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Care through digital connections

Enacting elder care through everyday information and communication technologies (ICTs) in Indian transnational families

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Publication date

2020

Document Version

Other version

License

Other

[Link to publication](#)

Citation for published version (APA):

Ahlin, T. (2020). *Care through digital connections: Enacting elder care through everyday information and communication technologies (ICTs) in Indian transnational families*. [Thesis, fully internal, Universiteit van Amsterdam].

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Chapter 5

DISRUPTED CONNECTIONS

On Participation in Caring for a Mother with Dementia

Keywords: aging, dementia, India, family, elderly care, care at a distance, transnational care collective, information and communication technologies (ICTs), global care chains, digital technology, family, transnationalism, migration, informal care

This chapter has been published as:

Ahlin, Tanja. 2019. "Disrupted connections: On participation in caring for a mother with dementia." *Somatosphere*. Published online April 2. <http://somatosphere.net/2019/disrupted-connections-on-participation-in-caring-for-a-mother-with-dementia.html>

For this thesis, I have edited the text style (font size and style, paragraph alignment) and I added one picture (Figure 6).

On a sunny, stifling afternoon, my friend, an Ayurvedic doctor, ushers me into a scantily furnished examining room of his clinic in central Kerala, South India. There, a small, stout woman sits on a chair. Her name is Mercy.¹ She is wearing a *sabhar kameez*, an outfit comprising of a long shirt, baggy pants and a scarf, rather than a sari, which would be more typical for a woman of her standing, senior and married with children. I try to dissolve the uneasiness of our impromptu meeting by smiling a lot as I go through the explanation of my research. Finally, she invites me to visit her home. She will cook dinner, she says, and I can meet her mother! I enthusiastically accept.

When I enter Mercy's house, I immediately meet her mother. A woman in her eighties, she is afflicted with severe dementia, diabetes and heart problems. She greets me, but doesn't seem interested in starting a conversation. So Mercy tells me her story in the kitchen, over steaming rice and vegetables frying in the pan.

Despite having five children, Mercy's widowed mother has found herself placeless in her old age. According to the conventional practice of elderly care in India, one of her three sons should take her into his home where his wife would cook for, feed and bathe her. Yet this is impossible in Mercy's mother's case: one son has cut all contact with her due to inheritance conflicts, the second son lives in another part of India, while the third son has moved to Europe. Mercy's mother does not want to relocate, having spent her whole life in Kerala. As Mercy herself is based in the US, her mother has had to move in with her other married daughter Rosa, who lives not far from the family's ancestral home. But this arrangement is in contradiction with the common social conventions – in India, parents are not supposed to stay with their daughters – a custom that Rosa's husband brings to the table day in, day out. Rosa, too, increasingly complains of the exhaustion of having to take care of a mother suffering from a progressive mental illness.

For Mercy and her brothers, displaced by migration, caring for their mother at a distance is next to impossible. Mercy's brother in Europe has offered financial help, but Rosa brushed his offer aside. Our mother needs somebody to feed her, by spoon, daily, and no amount of money could do that, Rosa reportedly said.

From the US, Mercy used to call her mother regularly, but phone calls have become increasingly difficult. How to talk on the phone with someone who has dementia and may not even remember having a daughter, let alone that she lives abroad? Mercy still calls, but ends up mostly talking to Rosa about their mother's condition. She has also currently taken their mother into her home while visiting Kerala for the winter. In this way, she is providing care not only for her mother, but also for Rosa, by offering her some respite from the caring tasks, if only for a short time.

But keeping their mother at home, Mercy's or Rosa's, is not a long-term solution. It simply cannot be sustained. The two daughters haven't the knowledge or skills, let alone the patience, to take care of somebody with dementia, Mercy asserts. As a nurse, Mercy is familiar with specialised care facilities and she approves of how elderly people are treated there.

"People are in a group and they teach them how to sit, eat, what to do ... It's good for them!" she says. "The nurses in these homes are trained properly, and they are paid for it so they should pay proper attention to these people."

So Mercy suggested to her siblings that they move their mother into a nursing home. And their reaction?

"They would kill me", Mercy says. "If we put our mother in a nursing home, they said, people would ask, how can this be, there are five children and no-one can take care of her?!"

It has to do with dignity, with them being 'good children', with their whole family being a 'good family'. In India, old age homes are thought of as being full of the most devastated, poor people, people who come from 'bad families' troubled by disagreements that lead to bruised, if not broken, relationships. From our conversation, it slowly emerges that Mercy and her siblings do indeed have a troubled relationship with their mother, with bitter memories that reach far back into their childhood. It seems that placing their mother in an old age home would bring these intimate tensions to the surface and make them visible to everyone around them.

The disagreement over the nursing home remains a painful point for the siblings. Mercy is refusing Rosa's and her brothers' calls because she is so angry with them. She has even declined their invitations to dinner, out of fear of not being able to hide her feelings of frustration over the issue.

Despite her siblings' protests, Mercy plans to visit a local nursing home. "But it's not only for my mother", she says. "I want to see it for myself, too." Her plans for the future are uncertain. What will happen to her once her husband, many years her senior, passes away? She doesn't want to be a burden on either of her two daughters who are creating their own lives abroad. And yet, clearing the dishes from the table, Mercy says quietly, "Maybe, hopefully, one of my daughters will take me in".



Figure 6. An elderly woman in the church, waiting for a wedding of her neighbors' son.

Photo by author.

When adult children are dispersed across countries and continents, what happens to their aging parents? What becomes of care in a transnational context? I tackle these questions through my fieldwork in Kerala and suggest that digital technologies such as mobile phones and webcams *participate*, together with children and their parents, in forming 'transnational care collectives'. Care is then shaped by who among family and non-family members joins in the practices of care at a distance, as well as what types of technologies are involved. When people cannot care by cooking for each other, care becomes about calling each other on the phone or webcam daily.

But I found the transnational care collective in Mercy's family to be elusive. There were cracks in their collective, created by the onset of dementia, as well as by decades of family conflict. The cracks appeared as the siblings' *inability, unwillingness or refusal to participate* in the transnational care collective. What kind of collective can be formed, if at all, if some family members are unable to join it, decline to participate, or are not allowed by other relatives to do so? Mercy could not care for her mother directly, if remotely, as dementia made it impossible for them to have a conversation on the phone. Mercy's brother was denied participation as Rosa refused the remittances that he wanted to provide in an act of care. Another brother declined to participate due to old disagreements.

Yet, as Annelieke Driessen (2018) suggests, the possibilities to participate in care are not necessarily a zero-sum game. In Mercy's family, care was there, with all

its imperfections and limitations. Mercy may think that the care that she and her siblings are providing is not 'good', but is it not care nonetheless? Fraught with tension, ambivalence and complex emotions, care was in the daily calls between Mercy and Rosa, which included discussions of their mother's condition. Care was in Rosa's daily negotiations with her husband about her mother living with them. Care was in the refused dinner invitations and in the phone calls not made out of frustration over different ideas of what 'good care' for their mother with dementia could be. Care was in visiting nursing homes, even as these visits were accompanied by Mercy's lingering fear of her own imminent aging.

It seems, after all, that dementia does not entirely preclude people and technologies from practicing care at a distance. Rather, it shapes the participation in the transnational care collective in specific ways. The phone, instead of connecting Mercy and her mother, connects Mercy with Rosa in their joint endeavour to organise and discuss care for their mother. Dementia also shapes the relationship between Mercy and her brothers, who have responded to the situation in different ways. Dementia as a mental health illness is not as tangible as people or technologies, but it nonetheless importantly influences relations and the ways in which care may be done. As such, dementia joins the care collective as a participant of its own.



Map-maker

2

Does the world need maps, where sign and symbol,
standing as proxies, get worked into scrolls?
You see them, mountain chains with raingods in their armpits
and glaciers locked like glass-slivers in their folds.
Desert, scrub, pasture – do they need shading?
They're all there for the eye to apprehend.
A family of cactus and camelthorn tells you
where one begins and the other ends.

These questions confound me, I'd rather paint
for a while – a ship on the skyline,
or cloud-shadow moving like a spreading stain.
Yet they live, pencil strokes that speak for rain
and thunder; and die – maplines ghosting round
a cycloned island that has gone under.

Keki Daruwalla