

FIELDS

Background

Harshini is a migrant from Kerala, South India. She is 34 and cares for her 76-year-old mother who has dementia. Dementia is a non-specific syndrome with varying effects upon memory and sensory motor control, depending upon which part of the brain has been affected. The disease has taken away Harshini's mother's memories, her awareness of the religious prescriptions that she lived by and her self-consciousness.

At times there are great difficulties for us. Although she is here, in her mind she always thought that she was back home. She was always talking about India. She would wake up early in the morning and tell me, "I'm going to the fields", and she would open the door and walk out and that was really scary. It happened a number of times that she had opened the door, walked out and got lost. On a couple of occasions we had to involve the police to find her. She had walked about two miles away from home. Then when I was away on holiday, my brother took the decision to put her into a care home because his family was finding it so difficult to look after her. He didn't ask me what I thought or what I wanted to do.

My mother, she was always a very religious person, without fail she would go to the temple and would do the puja daily, and even today although she is not aware of what she is doing with her hands, without a mala, her hands, her fingers are still working as if she is praying.

And the other thing is that she was always very strict about food. Food was not allowed from outside, even bread. Now she doesn't know what she is fed on. She doesn't know what she is eating. She just eats whatever is given to her in the care home. She finds it hard to express herself and without the language she is totally in her own world, totally shut down. Day by day she is getting weaker.

TUTOR GUIDE

This case story can be used to discuss the relationships between disease, culture and faith and to think about social pain with regard to the loss of personal and cultural identities. The discussion of neuroscience and social pain on the Case Stories website will help you with finding literature on research studies that have investigated the shared neural circuitry of social and physical pain.

You can also use the film 'Two Sighs' on the Case Stories website to discuss this story. Harshini's is the first story in the film.

Activity

Think about and/or discuss two main questions:

- What are some of the relationships between disease and cultural difference in Harshini's story?
- In what ways might social pain be a part of the story?

Disease, culture and faith

Increasing evidence suggests that neurology is continually being altered by social and cultural life but we know little about the dynamic mixing between biology and culture. Use 'Fields' to examine and to speculate about how disease might affect and be affected by cultural and faith differences at the end of life. Some interesting experiences in the story are:

- Prayer – notice how Harshini's mother seems to retain a religious practice from her past, in the passing of the (imagined) mala beads between her fingers. Some aspects of faith practice seem to be retained, despite other losses. Perhaps this was a religious practice that never relied upon rational/conscious thinking and therefore is affected in a different way by the type of dementia that Harshini's mother has?
- Wandering – is a common symptom of some forms of dementia, but notice here how migration becomes a part of the experience. When Harshini's mother wanders out from her home in the UK, thinking that she is entering into the fields of her village in India, different places and times become entangled. What might this reveal about experiences of dementia, loss and social pain for those who have migrated and their loved ones?
- Food – with eating in the care home, the difference between food that is religiously pure and that which is not have disappeared for Harshini's mother. One type of food corresponds to and stands-in for another. In the context of the wider story, what losses does this example suggest?

Questions about relationships

Identify and discuss different aspects of social pain for Harshini. These include:

- How the slow losses of personhood in dementia can emphasise a fragmenting of identity. For instance, the story articulates how Harshini's mother is not quite a Hindu, not quite in the present, not quite the mother that Harshini knew. How might such ambiguities affect the experience of loss?
- Related to the above question is how Harshini talks about her mother's dietary needs in the care home, where religious prescriptions were not observed. This neglect of Harshini's mother's religious practices also says something about Harshini's feelings about her brother's decision to admit their mother to a care home. With regard to the whole story, what might this example convey about matters of 'choice' for people with dementia and for some of their loved ones?
- Tensions in family relationships: How does Harshini talk about her brother's decision to admit their mother into a care home? What might Harshini be feeling about what happened? How could care professionals support Harshini and her brother?