diagnosis becomes a confirmation of what was already felt (Thomas likens it to a train approaching in Eileen's head). Despite this, denial and bargaining set in almost immediately: maybe it is something else? Eileen cannot bring herself to utter the word dementia and it is barely mentioned in the novel, apart from by the doctor.

In *Goodbye, Vitamin*, there is no revelation of the diagnosis in a doctor's clinic but, as in Thomas's novel, there is a reluctance to name (a non-naming) the condition on the part of the narrator's mother:

'Now Mom is asking if I could stay a while, to keep an extra eye on things. By 'things' she means Dad, whose mind is not what it used to be. It comes as a surprise. Things aren't so bad – Dad doesn't seem any different – on top of which, my mother hates to ask for anything. 'Just for the year' Mom repeats. (*Goodbye, Vitamin*, p. 4).

However, the similarity in 'naming avoidance' ends there. On the same page, the narrator of *Goodbye, Vitamin* tells the reader that 'there is, presently, no single test or scan that can diagnose dementia with complete accuracy . . . For now, it's a process of elimination . . . What my father doesn't have: hyperthyroidism, a kidney or liver disorder, an infection, a nutritional deficiency' . . . 'I'm just straight-up demented,' Dad says. (*Goodbye, Vitamin*, p. 4)

B. Conflict and ambivalence

Conflict is experienced by characters in both novels – those caring for their family members and those with dementia themselves. Such subtle and, at the same time, enormous changes in relationships and anticipated relationships create an internal, ambivalent form of conflict and turmoil in all concerned. For Eileen,

There had been times she'd wanted to kill Ed; now that he was declining so quickly, she just wanted him home until Christmas. It shocked her that her goals had dwindled to one, but that was all she could focus on, even now, eight months away from the holiday. Once Ed left, she knew, he was never coming back. (*We are not Ourselves*, p. 441)

At one point, Eileen tells us that she feels like a "widow whose husband is still alive." Once she comes to terms with Ed's decline, she wants to do everything for him she can – but this does not mean she doesn't mourn her former Ed. The contradictory changes in his personality are not lost on her either: She recognises that he "was being stripped of pride, of ego, ruined, destroyed. He was also being softened" (*We are not Ourselves*, p. 429).

At times the conflict is externalised and both male protagonists become irascible, aggressive and even physically violent at times. Ruth narrates an episode where she has cooked a dinner of pork chops and potatoes, a meal specifically requested by her father. But when she dishes up, he shouts at her, leaving her shaken and confused:

'He shouted that he wasn't a child and he knew what tomatoes were and that those were tomatoes, and that he was my father; and what was my problem, that I couldn't show him some respect. My first instinct was to put the steak knife away because I had never seen him like this, and because I was frightened. I put it in my back pocket. He saw what I had done with the knife, seemed insulted that I thought he might be dangerous, and took his plate and threw it against the wall. It shattered, on cue.' (Goodbye, Vitamin, p. 122).

C.Strategies / Occupation

The third theme deals with the ideas, plans and everyday expedients that family members come up with to cope with and manage the situation in which they find themselves and to help the person with dementia remain engaged and occupied – ways of adapting and changing routines or customary approaches in order to facilitate concomitant changes in the dementia sufferer.

In *Goodbye, Vitamin*, although Ruth's mother may not name her husband's diagnosis out loud, her on-line reading of the medical literature convinces her that 'it was the years of cooking in aluminum pots, cooking with canned goods, that led to dementia' (p. 14). As a mother who has enjoyed cooking and even making home-made popcorn for the movies, she now only trusts juices and vitamins. Ruth explains her mother's strategy to us: 'the house is virtually snackless. She's emptied the pantry of food she's deemed harmful. Everything is a potential cause of the disease. Cereals and breads contain sugar; and high blood sugar exacerbates the disease. Saturated fats raise the risk of the disease.' (Goodbye, Vitamin, p. 17). By avoiding certain foods, Ruth's mother believes she has developed a strategy to ameliorate the situation.

A key strategy which permeates the tone of *Goodbye, Vitamin*, albeit one which is never expressly 'applied' as such, is the use of humour. A sense of humour is a way of coping with the enormity of the various life and family challenges demanded, crises which occur on a daily basis. Humour is engrained in the collective psyche of the family. All four family members exhibit a dry and throwaway sense of humour which has always been part of the way they communicate with one another. At times, it could be read as black humour. The novel is peppered with throwaway lines such as Howard's comment on the lack of a precise explanation for his condition: 'I'm just straight-up demented' (Goodbye, Vitamin, p. 4).

This style of familial humour does not feature in the Tumulty family in *We are not Ourselves*. Halfway through the book, as she increasingly comes to terms with her husband's dementia, Eileen knows that she needs to strategise to cope with his inevitable deterioration. She visits the Alzheimer's Association 'to find out what kind of resources might be available' (*We are not Ourselves*, p. 349). The family lawyer advises her that one way of being able to afford nursing home fees would be to divorce Ed. While Eileen understands the logic of this, she finds it lacking in compassion and resigns herself to the fact that in order to pay for Ed's health care, she will have to 'work forever'. The novel gives accounts of a string of carers employed by Eileen to care for Ed at home while she works, none of which turns out successfully. Finally, Eileen implores her teenage son to stay with him during the day, an arrangement which also has disastrous results.

As a way of occupying her father's time and retaining his dignity, Ruth devises a plan, along with one of her father's students, to re-create 'history classes' which Howard will lead. She runs this idea past the dean, who is adamant that this is a safety issue and must not happen – if Howard turns up on campus, he will call the police. After some covert planning by Ruth and her friend, and with the blessing of her mother, the 'pretend' classes go ahead. They are held at different venues around the town and attended by 'ring-ins' or "enrolled students" – former graduate students who have always admired Howard's teaching and are prepared to go along with the plan. Her father dresses for the classes in an ironed shirt and a shiny tie; he parks in the university carpark and his students call him "Howard." The classes go well and Howard is able to carry out his work as he always did in the past: 'On the drive home, Dad

is chatty. He's happy, he's making plans. He wants to finish writing his book this month, he says. Maybe attend some conferences in the spring. "Sounds great, Dad," I say, as convincingly as I can' (*Goodbye, Vitamin*, p. 58).

DISCUSSION

Through the study of fiction of this kind, health professionals are given an invitation to experience a journey alongside a person with dementia and their family. In the two novels studied, the narrative is told from the sufferer's and their family's perspective, from deep within the family culture and its practices, as opposed to the 'outside' perspective of the health professional.

As discussed above, the understanding of dementia has shifted from being considered no more than a disease state to respecting the person with the condition, and ultimately has moved to the socio-political arena where dementia is viewed in broader terms and people with dementia are seen as co-citizens within society. New Zealand nurse researchers Gilmour and Brannelly (2009) describe a philosophical shift in thinking about dementia in nursing and medical discourses. They equally believe that the way dementia is viewed has progressed through the concepts of subalternity (disempowered or marginalised groups), personhood (respect, recognition and trust) to citizenship (the sufferer is a person with rights and responsibilities who is part of a community). Despite this shift, the authors believe that the 'historically dominant elite and authoritarian accounts of dementia' (p. 240) are still found in some nursing texts. This viewpoint deserves to be challenged, and such a challenge may well be reflected in fiction, short stories, poetry and the arts in general.

In what follows, the themes identified in this paper are discussed in relation to the dementia framework devised by O'Connor and Nedlund (2016) (Table 1).

Dementia as a sign of natural ageing

In the first stage of O'Connor and Nedlund's framework (2016), dementia is seen as a normal part of ageing. This certainly used to be the case, as 'senility' and 'senile dementia' were, at one time, common labels given to older people who were experiencing memory loss. While current medical thinking might acknowledge that some changes in memory and cognition occur as people age, dementia is certainly not seen as an inevitable or 'normal' consequence of growing older – nor is it in either of the novels studied here. The ageing aspect of dementia is particularly poignant in these novels as both sufferers are relatively young (in their early 50s) and both are well ensconced in mid-to-late academic careers. For this reason, the novels do not consider the ageing process (stage one of the framework) at all. In fact, in both novels the narrative begins with stage two, diagnosis.

In *We are not Ourselves*, the bold naming of the condition ('your husband likely has Alzheimers') comes from the health professional. The doctor reveals this by turning to Eileen and referring to Ed as 'your husband.' Immediately Ed is given a label and is not addressed directly, as if the diagnosis had nothing to do with him. Through this action he is marginalised, 'othered,' ignored – he is not one of them, and yet the diagnosis belongs to him.

Dementia as a biomedical condition

An emphasis on dementia as a biomedical condition is the second stage in the dementia framework. Although on one level the families in the novels seek a diagnosis and confirmation of what they already suspect, it is still a shock when the information is imparted as a stark, cold "detached finality," as Eileen learns (*We are not Ourselves*, p. 322). The families learn that certain behaviours, rather than a single-word diagnosis, need to be managed as they arise. Despite her reading about the 'plaques and tangles' in the brain that occur in Alzheimer's disease, on a day-to-day basis it is Ruth's relationship with her father which counts – the one she has always had and the new one they are establishing throughout the novel.

Person-centered dementia care

Tom Kitwood (1997) was the first researcher to coin the term 'person-centered care.' At the time, the concept of patient-led care was revolutionary – that the care tasks and lists of health professionals were of secondary importance and that 'one size does not fit all.' With the diagnosis confirmed, both fictional families move to the third stage of the framework, which represents a "shift to seeing the person beyond this," leading to "person-centered care." In reality, this means that both families move on, coping on an everyday basis insofar as the family context and their individual personalities and capabilities allow. This is new territory for them, as they have not felt the need to see their loved one beyond the parameters of a 'medical condition' before. On the one hand it is a straightforward task – but, in a flash, the person with dementia can change and suddenly seem like someone else, a person they do not know and have not met before. Thus 'person-centered care' can be challenging when the sufferer and their behaviour changes and strategies are required to move with the person, not against them. The characters in *Goodbye, Vitamin* perhaps demonstrate more 'successful' and resourceful ways of arranging things so that Howard can remain his 'own person,' utilising more flexible and creative strategies and a wider pool of support than Eileen and her son are able to muster in *We are not Ourselves*.

Dementia as a part of a socio-political discourse including citizenship

While a diagnosis of dementia is never received in a positive light (except that it may offer the relief of a confirmed hunch), viewing the condition in an entirely fatalistic sense contradicts the prevailing health policy doctrine and desired societal attitude. Today, the emphasis in government health strategy is on ageing well and dementia prevention and, if one has dementia, living positively and actively with the condition for as long as possible. In neither of our novels is the dementia discourse embedded within a political discourse (as per stage four of the framework), but social attitudes and discourses become evident through interaction with characters who sit outside of the main families. Stage four of the framework also embodies the notion of citizenship. In a sense, by setting up mock classes for Howard to teach in *Goodbye, Vitamin*, Ruth and others demonstrate respect for Howard as a person and a citizen, recognising that he still has a place in the wider social dynamic of work and useful occupation beyond the confines of the domestic scene. This most recent lens on dementia – a condition that an individual may have, but not one that ultimately defines them and how they live their lives – may appear more often in fiction as societal attitudes and care provision catch up with the theory of citizenship for all.

IMPLICATIONS FOR HEALTH PROFESSIONALS

This paper identifies the value of including fiction and the arts in general in the health professional curriculum. The portrayal of dementia in fiction has been used in this paper to present the lived experience of dementia from within the daily lifeworld of families struggling to come to terms with the unknown and learning how to live with a family member with the condition. Such insights into the domestic context of dementia could not be gained from clinical assessment alone. Fiction exposes an unfettered humanity which can inform and influence the health professional and help them see what a patient's reality may look like.

This paper creates an opening for discussion among health professionals on current attitudes and approaches towards dementia which arise from the intersection of the fictional narrative and recent dementia theory and health strategies.

CONCLUSION

It will be interesting to see if future novels having a central character with dementia embrace stage four; whereby the person is driving their own narrative (Emma Healey's *Elizabeth is Missing* has shades of this), their own decision-making and activity, and is viewed as belonging to a wider social community – rather than being focussed on a narrow, biomedical, understanding of 'care,' which is still the prevalent approach both in society and fiction. Although there is no 'right' or 'wrong' way to approach the realities of a person living with a dementia, the two novels discussed in this paper allow for consideration of three of the four stages of O'Connor and Nedlund's framework in relation to fiction, which in turn has the potential to expose health professionals to new ways of approaching health practices which start with the person at the centre.

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