FOREWORD

At the end of 1995, Gerhard Nijhof, medical sociologist, was diagnosed with intestinal cancer in an advanced stage. It meant a turning point in his personal *and* academic life. In early 1996, he was hospitalized for one month, undergoing several difficult operations. He then spent the next twelve months recovering and recuperating at home. During that year, he tried to decipher the notes he had scribbled down while in the hospital, which resulted in the publication in 2001 of a sociologically substantiated autobiographical account of his experiences in the hospital and at home, and what it means to be a seriously ill person. The writing, he remembers, was an integral part of his rehabilitation. This book is a translation and slightly revised version of the Dutch original.

Nijhof first studied medicine, but after one year he turned to sociology. His doctoral dissertation dealt with the relationship between social class and mental disturbances in the city of Rotterdam, which was followed by several books and many articles on this topic. More recently he focused his attention on language and text in the field of health and health care, in particular doctor–patient communication and the life stories of people with chronic diseases. From 1980 to 2003, he was a professor of Medical Sociology at the University of Amsterdam. In 2003, he retired from the university but continued writing and publishing.

Nijhof wrote this autobiographical account of his life as a patient for a wide audience and in deceptively simple language, "deceptively" because his reflection is also addressed to sociologists and other social scientists. It deals with the crucial epistemological question: Is it possible to understand and describe the experiences of those we study, in particular the suffering of the seriously ill? Scientists may make all kinds of claims about what sick people think and feel, but sometimes the sick know from their own experience that they are wrong; the researcher was perhaps fooled by his informants, or he misunderstood them because he did not have any affinity with their experience. Patients and other "experience experts" increasingly criticize researchers for not speaking their language, not picking up the issues that concern them, and not providing information and recommendations that are important to them. Instead, researchers are mostly writing for an academic audience and appear to be much less involved with and close to the people they study than they claim in their prefaces and conclusions. Participation in the anthropological sense of the term would be a more solid and true-to-life basis for the sociological study of sickness and suffering. But is it possible to participate in being a patient?

There are mainly three options for attempting to participate: As patient, as caregiver, or as concerned third party (relative, friend, and visitor), which implies three different roles. The last two are relatively easy; the first—the most relevant one—is, however, extremely difficult and tricky. For experiencing the experiences of the sick person, one cannot content oneself with walking between the beds like a doctor, nurse, or visitor; such a researcher should be a bedridden patient himself. In an earlier publication, Nijhof wrote: "Who knows best what is going on in the minds of dying people? The person who practices participant observation with compassion? Or the one who is close to the sick person? Or the interviewer who inquires into his recent experiences? Or the person who falls sick himself, who thinks about his condition and writes down what happens?" These are rhetorical questions; everyone agrees that the sick person is the best "equipped" "researcher" (provided, of course, that the patient is able to write reflectively about his experiences). Examples of sick people as researchers are, however, relatively scarce.

Two well-known examples of such researchers who were affected by a serious sickness and used their experience to write more empathically and more intelligently about illness are Arthur Frank and Robert Murphy. Murphy (1987) wrote about his illness over a period of eighteen years, from the moment the first symptoms of a spinal cord tumor presented themselves to his being restricted to a wheelchair and becoming entirely dependent on others. This ethnography about one person shows what illness does to social identity. His struggle for autonomy slowly grows into acceptance and finding deeper meaning. His reflection starts with an observation from the time when he still was an outsider to the world of disease and disability. He sees a severely disabled person in a wheelchair and wonders why such a person would want to live. He is unable to grasp that person's desire for life. When, many years later, he is disabled himself, he remembers that moment and is finally able to explain to himself and his readers how much life still holds for him.

Arthur Frank (1991, 2001, 2004) has written extensively about his own experiences of illness, using them as "data" that enhance his authority as an author of sickness and suffering. He (Frank 2001) takes the position of a patient who is approached by a researcher; that meeting can lead to feelings of disrespect and insult if the sick person feels he/she is being broken down into ethnographically and theoretically interesting fragments.

Gerhard Nijhof's *Sickness Work* deserves a place in the company of authors such as Frank and Murphy (and several others mentioned in his account). Moreover, it is an attempt from an insider's perspective to forge a new kind of medical sociology. For most medical sociologists, serious illness is not a personal experience. They conduct surveys or hold interviews and return to their universities or homes to analyze and write up their findings. The concepts they use reveal their provenance: the minds of healthy sociologists. Nijhof became acutely aware of this when he fell sick, encountering completely different concepts. One such concept was "techno-security." Social scientists had written extensively and critically about the "technologization" of medical care. Doctors and nurses are criticized for being busier with machines than with people. The machine becomes the patient's enemy, or at least his/her rival. Nijhof had rarely read anything about the sense of security that machines may bring to patients. For him, alternatively, the machines were sources of trust and security, magical instruments that kept him alive. When, shortly after his operation, a doctor told him the "good news" that he could leave the intensive care unit and return to the ward, he was scared. He did not want to be separated from the safety that the machines provided.

Another new focus point was the night as an unresearched or undiscussed phenomenon, unacknowledged in medical sociology, which only seemed to be interested in daylight. "I cannot remember ever having come across the word 'night' in any of my literature. Most sociologists sleep at night, and society is closed for them then. But perhaps night is absent from their work because they think little happens there, they think other people sleep at night, too. But that is a mistake." One of the disruptions of everyday life brought about by sickness is that the rhythm of day and night is interrupted. "It's no longer a matter of working during the day and sleeping at night. You don't work anymore. You sleep whenever sleep overtakes you, if you can fall asleep, and not if you can't fall asleep." Getting through the night is one of the most difficult tasks of "sickness work." The television, with its repetitions of daytime programs such as political discussions, football matches, tennis tournaments, and the Tour de France, saved him. His reflections on the night end in a plea for "every-night healthcare" (in contrast to "every-day").

A recurrent theme in his musings as well as in his most recent work, including his valedictory lecture (Nijhof 2004), are the concepts of normality and everydayness. "Sickness work" is a matter of changing the abnormality of being disabled and fragile into normality. "This book is mainly about technique, about the work of learning to do unusual things in an ordinary way, about developing routines," he writes. And: "Everything that had seemed exciting and unusual at first turned out to be quite ordinary after a brief stay." Recapturing normality, one could say, is a way of regaining a new form of "health." Abnormality is perhaps the most outspoken telltale sign of sickness. This thought is the central intuition of his later work on Parkinson's disease (e.g., Nijhof 1995).

His main "conversion" as a sociologist was his acknowledgment of the importance of the unspoken word. For years he had been studying words, spoken and written. Analyzing texts had been his main occupation, until he came to realize that people may keep silent about certain experiences. "When sociologists conduct interviews, they usually focus on the talk and rarely on the silence. We know that people are silent about a great many things, but it's their talking that we listen to. It's true that we encourage them to talk, but the things that people keep their mouths shut about escape us." That is the reason that interrogating sociologists miss so much of what sickness means to sick people. A sickness such as cancer is mainly surrounded by silence…

It should be noted that Nijhof wrote his reflections mostly in 1996 and that they were published in 2001. His critical comments about the status of his own discipline, medical sociology, must be placed within that period. Most of the shortcomings he called attention to, such as ignoring the night, the problem of fatigue, the work of nurses, the verticality of the horizontal patient, the trust in technology, the silence of suffering—in short, the patient's point of view—have since received considerable attention from medical sociologists and anthropologists. One could therefore say that his suggestions for a more true-to-life sociology were prophetic. The absence of present-day sociologists in his references should be seen in that light. No update has been attempted in this English translation of his work. The book takes us back to the year 1996 but also makes us wonder about today.

The main merit of Nijhof's book lies in the personal and professional reflection on one case of sickness, and taking that one case as a vantage point from which to explore wider areas in the experience of being critically ill. His story is similar to autobiographical accounts of colleagues such as Irving Zola, Robert Murphy, Arthur Frank, and Albert Robillard. Each of these authors had a specific focus; Nijhof's central experience and idea—as I just mentioned—was that the rupture of normality and everyday routine brought about by sickness had to be reversed through hard work and continuous readjustment. His account of the small details and imponderabilia of everyday navigation within the restrictions of sickness is as relevant today as it was in 1996.

Nijhof's pondering shows what the radical sharing of experience brings about in research on the meaning of sickness. Participating in sickness cannot be programmed, but when one falls sick, one may make a "virtue" out of this necessity. *Permanent receptivity* by the patient is the most felicitous way to achieve intersubjectivity in research, but sickness is at the same time a personal misfortune, a condition that obstructs research. Permanent receptivity of one's own condition helps one to grasp the opportunity to come closer to "the other." Frank (2004: 439) captures this permanent receptivity by turning around the well-known counsel that the researcher should go where the action is. We should rather be aware that there is "action" wherever we are, he argues. Gerhard Nijhof's reflection is an impressive example of this receptivity while being seriously sick. In the eminent translation by Nancy Forest-Flier, this book is both a testimony to sharing the intimate experience of sickness with others and a humble prolegomenon of a more experience-based medical sociology.

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