

In this article...

- How fictional narrative can increase understanding of people with dementia
- How nurses can use this to increase empathy and improve their practice
- How fictional narrative can be incorporated into clinical supervision

Using fiction to increase empathy and understanding in dementia care

Key points

The arts in healthcare can be used to humanise the care process

Literary novels depicting experiences of dementia can increase understanding and empathy in the care of people with dementia

Reading fictional narrative to gain insights into the dementia journey can help nurses deliver better care

Fictional narrative used in clinical supervision and group support could help nurses explore their feelings and encourage an understanding of dementia

Nurses caring for people with dementia should consider fictional narrative as a key tool to improve their practice

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Abstract The creative arts can be used to help people connect with their fellow human beings to support good mental health and wellbeing. This article looks at the value of fictional narrative in helping nurses develop the qualities to deliver sensitive and compassionate dementia care. It uses examples of literary novels to show how fictional representations of dementia can help nurses understand the experience of the disease from the perspective of patients and their relatives to increase their empathy and understanding, and improve their practice in caring for patients who have dementia.

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I ncreasing understanding of the experience of dementia is crucial to providing high-quality care and meeting the dementia challenge of an ageing population. In the UK alone, over 200,000 new cases of dementia are reported each year (Matthews et al, 2016), but the nature of dementia often makes it difficult for nurses and others to understand the dementia experience.

This article looks at the value of fictional representations of dementia in literature in terms of improving understanding and empathy among nurses for the provision of high-quality dementia care. It also asks how literary fiction can be incorporated into nurses' reflective practice and how it might facilitate helping friends and family involved in the person's dementia journey. Using examples from literary fiction, it illustrates how reading fictional narratives about the experience of dementia can help nurses develop the qualities necessary for the delivery of sensitive and compassionate care.

There is a growing recognition that the arts can complement healthcare (Crawford et al, 2015), and that creative arts initiatives

can help people connect with their fellow human beings as an effective way of supporting mental health and wellbeing (Barker and Winship, 2016; Crawford et al, 2013). Literary fiction is an example of this, whereby, in the words of Clarke (2011), "novelists, in effect, invite their readers to places where storytelling can cast light on everyday affairs". An example of how fiction can help us enter the minds of people who cannot articulate how they feel is given in Paul Sayer's award-winning novel, *The Comforts of Madness* (Sayer, 1991). This account of Peter, a patient with a catatonic condition, shows how it is possible to demonstrate the inner feelings of a person through fictional narrative.

When Crawford and Baker (2009) suggested that literature can describe the "dense specificity of human experience", they include experiences that might be hard to comprehend, such as those of people with dementia, who can sometimes watch their cognitive ability fade. This process is often witnessed by their relatives and friends, who may have the distressing eventuality of no longer being recognised. So how does literary fiction help

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nurses improve their understanding and care of the person with dementia and support for informal carers and loved ones?

Developing empathy

Reading fiction helps people connect with their fellow human beings and can boost empathy (Bal and Veltkamp, 2013; Barras, 2013); it can also benefit nursing practice (Bladon, 2019). When explaining its dementia care philosophy, Dementia Care Matters – an organisation focused on effecting change in dementia care – refers to the importance of understanding subjective experience: “All of us live in our own reality. Joining someone in their reality, entering their bubble, is the only way to reach people” (Bit.ly/DementiaCare-Matters). Below, we consider some examples of literary fiction that can help carers to do this.

Samantha Harvey’s (2010) novel, *The Wilderness*, is a thought-provoking book, which deals with the journey of Jake, a man with dementia, who is aware of his deteriorating condition. At times, the writing style deliberately confuses the reader by mimicking the outward effect of the disease and providing a sense of increasing disorientation in the progress of Jake’s dementia. We see, for example, his gradual confusion: “the streets become a jail; he is lost. One street just looks like another”. Jake’s sense of time and place become increasingly confused, and Harvey makes use of metaphorical devices to convey the sense of his jumbled world.

Still Alice by Lisa Genova (2015) follows the deteriorating mental state of a university professor. Readers are given clues to the problem, so they are watching and recognising what is going on before Alice herself really appreciates what is happening. As the story progresses, Alice narrates her own decline, gradually losing the ability to use language and becoming more distant from what she knows to be herself and her identity. At one stage, she looks at herself in a mirror, to find the reflection “didn’t quite match the picture that she had of herself in her mind’s eye”. This reminds us of the crucial importance of helping people maintain their identity, which is a key feature of dementia care (Kitwood and Bredin, 1992).

Rieger (1994) says the fiction writer’s sensitivity to the inner landscape of characters’ minds allows a power of precision “unmatched by the more objective methods of psychological science”. Using fiction to connect with the inner feelings of those living with dementia allows carers

Box 1. Tips for reflection

- How did that book/story make you feel?
- What issues does the novel/story raise that you might need to consider?
- What improvements could you make to your practice after reading this text?

to develop the empathy necessary to support them, by vicariously sensing experiences that are frightening, anxiety provoking and even terrifying.

Fiction writers adopt certain techniques to convey these experiences, and Taylor (2015) points out that they often use an unreliable narrator to “destabilise an audience in a way that mimics the confusion of a character”. A good example is *Elizabeth is Missing* by Emma Healey (2014). Although essentially a crime novel, this book follows Maud, who is struggling with dementia, and her attempt to find her missing friend, Elizabeth. The jumble of days and the mixed images and thoughts are conveyed well to the reader, as Maud mixes up the disappearance of her friend with that of her sister when Maud was younger.



Healy manages to convey the anxiety, confusion and fear Maud experiences in the progress of her dementia. The mixing of the present and past provides a telling illustration of the confusion that must be felt by people with dementia. Maud says: “I forget things – I know that – but I’m not mad. Not yet. And I’m sick of being treated as if I am”. The pain and frustration of the disease filters through in the smallest details: “It’s such a little thing – knowing where to put cutlery – but I feel like I’ve failed an important test. A little piece of me is gone”.

Out of Mind by Bernlef (1988) is narrated in the first person, providing a troubling perspective on the subjective experience of dementia. The author manages to structure the disintegrated thinking of his narrator, Maarten, so his confusional difficulties are communicated to the reader. As in the examples already given, the way in which Bernlef portrays the memory problems and speech difficulties reminds carers of the need for patience, tolerance

and, perhaps crucially, the importance of allowing people time when they are having difficulty finding the words.

Reflective practice

Reflective practice is a key nursing skill (Oelofsen, 2012) and the kind of reading experiences described above are worth incorporating, as part of the process of lifelong learning and continuing personal and professional development (Bladon and Bladon, 2019). The process of reflection through fictional reading constitutes what Schön (1983) calls “reflection-on-action”; these learned skills can be used when delivering care, to represent another part of the process, that of “reflection-in-action”. Tips for reflection are given in Box 1.

Supporting patients’ relatives and friends

Reading fiction can help nurses in other ways, such as when supporting significant others. Relatives and friends of people with dementia often experience great emotional strain, and this is a recurrent feature in fictional dementia narratives. *Out of Mind* sensitively manages the shared experience of Maarten and his wife in coping with Maarten’s illness as they both age. In *Still Alice*, Alice herself is heard to apologise for her condition, and there are passages of heartfelt interaction between her and her husband, John.

Similarly, in *An Absent Mind*, by Eric Rill (2015), the protagonist, Saul, describes his Alzheimer’s as his “slow dance with death”. We see his sense of humour and his moments of lucidity, as well as his confusion, and also gain an understanding of the impact his disease has on those around him. Through his wife, Monique, we see the frustration and anger that relatives and friends can experience: “Saul may be the one with Alzheimer’s, but I’m the one suffering a long and miserable life”. We also see the compassion necessary to care for someone with dementia when Monique reflects on her situation and asks herself if she should have been “more appreciative of what we did have together”. She continues: “Sometimes I ask myself what gave me the right to judge him?”.

In *The Corrections*, Jonathan Franzen shows us how a wife and children cope with their once all-powerful pater familias. Alfred is reduced to dependency by his progressive cognitive impairment and there are passages where his confusion is witnessed by his wife, Enid: “He’d lost track of what he wanted, and since who a

person was what a person wanted, you could say that he'd lost track of himself". There is a point where the family are forced to move Alfred downstairs: "So in the house of the Lamberts, as in St Jude, as in the country as a whole, life came to be lived underground". Enid's reflection speaks of the changes and accommodations that people around the person with dementia sometimes have to make, showing how the disease can have an impact on many people, not just the individual who has dementia.

In *Rough Music*, by Patrick Gale (2000), a son and his brother share the guilt of placing their mother in a nursing home, an experience that has parallels in many real-life accounts written by family members (for example, Grant (2011)). In *Rough Music* there are two people dealing with a spouse with dementia, but they are doing so at different stages of the disease, which provides an interesting point of contrast. Sylvia, whose husband's dementia is at an advanced stage, writes to John, the other character in the novel also caring for a spouse living with dementia, warning: "double incontinence is a treat in store, along with irrational terrors, violent mood swings and the knowledge that your loved one is going somewhere you cannot follow". John is not put off and finds the information strangely comforting. This suggests how the impact of progression can be foreshadowed, and how the impact of that eventuality can be softened by support.

"Using fiction in clinical supervision and group support settings could enable participants to explore their feelings and encourage understanding of dementia"

Shared experience

Fiction is not just an aid to understanding, but can also be employed in other settings, such as in clinical supervision and group support, to allow participants to explore their feelings and encourage their understanding of dementia. Poetry used in a dementia care setting has been shown to stimulate service users and create connections with others (Sheppard, 2018); it is possible that fiction could be employed in the same way to help service users connect with both their professional and informal carers.



Having a better idea of the confusion people with dementia often experience can result in being able to offer more-empathic care

Conclusion

According to Oatley (2016), people who read fiction "improve their understanding of others". Although fictional depictions are not an exact record, good storytelling can give nurses an insight into how patients in their care are feeling. Examples from literature show how fictional representations of dementia can encourage empathy, aid understanding and humanise suffering, enabling carers to improve the support they give to people with dementia.

Nurses can also use such insights when supporting patients' friends and relatives as part of a holistic approach, which is consistent with best practice in dementia care. Nurses should, therefore, consider literary fiction as a key tool with which to improve their practice when contemplating good dementia care. **NT**

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