

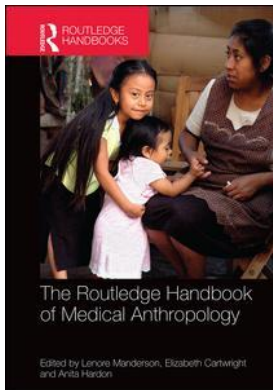
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### **Ways of Caring**

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Cell Phones in Africa, 2012. Akwapim South District, Ghana.  
© 2013, Mark Nichter. Printed with permission.

### *About the photograph*

*Cell phones in Africa have great potential for disease monitoring and to facilitate decision making about health care, where women are required to consult their husbands before taking action. A woman in Ghana, visiting a clinic with her children so that she can be treated for a chronic ulcer, checks in with her husband via cell phone to inform him about the costs of treatment and how often she will need to visit the clinic. Nichter was the social science adviser to Stop Buruli Network West Africa, and was working with a local social scientist and a medical doctor to understand how cell phones might improve treatment outcomes.*

—Mark Nichter

# Ways of Caring

*Elizabeth Cartwright, Anita Hardon  
and Lenore Manderson*

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In this chapter we tack back and forth between critically thinking about the activities involved in and the technologies of caring, and reflecting on what it means to care for others—an act that is as ubiquitous as it is primal. Some kinds of care, undertaken at home, are short term in response to an acute and relatively minor infection. Longer-term care involves far broader tasks, as in caring for older people and for people of all ages with chronic health problems or communication and cognitive difficulties. We juxtapose the mechanical realm of increasingly high-tech medicine with human interactions that we carry out to physically and emotionally support one another. Our intent is to position ‘technologies of care’ as tools, implements, and prosthetic extensions of our desire to intervene with fate, to show love and compassion, to alleviate suffering, and to make our lived experiences of life and death better. We move from a discussion of the act of caring for others in the most basic, physically present kinds of settings, to a consideration of new ways of delivering care via systems of communication and monitoring of patients from a distance. We then discuss some of the complexities of implementing new systems of telemedicine, for instance, in very remote, culturally distinct regions of the globe. Finally, we turn to the very well-informed patients who interact with one another via the Internet and who are creating new forms of socialities based on their conditions and innovative understandings of their illnesses, possible treatments, and ways of getting the support that they need.

## Caring

One dimension of care includes the biomedical approaches to care in hospital and those that continue on as people achieve the status of outpatients. It involves logical continuums of finishing up medicines and the post-acute phases of the healing of bodily wounds (Mattingly et al. 2011), but, as we have noted in Chapter 7, it also includes more complex everyday routines in the face of chronic conditions, where care is needed for long periods, sometimes indefinitely, and where routines can increase in significance as more attention needs to be focused on them. To accommodate this, as we have already noted, dialysis machines, oxygen pumps, ramps, rails, lifts, and monitors are imported into home settings, converting the home to hospital and the home-carer—a family member—into an allied health professional (Sakellariou 2015).

The tasks of caretaking can seem to stretch out into the future in an interminable manner. Anthropologists have described the process of caring for an aging relative from a very personal vantage point, especially with respect to the long-term care needs of spouses and parents

who were afflicted with Alzheimer's disease (Kleinman 2009; Taylor 2008). Kleinman's poignant description of how he cared for his wife of many years when she became ill with Alzheimer's, how he helped her move from room to room, dressed her, and fed her in an intricate dance that became increasingly complex as her condition worsened, clearly shows the intimate, moment-by-moment details that must be attended to just to make it through the day. Taylor's auto-ethnography of caring for her mother, as dementia took hold, highlights the evolving nature of caregiving when a patient is slowly deteriorating, as different resources need to be shepherded by the family, and as the emotional and physical demands of all aspects of care become increasingly difficult. Cultural differences abound in responsibility and configurations of caregiving, but the basic components of care, safety, carrying out of daily activities, and human presence surface recurrently.

Different physical and cognitive patterns of difficulties play out in different ways and warrant significant anthropological attention as our global populations live with chronic illnesses, and live for longer periods in states of serious ill health (see Chapter 7). The extremes of caregiving are seen in the frail, unhealthy elderly, who in various circumstances and settings are institutionalized and may have diminished cognition. The bodily exegesis of able-bodied caregivers putting the profoundly disabled elderly through their activities of daily living creates a situation of literally living the text of a life for another: moving limbs through space into wheelchairs, moving food onto spoons, into mouths, reminding to chew, reminding to swallow, toileting, bathing, and dressing. The work of such caring is often done by strangers, but also by children, spouses, other relatives and helpers, paid and unpaid. It is always taxing in many ways. These acts take their toll on caregivers, and result in frustration for those receiving care, for whom the loss of independence, often tempered with confusion, can be deeply distressing.

With medical technologies entering the home, and with Internet and smartphones enabling communication, more and more parts of care can be performed at a distance—that is, virtually. What is it that constitutes 'care' and how is that approximated, changed, and electronically reproduced across distances via technologies of communication? How is love transmitted through space and made real to those for whom we care? While there is not much new about long-distance relationships of one kind or another, the importance of virtual caring is growing exponentially as technologies of communication and perception increasingly act as prostheses between children and aging parents, homebound patients and medical personnel, and between patients experiencing similar problems. There is certainly a co-construction in the act of caring—there is the bodily participation, the touch, smell, and warmth that provides grounding and comfort. How do we convey these aspects through the screens and connectivity of our ICTs (information and communication technologies)? Greenhalgh and Swinglehurst (2011) have argued that ethnography is an effective methodology to use when looking at how ICTs are introduced into complex social systems, such as that of health care. They emphasize that the success or failure of the introduction of a new technology into a health care system is best understood via the small, everyday social interactions surrounding the use of the new ICT.

'Smarthome' technology is rapidly becoming available to those who have the resources; in the case of the elderly, it is particularly important as a tool for facilitating their independence and ability to stay in their homes for as long as possible. The QuietCareSM system, for instance, is a smarthome technology marketed by Intel-GE Care Innovations. It is based on the work of medical anthropologist Anthony Glascock and his colleague David Kutzik, a sociologist (2006). The QuietCareSM system is built on their cross-cultural, gerontological research, which led to the invention of a system of small motion-detectors that can be located in the homes of people who are elderly and frail, or disabled, to monitor their activities and to send out alarms when needed. The system uses sensors and WiFi to monitor Activities of Daily Living (ADLs)—bathing, dressing, using the toilet, eating, getting in and out of bed, and walking—along with the necessary

Instrumental Activities of Daily Living (IADLs), such as meal preparation, managing money, grocery shopping, making phone calls, doing housework, taking medications, and doing laundry (Glascock and Kutzik 2006: 60). The system ‘learns’ the regular movements of individuals as they carry out their normal daily routines and will alert the caregivers, who are able to remotely monitor the information from the sensors 24 hours a day, if something is out of the ordinary. These two researchers noted that for a technology such as this to be acceptable, one of its most important attributes must be that it is unobtrusive and that it monitors objects, not people. This system, and others like it, are being refined and made more effective, and are increasingly being used around the world.

In ethnographic research that explores the uptake of virtual caring technology, López and his colleagues (2010) describe the experience of being one of the remote ‘caregivers’ at the Catalan Red Cross Home Telecare Service in Barcelona, Spain. They point out some of the realities that go into the decision-making process at the central monitoring station when an alarm, such as that described for the QuietCareSM system, goes off in one of the homes in their Spanish system. Working at the central monitoring station, individuals who are oftentimes health professionals or para-professionals communicate with registered patients in the event of an alarm being triggered, muster neighbors or kin to physically check on the individual if no phone contact can be established, call ambulances, and perform other triage-at-a-distance. Similarly, technologies such as those described in the following case, by Thygesen and Pols, show how the Internet and various mobile devices are used to create networks of information, intimacy, and support for e-care networks of elder caretakers in Norway.

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## 8.1 Care, Self-Management and the Webcam

### *Hilde Thygesen and Jeannette Pols*

We all know these texts: Europe is aging, facing a tsunami of older people and people with dementia for whom a shrinking younger generation needs to care. Something should be done about this situation, these texts continue. The industry needs to produce technologies to efficiently support people who grow old and deal with disease at home, rather than in health care institutions. Older people should start caring for themselves with the help of these devices. They should become experts in ‘self-management,’ a term that has become the buzzword in European health care policy. As is usually the case with buzzwords, self-management means different things in different contexts. It is usually interpreted as the individual activity of caring for oneself or ‘managing one’s disease’ with the help of professional information and devices. Implicit is the idea that older people will suffer from chronic diseases rather than acute conditions, strengthening the idea that lifestyle changes and prevention from deterioration are important activities.

Ethnographic studies are excellent ways to critically analyze buzzwords. Rather than blindly accepting that self-management is the way to understand how people care for themselves, we can study how people actually do this. Drawing on ethnographic data from a Norwegian webcam care project, we show what self-management comes to mean when we study what people *do* when they care. Our questions in this case are: who is the patient that needs to manage him or herself? Who cares, or manages, and who does not? What defines ‘care’ here?

### *SafetyNet and Its Patients*

SafetyNet (TrygghetsNett) is a public care service that uses a protected webcam system to aid persons living with a sick spouse.<sup>1</sup> The service started as an initiative of the municipality of Nøtterøy, in south-eastern Norway, directed at spouses of persons with stroke and dementia and is coordinated by professional nurses. Most people suffering from stroke and dementia are older than 65; their

spouses too are older and suffer from different age-related diseases. Caring for a person with stroke or dementia can be a very demanding 24-hour-a-day job, even with home-based nursing services. Hence, the municipality targeted family caregivers as being particularly vulnerable. After a couple of years, the service was expanded to all 12 municipalities in the region and extended to include the parents of multi-disabled children and families of persons with alcohol or other forms of substance abuse. So the 'patients' involved in intervention were not the people with the 'medical problems' but their family caregivers. It was they who needed support for their role in the caring and management of the 'actual patient.' Care, in this context, is a burden that can turn caregivers into patients. Caring for others, rather than the self, is of course unavoidable when one's partner has a stroke or dementia, but it is overlooked in the discourse of self-management. Here we discuss the kinds of problems that the Norwegian caregivers experienced using the system.

*Professional caregiver (coordinator):* I have really experienced what it is like being a spouse/family caregiver [through my role as coordinator of SafetyNet]. We get [a lot of] insight into the lives of people. I used to think of family caregivers as pests and a bother. They never say 'thank you,' but always demand more. I thought, for instance, that men would never stay home to nurse their wives. But they do. And when the partner gets chronically ill, the world gets narrow for the spouse, too. We found that a lot of them were very isolated. We quickly realized that these people were very alone with their problems. At our meetings I often try to engage them with humor. "Are they [the partners with dementia or stroke] nice to you?" I asked at the meeting last week. Then someone answered that this was really difficult. "If anyone has had it with the sick person [gestures to the throat], speak up now," I encouraged them. And then a huge discussion started. They talked about feeling cornered, cut off, and tied up and that their efforts were not appreciated. Many felt that they couldn't do enough. Some were mourning. There were many bad feelings floating around the room.

The role of the caregiver is difficult, even if they do not suffer from a disease themselves. Their emotional investment and the lack of recognition of their care made them very different from a professional caregiver; it turned them into patients, too. The idea behind SafetyNet was to allow family caregivers to link up with and support each other. Through the combination of peer support and public service coordination, the idea of SafetyNet was to strengthen family caregivers in order to keep caring for their spouses longer.

*Hans (participant):* My wife did not want to move to an institution. So when we started with the senior center from 9 to 2pm she did not want to go. I had to trick her into going. It was like that all the time and it was very difficult. It took a long time before it got better. But it did get better after a while. She also got a permanent room in the nursing home, but she did not want to be there. It was a terrible struggle. And at that stage I was in constant contact with the girls at the SafetyNet base who said that "You just have to keep going, Hans!"

SafetyNet was developed so that the sick person would be able to live at home for a longer period of time. This was considered positive, as for many people living at home provided a higher quality of life than living in an institution. Additionally, it is cheaper for the municipality if the patient lives at home. Family caregivers are key to achieving this.

How did the family caregivers/patients support one another in the SafetyNet project? One of the first things that they exchanged was knowledge and expertise.

*Anna (participant):* Just an example. There was a man [in the group] who had a hole in his bladder. And he had a problem with the use of a catheter, about finding ways of connecting bags. He was left sitting at home because they [the home nurses] thought it was not possible. And he couldn't get out of the house. "Yes!" I told him, "It is

possible!” So I could help him by telling how I had solved this with my husband. In this way we help each other.

Typically, the practical problems the group discussed were accompanied by complex moral demands and feelings. How to be a good caregiver was a common topic. Anna, again:

We help each other, not the least psychologically. We all have periods of crying . . . My husband is going to the rehabilitation center on Monday [for three weeks of ‘respite care’ aimed to unburden the informal caregiver], and when it gets close I get like this [tearful]. He does not understand why he has to go, even though he accepts he has to. But he would rather be at home, he keeps saying. So I try to explain to him that in rehab he will get the chance to exercise every day. And I had to be tough and tell him that I need these three weeks. Now, after four years he understands. But it is not easy. He keeps telling me that he prefers to be at home.

Three weeks of respite care in the rehabilitation center helped to unburden the family caregiver, but turned out to be difficult to implement. Carer and patient can now *both* be identified as the patients—and their care needs can be at odds. Support from the SafetyNet group was of great value here. The recognition and the mutual support between members was an important success factor in the way care took shape. Sarah compares the relations within SafetyNet to those in a family: “We who are part of SafetyNet have actually become like a family. We get very close to each other and we know each other well.” Yet the success of SafetyNet exchanges is characterized by participants *not* being family.

*Professional caregiver (coordinator):* Many of them have children. But children are children. They are not to be involved in trouble and care. This is an attitude that many old people have. They [the kids] have problems of their own, and should not be bothered with those of their parents. At first, I did not understand why they did not want to involve their daughters and sons in SafetyNet. But SafetyNet was something that was ‘theirs.’ Their relations to the children were possibly the only thing they had that was normal. It was also an assumption that the children would not come and visit if they complained too much.

SafetyNet participants believe that their relationships with their children should be free from concerns and burdens of care. They wanted to keep things light with their friends too, and SafetyNet provided people with a forum to share their problems.

*Sarah:* When I say that we in the forum [SafetyNet] are family I me . . . well, there is a difference compared to our ordinary friends. Firstly, they [ordinary friends] are fewer and when they are visiting we don’t sit and talk about things that we are concerned about in everyday life that we find problematic. With our friends we are supposed to have a good time and live a normal life like before. When I am in contact with someone in the SafetyNet group, things are different because we can share our problems. Everyone has got something! Having lived here all my life means that I know a lot of people. But it is different in this forum. We have something in common. Sometimes when I feel like talking to someone I click on the ‘want someone to call me’ (*pratesyik*) icon on the display, and if someone gets in touch then it is always very good. Then we are both happy.

In SafetyNet relations, people could be caregivers, receivers, and friends:

*June (participant):* Hans arranges a summer party every year, and it is very nice. Everyone in the forum has a handicap, so the tolerance is high. Everyone helps each other as much as possible. Some do not like social occasions because they are concerned about spilling food when they are eating and those kinds of things. But it gives us safety to know that we are together and not alone.



Care had become an everyday activity for all. It included dealing with spilled food, but was also focused on not letting individual's disabilities get in the way of enjoying life. Patients and caregivers could be tourists, rather than patients and caregivers.

*June:* One other thing is that we have found another couple in the [SafetyNet] forum that we did not have contact with before. And we have traveled together every winter to Spain, to a place that is accessible, and that has Norwegian physiotherapists and nurses. For three years we have traveled with this couple. In the restaurants there they are used to people who sit in a wheelchair and that might need a bib on when they eat. This means a lot. We have had an agreement with a taxi that takes us on trips.

At the time of the fieldwork, there were 13 participants, 6 persons with a spouse suffering from dementia or stroke, and 7 persons who were 'solo.' The solos bothered the organizers of SafetyNet, because they stayed with their newly made friends and did not want to quit being a part of SafetyNet when their spouse died. The organizers worried that the solos were taking the place of other caregivers who might benefit from being a member of the group. The solos did not want to leave the SafetyNet community and friends that they had made during the difficult times of caring for their spouse. They had established new and valuable contacts with the members of SafetyNet and did not want to give up these friendships, but also, their role changed from occasionally asking and occasionally giving help, to having time on their hands—and motivation to spend it with their SafetyNet friends.

*Petra (participant):* I am in touch with someone in the forum every day, but not as often with the base [the professionals/coordinators of the network]. So it is the other members of the group that I am in contact with. I don't have just one or two—it varies who I am in touch with. Some are easier to talk with than others. And those in the solo group have more time than us, who are family caregivers. So it is easier to contact them. I think it is a good thing that the solo-people are taken care of. You cannot close them off despite the fact that they are no longer caregivers.

The idea that the informal caregiver needed support because their 'disease' was the disease of their partner implied that they were 'cured' once their spouse had died. But this was not how it was for the solos. Their friendships from the SafetyNet experience lasted and changed to meet their new needs once their partners had died.

*Jan (solo participant):* In particular I have one close friend. I met him through the [SafetyNet] forum. He started at the same time as me. We have been in Croatia and on the Donau together since we were widowed. We are in touch every day. Today he is at the eye specialist, but I expect that he is at home by now. I can see that he is logged on [the forum].

Jan had found new people to care for after his spouse passed away. Care shifted into something that made the members of the solo group feel good. It also assured the other participants of lasting and accessible care.

*Jan:* We in the solo group are much freer. We can decide everything ourselves. This is something that it not possible when you are two. We meet as often as possible. Last week two women [in the group] suggested a trip to the café. And then we ended up being seven or nine. Doing these kinds of things is very nice, it's cozy. And it strengthens the ties between us. When we are together we talk about all sorts of things.

*Petra:* We have all the time been conscious about keeping a light tone. This was not to be a site of mourning! It was to be, we could have a bit of fun actually. We were away for a bit [from the seriousness/grimness of the situation at home] and had something else to think about.

Caring and being cared for became a meaningful and 'fun' activity. It did not stop with the end of disease. Jan kept himself healthy and happy by continuing to care within friendly relations with people he was close to, because they had been through the same problems. Jan succeeded in giving his life a new purpose and in passing on that enjoyment to others as well.

## Conclusion

Care for others changed from being a burden to being something to live for. Care could incapacitate the family caregiver when it went one way, changing the former relation with the spouse completely. The family caregivers were emotionally burdened, on the one hand by the wish to care for their spouse, and on the other by their own limits and their lack of recognition and support. Their caring work turned them into patients. In SafetyNet, the caring relationship was different. People could switch between getting and giving care, and being part of a community with recognizable difficulties to live with. This made the new relations strong and valuable to the participants. Care for others emerged here as the way out of being a patient. Interestingly, the mutual care made the SafetyNet relations different from relations with family and friends. Here caring was not about medical aids and technology, nor about self-managing, but about supportive relations.

## Note

1. The SafetyNet website is a secure, online forum organized and coordinated by municipal services. The actual forum has two parts. The first is the written forum, where the members can write notes to be read by everyone in the forum. The other—oral/immediate part—is where you can make calls (like Skype) where you see each other on the webcam. This is one-to-one communication. When online a small panel shows the accessibility of the other group members. When logged in the names of the participants are listed, and on a small panel beside it the availability-status shows. If you are away on holidays or busy, you can click the 'unavailable' button and the other group members will see this when they log in. Or you can choose just to be 'logged in.' If you are in need of contact, you can click a button named *pratesyke* (in need of a good talk).

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Thygesen and Pols's case illustrates how new connections spring up among communities of caregivers when they have access to computerized communication; real friendships are established and new possibilities are opened up for the elderly individuals involved in the Norwegian caregiver support program. In her case study below, Tanja Ahlin describes the more 'naturally occurring' long-distance webs of medical decision making that exist between elderly parents and their far-flung children. Ahlin's study participants use telephones and computers to stay in touch, share information, and make decisions. Information about a family member's conditions are exchanged across continents. Requests and demands are made on both those at home and those who are residing around the globe, as care is strategized and enacted between physical locations where access to diagnostics, medicines, and trained practitioners all vary. In these instances we are not just talking about biomedically oriented care, for traditional and alternative treatments and practitioners are also an important part of this mix.

## 8.2 E-Care in Kerala

*Tanja Ahlin*

“We knew she was gone before they reached Kochi,” said Jane, a specialist nurse from Kerala, India, working in the United States. The death of her mother-in-law, Vimala, who was in her seventies, was sudden and completely unexpected: when she died, the family was seeking to obtain a visa for her to join Jane, her husband and their two young daughters in New York. At that time, the mother-in-law was living with Jane’s husband’s brother. Jane and her husband learned that she was sick when they called on the day that her visa paperwork was supposed to come through, and she was not able to speak on the phone. Jane told her relatives to take her mother-in-law to the hospital immediately. But the doctor who was supposed to receive her was on a leave, and so the relatives took her to Kochi, about two hours drive away. On the way, Vimala vomited blood. Jane was on the phone throughout this period, giving directions to keep Vimala’s head straight and in position where she could drool, so prevent her from choking. Her advice was especially appreciated because she was a health care professional; her relatives had no experience with such emergencies. Today, Jane is still guessing about the possible cause of Vimala’s death, but perhaps it was an abdominal aortic aneurysm, a common fatal event whereby the ruptured aorta in the stomach causes severe internal bleeding. “While they were driving, we kept asking, how is she doing, how is she, but we knew,” Jane finishes describing her memories of the last time she took care of her mother-in-law, at a distance by phone.

Now in her forties and from a middle-class family, Jane is one of the many nurses from Kerala, mostly Christian, who have left their home country to try their luck abroad. One reason for migration of nurses, as of other professionals from Kerala, is related to the gap between high levels of educated people and poor availability of appropriate employment for them (cf. Chua 2014). Although there are no exact numbers of how many women, and more recently men, have done so over the past decades (see Percot 2006 for some estimates), families will often send a son to become a priest and a daughter to become a nun or a nurse, an offering of children to live in the service of God and society although historically, unmarried women who migrated abroad alone were viewed with suspicion and ambiguity. More recently, however, growing numbers of single and married women have left Kerala to work abroad, and parents now talk about them with pride. In some social classes it has become the norm for young girls, especially, to become nurses and migrate abroad. In Kerala, where there are little options for health insurance or pension available to non-public employees, lower- and middle-class elderly are particularly vulnerable. Educating at least one child as a nurse and sending him or her abroad has become a kind of informal insurance for parents who then need not worry about the high costs of weddings, home renovation and potential health care costs. As one widow explained, “because my children are abroad, I live happily here. They work and make money. They give me more than enough money and isn’t it because of that, I am living lavishly? If they sit with me, will I enjoy my life? No.” The money that her children provide is more than enough to buy her food and other necessities; her income in old age is secure. If she needs any help, in case of health emergency or anything else, she can still rely on her extended family members living nearby. While her children are always in her mind and she prays for them daily, she understands that they have their own children to take care of and is satisfied that they come to visit her during their annual leave. She was genuinely happy, very much in contrast to the popular belief in the devastating abandonment and loneliness of elderly people living alone after their children had migrated (Lamb 2009). I encountered very few cases where the migrating nurses had little or no contact with their parents. In a women’s shelter, run by one of the local churches, I met a divorced woman whose daughter was a nurse in the Gulf. The two had no contact, but that was the case already before the daughter left Kerala to work abroad. Also, I found no parents of migrating nurses in the geriatric hospital I visited, through there were more than eighty patients there.

### *What Can Children Do from Afar?*

Let us return back to Jane’s family. Jane, the second of three sisters, had been caring not only for her mother-in-law, but was also taking care for her own parents. An older sister lived in Kerala, only a couple of streets away from their parents’ home, while the youngest one lived and worked as a nurse in Oman. All of them were married and had children of their own. Ideally, in Kerala, the youngest son

and his wife would live with the parents, take care of them and as compensation inherit the house. By contrast, Jane's parents lived alone with a maid, and because Jane was the one who agreed to help them financially to renovate their home, she would eventually inherit it. When there is no son in the family, the responsibilities of care depend on agreements and personal engagement of daughters and their husbands. Calling her parents from the US by phone twice a day every day, Jane was highly involved with their everyday life, though this was not required by any social obligations. Jane and her parents relied on the phone as their communication tool of choice, because it was easy for the parents to use, while they had no experience of using a computer and so Internet-based webcam contact was not possible. Jane called me from New York after having returned from her night shift and calling her parents, and in our phone interview, she told me:

I think it's all about your attitude, wherever you are. I think I am the one always there for them, whenever they need someone to stay with them, I am the one to find out what is the problem with them, and I am the one who is always calling the others around. I call them every morning and every night.

Jane was particularly concerned about her father, now in his late seventies, who had been suffering from Parkinson's disease for about eight years. At the onset of the illness, he had taken some allopathic drugs, "but only for one day," his wife told me. Jane's mother had not appreciated the side effects her husband experienced—he had been so sedated he would only sleep—and although she had spent a small fortune on the prescription and the medicines, she had thrown them away the same day. She had then talked to Jane about her idea of using āyurvedic drugs. Remembering those days, Jane told me that she knew her parents well and she understood what they needed; not knowing the person on the other side of the phone so intimately would, in her view, make such care at a distance much more difficult or even impossible. Her mother was well familiar with plants and had been preparing herbal remedies for years. So when they had proposed to try āyurvedic drugs, Jane had supported the suggestion. Almost a decade later, Jane's father's condition had improved significantly, such that he barely trembled, his memory was sharp, and he could see clearly and even write again.

Besides monitoring her father's chronic illness at a distance, Jane had also been there for her parents during an alarming health crisis about four years ago when her mother, now sixty-nine, had had a stroke. As Jane recalled in our interview, she was at work one day when she had a nagging feeling to call home although it was half past two in the morning in Kerala. She did not want to wake her parents, so she called her brother-in-law living nearby. Her call found him standing by the car in front of her parent's house, ready to take her mother to the hospital. At the nearest hospital, the staff said the doctor would only come in the morning. Jane's mother then received an injection and an X-ray was done, but then the family decided to take her in their family car to a hospital in Thiruvananthapuram, the capital of Kerala, about four hours drive away. All the while, Jane was on the phone, on and off, checking on her mother's condition and giving advice on what to do.

As a nurse, her knowledge was invaluable during this event, but there were clearly limits to what she could do for her mother by phone. Within several days, just at the time when her mother was discharged from the hospital, Jane was able to take a family emergency leave from her work and flew to Kerala. Her younger sister, too, flew home from Oman within a week, although she had recently given birth. Jane then stayed with her parents for over a month and learned from a professional physiotherapist how to massage her mother properly. By the end of her stay, Jane's mother was able to slowly walk again and today she has no problems at all, other than occasional slurred speech.

Jane's family was not the only one in which the children would fly home when a life-threatening health problem occurred. One of the nurses, working in the Maldives, told me of her colleague, also a nurse from Kerala, who returned home after her mother experienced a heart attack. But first, the nurse established a phone contact between the cardiologist in India who was treating her mother and a cardiologist in the Maldives who was working in the same hospital as she. The nurse reportedly did so because the two specialists "spoke the same language." In this way, she was able to confirm what exactly was happening and how serious her mother's condition was, and, on the basis of this acquired information, she decided to take a ten-day leave.

In contrast, when some older people I talked to experienced accidents or health problems such as diabetes and high blood pressure that were not life threatening, they would not always share that with their children over phone. This was irrelevant with respect to the geographic distance between the parents and their children, as the children could be living only one-hour flight or a two-day journey

away. The parents decided to do so, they told me, so as not to worry their children unnecessarily, as there was nothing they could do to help from a distance. In this way, the parents were ‘caring back’ for their children, protecting them from unnecessary worry and perhaps feelings of guilt about not being able to help right then and there.

The fact that not all care can be provided through the phone also played a crucial role in Jane’s decision to find a live-in maid for her parents. After her mother’s stroke, Jane searched for and then employed a ‘girl,’ actually a middle-aged, childless Malayali woman, available to move in with her parents in order to cook, clean and do other chores as needed. Throughout my fieldwork, many people complained about the increasing difficulty of finding servants and maids in Kerala. Due to remittances sent home by Keralites working abroad, a significant proportion of whom are nurses, the standard of living has increased for all. This, according to my informants, made it practically impossible to find reliable servants, as the women who had carried out domestic work in the past would now receive their income from their children abroad. In line with the literature on global care chains (Yeates 2012), I expected that this lack of workforce in the domestic care sector would be replaced by migrants from some poorer North Indian states or other countries. However, although I could observe a significant number of men coming from Indian states such as Assam, Bihar or West Bengal as construction workers, I have not seen or heard of Indian women migrating to Kerala to work as housemaids. Several of my informants confirmed this observation, adding that there would be the problem of language (non-Keralites would not speak Malayalam) and, even more importantly, who could ever trust them? Jane’s family was thus more of an exception than a rule among the families I met and interviewed, as most of them would not have a Malayali maid or a maid from a different state.

### *The Dying of Distance*

While Jane and her family relied on the use of the phone to stay in touch, quite a few families I encountered used an Internet-based calling service, namely Skype, which had become a household word. Those parents, like Jane’s, who did not use this kind of communication told me that was because they did not know how to use a computer and therefore often did not even own one. However, in one family, I observed how Skype could be crucial in keeping in touch and providing care between family members. With two married daughters working as nurses in the United Kingdom, the parents in this family relied on the technical knowledge of their youngest daughter, also a nurse but still living at home while studying English to pass her IELTS exam. They used the free web calling service (Viber) to talk to both daughters abroad. Additionally, every day in the late afternoon or evening, they would set their laptop on the kitchen table to simply spend time with their middle daughter, her husband and their two young sons. Sitting with the youngest daughter and the mother of the family by the table, I was surprised by this: the conversation was far from the focused, static kind of communication between people sitting still by their computers and staring at the picture on the screen. Instead, the computers were the only things that were still; the conversation partners on both ends moved about the room, looking for something in the kitchen, playing with their small children, talking on the phone to somebody else, and so on. On that particular afternoon, the daughter in her house in the London suburbs was brushing her hair and preparing to go out, but she called to ask her mother for advice as she had forgotten to take her dose of some post-partum āyurvedic medicines. The mother, leaning across the table and looking straight into the screen, first scolded her daughter for being so careless about her health, then gave her precise instructions on how to proceed.

The computer became a window in space through which both the parents and the children felt as if they are “there, with them, in the same place,” as one of the nurses I talked to said. Or as another mother told me, “since I can see (my daughter working in Saudi Arabia) and talk to her (every day, sometimes more than once a day), I never feel she is far away from me.” For some moments at least, the distance collapses as parents and children not only communicate daily, but are also able to simply ‘spend time together’ and take care of and provide support to each other as if they were within reach.

### *Acknowledgments*

The material for this case study is based on my fieldwork in Kerala, India, which took place from January to March 2014. I carried out semi-structured in-depth interviews and participant observation of parent–children communication among seventeen families. Two interviews with the daughters

working abroad were carried out over the phone and one over Skype. I also conducted interviews and observation at an English-language school, an old-age women's shelter, a geriatric hospital and a non-governmental organization tending specifically to the elderly. The interviews were carried out in English and/or Malayalam; the Malayalam interviews were conducted with the help of two interpreters or bilingual family members. I am most grateful to Dr. Leyanna Susan George and Dr. Harikumar Bhaskar for their invaluable help and support.

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## Practicing Virtual Medicine

Medical anthropologists have become increasingly interested in how humans interact with technologies of diagnosis and healing. Clinical spaces in high-income settings, and those that have the necessary wealth in low- and middle-income countries, are filled with a rapidly changing amalgamation of ways to peer deeper into bodies, transmit images and texts, and facilitate communication between practitioners, patients, families, and communities. At the same time, technologies created as small, portable, durable, and sustainable tools for clinical use are increasingly cheaper to manufacture and easier to use. It is difficult to imagine a clinical tool that is not being re-imagined via new technologies of connectivity, screen availability, and minimization of size. Mobile technologies supplement the services available at fixed points (e.g. Telecare), as we discuss further below, and accelerate the transfer of clinical data and pathology reports and images, and support consultations, via email, What's App, Facetime, and Skype, between people and places. They extend biomedical knowledge, help retain clinical records, and increase quality care even as they amplify the panopticon of the clinical gaze (Foucault 1973).

Telemedicine is now a major player in the delivery of care worldwide for those with the resources to afford it. Starting in the early 1990s, the industry of telemedicine now connects practitioners, patients, and support groups to information bases, technical advice, and medical interventions (Sinha 2000). Industry blogs posit that telehealth will grow worldwide from approximately 350,000 users in 2013 to 7 million by 2018, with a concomitant rise in electronic medical visits from their 2015 level of 100 million. A blog posting on the website for Intel puts it this way:

To control spiraling healthcare costs related to managing patients with chronic conditions as well as to navigate new policy regulations, 70 percent of healthcare organizations worldwide will invest in consumer-facing mobile applications, wearables, remote health monitoring and virtual care by 2018. This will create more demand for big data and analytics capability to support population health management initiatives.<sup>1</sup>

The complexities of healing, as described in the anthropological literature, inform us about the multiple levels of interactions between healers and their patients. Brigg's work (1994) with the Warao shaman of Venezuela, for example, makes explicit how curers gained agency over

a distressing symptom such as pain from a wound, and then, through using traditional curing songs infused with knowledge of the social context within which the accident occurred, through words, music, and touch, created an emotional atmosphere that facilitated healing. This suggests that words have real power. Briggs argued: “I suggest that shamans gain power by collapsing discourses about pain and suffering undertaken by patients, their relatives, and the community at large into curative songs and practices” (1994: 164). The significance of clinical assessment, and the use in this context of sensory perceptions, sound, and speech, are no less relevant in a contemporary medical setting than they are for shamans and herbalists. Here, there are interesting questions for medical anthropologists: What parts of these embodied healing performances are still present in telemedicine and e-health? What parts are lost, and how is this corrected or countered as virtual medical care is extended from emergency obstetric to psychiatric care to surgery? How are these technologies appropriated into new configurations of embodied healing performances?

Annemarie Mol and her colleagues (2010) provide us with a new and interesting way of thinking about caring when they highlight the act of “tinkering.” Resisting the obvious comparison between ‘cold’ high tech and ‘warm’ human caring, Mol and others show how people use technologies in unexpected ways, while caring for the unexpected. Tinkering occurs as caregivers make adjustments and compromises when the rigid protocols of biomedicine need to be enacted in emergencies or in cases where the necessary accoutrements of medicine are not available. As one moves further and further out from large, well-resourced hospitals and clinics, to settings where even the simplest of technologies are often not available, such tinkering becomes even more important.

Emergency personnel in rural areas encounter situations that often demand adjustments and creativity. Biomedical emergency medical systems are built on communication, transportation (ambulances, both ground and air), and a chain of practitioners trained to certain standards. While many situations are ‘cookbook’ or not unexpected, others are difficult in ways that cannot be anticipated, even for the experienced medic. When equipment fails or has been left behind, one needs to improvise with what is at hand: a oral-gastric tube used in place of the missing Foley catheter to empty an over-full bladder, a folding aluminium camera stand used instead of a Kendrick’s Traction Device for a broken femur, a well-placed finger in lieu of sterile pads to stop a hemorrhage—one does the best that one can, with what is at hand.<sup>2</sup> Tinkering involves making small adjustments to equipment, pharmaceuticals, spatial arrangements, and ways of monitoring and documenting. Those caring for patients inevitably tinker, whether they are family members or medical professionals. Acknowledging this aspect of caring allows medical anthropologists to see beyond the written protocols to the rich environmental contexts in which humans interact with other humans, with the goal of caring for ailments both short- and long-term in nature.

### **Changing Access to Technology, Changing Configurations of Care**

As the above discussion suggests, electronic communication within and between clinical sites has become part of the clinical daily regimen, not only in areas with many resources but also on the periphery. Innovations such as telemedicine used to deliver care in isolated hospitals in the Peruvian Amazon and other remote regions demonstrate the value of the introduction of such technologies into various medical systems, but also how, when different ethno-physiological understandings coexist, unexpected changes occur in what clinicians and their patients experience in the process of digitization (Miscione 2007). In the Amazonian case, a telemedicine system was implemented but was only partially successful, as patients continued to delay coming in to the telemedicine clinic in favor of using their traditional healers and as practitioners struggled

with intermittent Internet service and a record-keeping system that wasn't flexible enough to be used with the new technology. Implementing a new way for practitioners to access information changes attributes of the medical personnel from the point of view of the patients; seeing the new technology in use may confer more prestige, fear, or confusion on the part of the patients. Another aspect of implementing this kind of system is that it can provide practitioners with new ways of establishing agency over biological processes, through their increased ability to name conditions that were not diagnosable or known in the past, and through more effective and timely evacuation to better-equipped facilities.

Patients use the Internet to gain agency over their conditions. Increasingly patients undertake research into their own conditions, and arrive at the doctor's offices with the latest journal articles in hand. They expect to be involved in thinking through their diagnostic procedures, and they want to understand the options available to them, in order to decide on the treatment regimen. These informed or 'expert' patients may sometimes take the next step of working through social media to create disease nomenclature and arrange for new innovative treatments, as described by Gesine Hearn below. This movement of biomedicine can be thought of as a form of colonization, and like other forms of colonization it is incomplete, contested, and differently interpreted in each new place. Using the Internet and social media to exchange ideas about one's illnesses, to find fellow-sufferers and to seek out a range of possible treatments is something that did not occur before the widespread use of computers became common in the 1990s. The following ethnographic case study takes us to spaces that are newly colonized with things medical. Hearn highlights how Internet-based social groups come together and create common understandings and ways of enacting difficult-to-diagnose medical syndromes such as Chronic Fatigue Syndrome (CFS). Before the Internet acted as a communicative infrastructure for individuals suffering from these sorts of conditions, there was less awareness and certainly less group action with respect to identifying key symptoms and possible treatments. This creates a different kind of platform for patients to use to demand attention and treatments for contested illness syndromes like CFS.

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### 8.3 Identities and the Internet

*Gesine Kuspert Hearn*

For ten years, I have followed the webpages of online self-help organizations for Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), and Irritable Bowel Syndrome (IBS). I was initially interested in how these virtual organizations viewed functional syndromes, contested diseases without a known etiology, and managed to establish research funding, diagnostic criteria, and public recognition for these diseases. I then compared US and German self-help organizations for CFS, FM, and IBS. Below, I focus on the formation of disease identities, virtual disease communities, and the presentation of the disease.

The uncertainty, invisibility, and chronic nature of these functional syndromes pose specific challenges for sufferers. Patients hope for a diagnosis and treatment, but due to the lack of any structural organic damage or pathology, biomedical diagnosis is difficult. Pain is a prominent symptom, but other physical symptoms include headache and fatigue. Sufferers often also complain about other psychological and neurological problems, including depression, anxiety, sleep disturbances, or trouble concentrating. As a result, doctors often consider these afflictions as being 'all in the head.'

In both Germany and the US, science-based allopathic medicine dominates the health care market. The American view of disease is predominantly mechanistic and based on the belief that external forces cause disease which, with American pragmatism and a 'can-do' attitude, results in an aggressive approach to diagnosis and treatment, including of these conditions. American medical textbooks emphasize the plethora of non-objective physical and psychological symptoms and the absence of



an apparent pathology. The medical profession disagrees about the possible causes of functional syndromes, with arguments ranging from strictly biophysical pathologies, psychological and psychiatric problems, the interplay of biological, psychological, and social factors, to medicalization (Hearn 2009). The preferred treatment option combines anti-depressants and cognitive-behavioral therapy.

In contrast, in Germany, a more holistic view of disease prevails. Emotions are believed to play a pivotal role in health and disease, leading to a more open attitude towards alternative approaches and an emphasis on psychosocial factors of disease (Payer 1989). This more holistic view is evident in the German medical literature. ‘Typical’ psychological and social characteristics of patients with functional syndromes are often mentioned. Additionally, the German medical literature lists *psychosomatische Grundversorgung* (psychosomatic basic care), including psychotherapy and differential diagnoses, as an important treatment component for functional syndromes. Most medical articles suggest a biopsychosocial treatment approach.

Chronic conditions have a tremendous impact on the daily life and the identity of those who experience them. Chronic pain is particularly destructive and invasive; it tends to ‘unmake’ the normal world of sufferers (Scarry 1985). Chronic illness and chronic pain often result in biographical disruptions and ‘assaults’ upon self-identity (Charmaz 1991). However, patients can also re-organize their biographies and lives by assigning meaning to their suffering. Narratives help to create such meanings, and to create identities and communities.

### *Self-Help*

Self-help is about sharing first-hand experience of personal crises and coping with those crises. In the US, self-help groups were first formed in the 1940s, and they exploded in the 1970s with growing health care consumerism and rising health care costs. In Germany, self-help found increased acceptance in the 1980s; groups in Germany are partially funded by the German sickness funds and their work is supported by state-funded clearinghouses. Self-help organizations are either dedicated to a group of similar ailments or one particular disease; they are an explicit example of biosociality. Members are typically sufferers, but relatives, friends, or professionals working with these people also tend to join.

The Internet provides a new forum for self-help, enabling intensive and rapid exchange of information on a national and international level and providing a very useful venue for advocacy. Online self-help is particularly helpful for people who are geographically isolated or trapped at home by their afflictions or responsibilities (see also Thygesen and Pols, this volume). Today, many self-help organizations operate in virtual spaces. Self-help groups and organizations have had a positive impact, in particular on containing health care costs, but they have also been criticized for disseminating misleading information, undermining professional authority, negatively impacting patient-provider relationships, and fostering narcissistic and self-indulgent behaviors.

Increases in longevity and the resulting higher prevalence of chronic diseases have prompted the need for better informed and more active patients. Patient participation and cooperation have been encouraged, and this has led to changes in patient-physician relationships. Patients increasingly see themselves as lay experts and consumers of health care. The changing boundaries between experts and lay people are noticeable. Patients have successfully influenced diagnostic criteria, disease categorizations, research funding, and legislation.

In the US and Germany, patients with functional syndromes have established self-help organizations to support sufferers and lobby for the recognition of their ailments as serious organic diseases. These organizations do not differ in the presentation of the disease and the services they offer to sufferers, despite different health care contexts, different funding sources, and the different lobbying mechanisms in the two countries. Organizations in both countries validate the patients’ experiences by generating narratives and thus meaning for their suffering. They also construct the face of the disease. Below, I discuss four leading US and three German online self-help organizations for CFS, FM, and IBS. I observed the websites of these organizations from January through March 2014.

The American self-help organizations started as local self-help groups and developed into national patient organizations, of varying size, revenue, and organizational structure. The main sources of revenue are membership fees and donations. Revenues pay for the websites, telephone hotlines, publication and dissemination of information materials, the organization of research symposia, awareness campaigns, and lobbying efforts. Some of the organizations fund research projects. The three German organizations, all established by sufferers, are *eingetragene Vereine* (registered organizations) and

*gemeinnützige Vereine* (charitable organizations), and were the only national online self-help organizations. None provide information on the amount of revenues and expenses. The German organizations maintain websites similar in size and design to the American organizations. Information and advice is addressed to sufferers, doctors, and the public, and is provided through newsletters, journals, brochures, online publications, and telephone hotlines.

The explicit goal of these organizations is to assist and empower sufferers, and in doing so, carefully choose disease labels and use language that signals organic pathologies and the seriousness of the diseases. For example, the US self-help organizations label Chronic Fatigue Syndrome as 'CFIDS/ME' (Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalomyelitis). They also engage in advocacy, fighting for the scientific recognition of their diseases, more patient-oriented research, and increased research funding. They advise sufferers about medical, social, psychological, and legal aspects of their disease, and post official diagnostic criteria, personal illness accounts, new research findings, and current research grants and trials. Free articles can typically be found on the websites. Paid membership usually includes access to newsletters and addresses of 'good' doctors and local self-help groups.

### ***Searching for an Identity***

Why do patients seek out these online organizations? The organizations tell us that people suffering from functional syndromes are frustrated, misunderstood, isolated, and alone. They feel victimized. No one understands the dramatic impact of the disease on their life, the pain, and the suffering they constantly endure. They are misunderstood because their diseases are invisible and often not validated with a medical diagnosis. They have seen many doctors and at best have received some psychological diagnosis. The sufferers insist that their problems are physical. They need answers for a life and an identity disrupted by an affliction no one can see or name. They need advice on how to navigate daily life; they need to know if they are eligible for social services; they need to know where they can find help for the mounting problems they have encountered since they have fallen ill. They want to know if there are others like them.

Sufferers first need to figure out if they have IBS, FM, or ME/CFS, and further, 'who they are.' The online organizations provide detailed information on the syndromes, detailed lists of symptoms, and online diagnostic tests. They ask, "Does this sound like you?" The organizations emphasize that these are "screening quizzes . . . not a real diagnosis." Symptom checklists help the sufferer assess how well his or her symptoms fit with the diagnostic criteria of particular syndromes. The hope is that the self-diagnosis will lead to a formal diagnosis. Fittingly, the Massachusetts CFIDS Association calls its guide to self-identification "A CFIDS Initiation" and lets readers know that "initiation rites into the CFIDS/ME club are pretty much the same" for all sufferers.

All organizations emphasize that official diagnoses can only be made by physicians. Here the organizations also provide help to people in the process of becoming a patient: sufferers can obtain educational materials for their physicians, direct physicians to the webpages of the organization, and most organizations provide lists of 'good' doctors—physicians who can and will diagnose CFS, FM, and IBS.

### ***Acquiring an Identity***

Once officially diagnosed, the person afflicted with CFS, FM, or IBS becomes a patient with a specific disease. The feelings of fear, frustration, and confusion are now replaced with efforts to launch a new lifestyle. The misunderstood victim is whole again, a 'survivor' with a new identity: "you won't feel so fragmented!" But there is much adapting and learning to do: what sufferers characterize as developing a CFS radar, learning the medical lingo, catching up, managing counter-fear, getting informed, finding out what works, playing an active role in research, and standing up to doctors.

The message is clear. Patients with functional syndromes, although they now have a medical diagnosis, cannot simply let medicine take care of them. There is no cure for CFS, FM, or IBS. The diseases are chronic and available treatments only alleviate some symptoms and only for a while. The online organizations encourage patients to get and stay informed, and get involved; this will, they promise, empower new patients to manage their lives with these "complex, debilitating, and often

disabling diseases.” They urge patients to be active, to become experts of their diseases, and to make lifestyle changes, as the following quotes from webpages illustrate:

Try to take an active role in your own health care. Obtain educational materials from your doctor and an organization such as IFFGD to learn more about IBS and how to best manage your symptoms.

*(IBS Self-Help and Support Group 2014)*

As patients, we are educating the medical establishment, one-on-one from the bottom up.

*(Massachusetts CFIDS/ME & FM Association 2014)*

Try not to let the initial stage of confusion and fear pull you down. Instead, as you add knowledge and connections with other patients, imagine yourself standing in the center of a circle. All the information you need is on the outside edges. As you pull the pieces from the edge toward you, you are in charge and getting continuously more knowledgeable.

*(Massachusetts CFIDS/ME & FM Association 2014)*

The self-help organizations provide extensive information on living with the disease, including relationships, holidays, pregnancy, workplace, diet, and stress management. Personal stories of struggles and success by fellow patients help guide and reassure new patients. The website of the American organization for IBS posted 45 pages with personal stories on its website. The proposed adaptations are all encompassing, and space, place, identity, and daily life will all change if patients follow the well-meaning advice on the web. Patients are also advised to discuss such issues with their physicians. Websites include links to medical research centers and medical articles are posted on the webpages of all organizations. And the new patient should make him/herself available for furthering knowledge about the disease: “donate blood samples,” “participate in research trials,” “fill out surveys.” Thus a person transits from puzzled lay person to well-informed citizen, victimized sufferer to empowered patient, knowledge seeker to object of knowledge formation.

Standing up to doctors and becoming a research object does not only benefit the patient—it benefits the whole community of sufferers. Being a patient with a specific disease validated by a medical diagnosis also means that you are now like ‘us’—those who have the same diagnosis. Patients join an existing community and they acquire a new status as member of a disease community. They are now “people with FM,” “Fibromyalgiker,” “a patient with CFIDS/ME,” an “IBS patient.” There is “us” and “them,” those who are ill and those who are not. Those who do not have the disease are not able to “relate to them as well as someone who has walked the same path”; they have the “view from the outside.” New community members have to learn “the medical lingo” and “catch up” with the “old-timers.” Speaking the new lingo will further separate them from others. To consolidate the community, activities for patients are offered: events, conferences, lectures, and advocacy. To affirm the community, celebrations take place: anniversaries, accomplishments.

### **National Differences**

US and German self-help organizations do not differ in the presentation of diseases and the services they offer. German organizations offer more free information, but the language is more impersonal. The formal *Sie* (You) is used on all webpages, and readers are rarely directly addressed. The organizations gather and synthesize medical information as a service to the patients. They refer to themselves as “your . . . self-help team,” a team that is more “experienced.” Such language implies a hierarchy of expertise. The patient seeking information is the layperson; the employee or volunteer of the organization is what Alfred Schütz called the “well-informed citizen” (1946). At the apex is the medical professional, ‘the expert,’ authoring much of the information for the German organizations. The advice from these professionals often includes alternative and complementary treatments, not surprising given a more holistic German medicine. Politically, the German self-help organizations engage in little more than awareness campaigns, due to different political structures and opportunities for political participation in Germany and the fact that they are partially funded by German sickness funds. The German organizations are also more internationally oriented. Information from and about foreign countries and translations of publications from American self-help organizations

are posted on their websites, as are links to foreign research and medical centers, medical experts, and other self-help organizations. The German organizations explain the high number of American research articles on their websites as reflecting better funding of research in the US.

Most of the American organizations started as local self-help groups and then developed into leading national patient organizations. The main sources of revenue of the US organizations are membership fees and donations. Some of the organizations fund research projects. While a lot of the information on the webpages is free, more detailed information (such as addresses of 'good doctors') is only accessible to paying members. The American organizations are less internationally oriented and much more active in advocacy.

### Discussion

People afflicted with CFS, FM, and IBS, diseases with little biomedical validation, feel misunderstood, isolated, and embarrassed as their lives unravel due to the debilitating effects of these pain syndromes. They find support in online self-help organizations. The members of the organizations are like them. They seem to understand. And they have answers to all the pressing problems and issues sufferers face. Sufferers begin to rebuild their lives and identities: they are now people who belong with others like them; once officially diagnosed, they can legitimately claim a new identity as a patient with a particular disease; they are now members of a community of patients with the same disease. This is the story told by self-help organizations. The story generates the public face of the diseases, disease identities, and disease communities.

Initiation of the 'novice' takes place in the virtual space. The medical diagnosis in the real world affirms the new identity. The new patient then returns to the web to join the virtual disease community. However, successful treatment and getting healthy requires that their newly acquired identity has again to be re-constituted; new communities have to be found. This is particularly disruptive for people who were alone and isolated before, and it is not clear how connected patients actually feel. How involved are they with these virtual disease communities? How much interaction takes place? Does the story told by self-help organizations reflect the experiences of the patients?

Human problems are increasingly represented in biomedical terms. People expect answers from medicine for their afflictions and suffering. The self-help organizations firmly believe that CFS, FM, and IBS can be understood in biomedical terms, and thus cured. The organizations portray the image of a serious debilitating disease. However, those involved in the organizations, and present in the virtual community of sufferers, might just represent a more severely affected segment of the disease population. They might be people who lack social capital and coping abilities and thus need more help; or they might be sufferers who have more social and economic resources, such as Internet access and Internet literacy. If this is so, then whole disease categories and definitions might be based on the most serious cases of a 'patient elite' instrumental in establishing these. Here, the social construction of disease, disease identities, and disease communities takes place at the micro-level of virtual individual interaction, the meso-level of virtual communities, and the macro-level of interests organized online. The Internet is a powerful tool in the construction identities, communities, and diseases.

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The new biosocialities that result from these kinds of self-help groups are a clear example of new ways that we are acting via our ICTs, as we are becoming more dependent upon these technologies for our everyday existence. What it means to be human is being modified, as we explore later (Chapter 15); the ramifications of this warrant a critical medical anthropological approach as they unfold. The virtual spaces described by Hearn are not only sites for exchange of understandings. Through interactions between people suffering from the same conditions, and through their reports of the kinds of treatments that they try out, new knowledge about diseases and treatments emerge.

## Looking to the Future

As new phases of ‘cyborgification’ occur, we integrate machines into our lives in ways very human (Manderson 2011). Rituals of diagnosis, intuition, and emotional reactions to the ICTs are just as important in the clinical realities of patients and practitioners, as are the digitalized and conceptualized patient data that is produced around the clock (Cartwright 1998; Murray 2012; Smith-Morris 2015). Anthropology’s long history of understanding the embodied experience of illness as it is embedded in the subjectivities of everyday life gives the discipline a rich source of theoretical and ethnographic material upon which to draw, as we interrogate what it means to be a human in the midst of so many machines (Biehl and Moran-Thomas 2009).

Innovations in portable interpersonal and interactive communication equipment also address social and cultural barriers, and are improving the process of diagnosis. The expansion of the use of medical technologies allows doctors and other health providers to keep pace with rapid changes in clinical diagnosis and changes in ideas about care; clinicians in effect are being asked to change how they deliver care. Mobile devices such as smartphones, for example, are used for decision support, alerts and reminders, and information on demand, but also, with the use of peripherals, for data collection, such that smartphones and tablets are now the basic technology for monitoring and screening in pregnancy in many resource-limited settings (again, see Chapter 15 when we return to this theme). They review ophthalmic patients and test for visual acuity, deliver patient and physician education, and transmit advice during remote emergency care, so providing health professionals, wherever they are, with assistance in diagnosis and treatment. Along with the ability to gather vast amounts of bio-data and to transmit it from site to site (Ventres et al. 2006) comes the possibility of creating new databases of physiological information to augment our understanding of humans as they function under various environmental conditions—for instance, in extremes of cold, altitude, heat, malnourishment, and the presence of multiple diseases and co-morbidities (Singer and Scott 2003). We can now gather data on intertwined pathological states and record it in ways not imagined only a decade ago. The data generated by the constellations of new devices that can aggregate data across multiple platforms can put to test our present understandings of what ‘normal’ physiology is. New research questions and new ways of answering those questions are being facilitated through the innovations in caring discussed in this chapter; finding imaginative ways to build upon medical anthropology insights from the past to refine our knowledge of how we care for one another is our challenge for the future.

As caring for ourselves and for others becomes more and more virtual, our research methods have had to adapt. Virtual ethnographies, in which medical anthropologists participate in online forums to gain understanding of new care modalities and understandings of health and disease, can help us gain insights into new care modalities. New software allows the ‘scraping’ of content of such Internet sites and discussion forums, and content analysis of large data sets. In exploring

such new technologies, anthropologists need to rethink ethics. How do we participate in virtual spaces as researchers? How do we present ourselves? And by what means can we communicate our findings back to the virtual communities?

## Notes

1. <https://communities.intel.com/community/itpeernetwork/healthcare/blog/2015/02/04/part-ii-5-significant-health-it-trends-for-2015>
2. Thanks to Mark R. Romero, nurse paramedic with the Lifeflight Network helicopter rescue team, for these insights.

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