Why shared decision making is not good enough: lessons from patients

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ABSTRACT
A closer look at the lived illness experiences of medical professionals themselves shows that shared decision making is in need of a logic of care. This paper underlines that medical decision making inevitably takes place in a messy and uncertain context in which sharing responsibilities may impose a considerable burden on patients. A better understanding of patients’ lived experiences enables healthcare professionals to attune to what individual patients deem important in their lives. This will contribute to making medical decisions in a good and caring manner, taking into account the lived experience of being ill.

When the Dutch poet, writer and performer Bart Chabot was diagnosed with a large but benign tumour in his head (acoustic neuroma), he soon established he had three treatment options.1 The first was surgery in Leiden, where the tumour would be removed at the cost of Chabot’s left-side hearing. This sacrifice is the consequence of operating the tumour right through the ear in order to minimise the risk of touching the nervus facialis which would lead to a disfigured face. Chabot’s second option was treatment in Tilburg. Here, neurosurgeons have a Gamma Knife at their disposal, a device for high intensity radiation therapy. The precise delivery of γ-radiation would stop the tumour from growing but leave Chabot with the uncertainty of a tumour leftover in his head. A third option was surgery in Amsterdam, where there was a chance Chabot would keep his hearing. In Amsterdam, an acoustic neuroma is removed by making an opening behind the patient’s ear instead of sacrificing the patient’s hearing. This, however, would bring along an increased risk of affecting the nervus facialis. What should he do?

Chabot found it very difficult to make a decision. The surgeons who provided him with information were very clear on the facts. They explained the exact treatment procedure, reassured Chabot of their ample experience, and mentioned the risks and side-effects. Chabot reduced his options to Leiden and Tilburg. Surgery or radiation? Losing his left side hearing and balance or living with the uncertainty of a tumour leftover in his head? ‘I am a lay person who is in the dark,’ he determined (p. 78). Instead of deliberating rationally about his treatment possibilities, Chabot wondered what he and his family may expect. He compared himself with other patients who seemed to be in a worse situation. Chabot shared his uncertainty with others and found out that many of them responded with a look that said ‘it is your head, the customer is always right, you may decide’. Finally, he consulted with a friend he trusted, a neurologist. Chabot’s friend consulted with other colleagues, spoke to the neurosurgeon in Tilburg and recommended a Gamma Knife treatment. This accorded with Chabot’s own intuitive preference. Having surgery is an option when radiation fails, Chabot and his friend finally argued.

SHARED DECISION MAKING?
Shared decision making is increasingly considered the norm. Recently, Stiggelbout et al2 claimed that it is an ethical imperative under the four medical ethical principles of respecting autonomy, beneficence, non-maleficence and justice. They characterise shared decision making as a complex intervention in which patients and clinicians make decisions together—as partners—using the best available evidence. Medical decision making is approached as a shared process with shared responsibilities in which clinicians present the various treatment options, benefits, harms and probabilities and patients weigh the pros and cons and gradually develop their preferred decision. However, the experiences of Chabot suggest that it is not so much the decision as such but the situation in which the decision is to be made that bothered him. Making a good and informed choice is not necessarily the same thing as making a decision in a good manner, that is, making a decision that fits with the lived experience of the person whom it concerns.

Mol frames these two perspectives on decision making as a logic of choice and a logic of care.3 According to her, good care is not about making the right choice; it rather takes into account the experiential context in which choices have to be made. Table 1 offers an outline of the two logics Mol presents focusing on the roles of patients and professionals and their relationship to each other. A logic of choice focuses on the ability to choose and to make an informed and distanced judgment on one’s own life. A logic of care, however, takes a closer look at the practices and situations that make up the context of decision making. A logic of care perspective draws attention to the issue that making such serious decisions means that patients and families need to figure out how to live their lives while dealing with illness and disease.

That is why in order to improve healthcare the articulation of a logic of care seems to be more fruitful than articulating a logic of choice through shared decision making. A logic of care takes the needs that emerge in the messy, open-ended and ever-changing healthcare practices as a starting point instead of splitting up responsibilities and weighing relevant arguments, values and
preferences as a logic of choice does. ‘Thus, in the logic of care it is not the noun that is crucial, life (an object that may be judged), but rather the verb, to live (an activity of which we are the subjects)’ (p. 94). Mol argues for a better understanding of these caring practices, in which patients and clinicians are involved. Good care in everyday practice is rather a collaborative enterprise in which health professionals and patients continuously cocreate and codirect the course of events that make up a patient’s life.

Helping to make a medical decision in a good manner requires insight into the lived experiences of patients. This is apparent when studying the experiences of doctors, nurses and medical ethicists who became ill and needed professional healthcare. These patient experiences show that even for them decision making inevitably takes place in an uncertain and messy context: a context in which sharing responsibilities may impose quite a burden on patients, and healthcare professionals time and again have to attend to what individual patients deem important in their lives.

EXPERIENCING PATIENTHOOD

Both doctor-patients, nurse-patients and medical ethicist-patients were struck by the experience that patienthood meant feeling vulnerable and disempowered. General practitioners (GPs), for example, who had been seriously ill experienced being a patient as synonymous with emotions like anxiety, uncertainty, shock and loss of control. This made them both acknowledge the disempowered status of non-medical patients and becoming more aware of the social aspects of healthcare.

One of the key lessons nurses (see box 1) had learnt during their hospital admission was the lack of energy and initiative they felt while in a hospital bed. One of the interviewed nurses told her was regularly annoyed at work when patients walked down the ward for a toilet visit in just an undershirt until the moment she experienced her own lethargy as a hospital patient and behaved in the same way. Nurse-patients also found it difficult and disempowering to be confronted with various physicians who all had their own questions and different, non-alining messages. It increased their uncertainty with regard to their illness and treatment.

Medical ethicists who became cancer patients and wrote about their experiences learnt that making an informed medical decision is far from straightforward. They all struggled to make sense of confusing, contradictory, and questionable claims about treatment options and obtaining clear information concerning benefits, risks and alternatives was sometimes difficult. Patient autonomy can be challenging, medical ethicist Dresser noticed. She refused a feeding tube during radiation treatment and this decision turned out to be a serious threat to her health. ‘Even the most educated and savvy patients facing serious medical decisions may not be very good at applying their values and preferences to this new kind of choice’, she concludes (p. 66).

Medical ethicist Dan Brock had always been an advocate of shared decision making until he had to deal with prostate cancer himself and was diagnosed with multiple sclerosis. Shared decision making assigns more responsibility to patients but ‘that responsibility can be hard for patients to handle’ he realised (p. 53).

IN THE HANDS OF THE DOCTOR

His illnesses taught medical ethicist Dan Brock that in practice, shared decision making requires much more than a discussion of the medical facts. More important than the decision itself is to help patients ‘understand the ways that different treatments could affect their well-being, values, and plans for the future’ (p. 53).

Their own illness experiences made physician-patients, nurse-patients and medical ethicist-patients see how their dependency compelled them into the hands of health professionals. All seven medical ethicists who contributed to the recent volume Malignant realised how utterly dependent patients are on doctors and nurses. Paediatrician and bioethicist Norman Post writes: ‘Even a patient like me, a person with extensive medical training and experience, must at some point put himself in the hands of his doctors and trust that they know what they’re doing’ (p. 23).

| Box 1 Nurses as patients |

In cooperation with the Nurse Advisory Council of the St Elisabeth Hospital in Tilburg, two lunch meetings (140 nurses) were organised on the question ‘Does illness make you better?’ Central in these meetings were the stories of three nurses who had been admitted to their own hospital as patients and had learnt lessons that influenced their caring practice ever since. They were interviewed on stage and shared their illness experiences with colleague nurses. The key message was: when you’re a patient, you’re not the same person as in daily life. Their stories evoked a lively discussion with the audience. The report of this discussion is used as one of the inputs for the current paper.
Several nurse-patients in our meeting (see box 1) noticed that clinicians often implicitly presumed they were knowledgeable about their disorder or about hospital customs because of their professional background. It showed them the importance of impartiality and approaching patients as individuals as much as possible. This is also acknowledged by GPs who suffered from significant illness. They experienced that their relationship with clinicians was the most productive when their individuality as doctor-patients was acknowledged, taking their unique hopes, fears and expectations into account. The GPs also felt that their illness experiences increased the depth of their understanding and enhanced their emotional connection with all patients, when back at work.

Furthermore, another study among doctor-patients brings forward what they had learnt about the delicacies and intricacies of communication. Their illness experience showed these physicians the importance of attuning the presentation of poor prognoses to patients’ experiences, the important role tone and gentleness play in communication, and the significance of non-verbal interaction in patient contact. Both studies point out that having been patients themselves made physicians realise how important it is to give patients the confidence to ask questions and negotiate their own solutions.

Shared decision making does not always imply matters of life and death. It also concerns supporting patients to maintain a life worth living, despite the consequences of their illness. As the illness experiences above make clear, their dependency compels patients to put themselves in the hands of healthcare professionals. This dependence applies for adequate medical expertise, but also for responses of healthcare professionals that fit in with the highly individual experiences of patients.

TO CONCLUDE: TOWARDS CARING DECISION MAKING

Putting patients at the centre demands a healthcare approach that departs from what patients live through when they are ill. Putting patients at the centre of all decisions, as Stiggelbout et al argue, reflects a part of patient-centred healthcare. The messiness of informed decision making in clinical practice—where patients are sick, vulnerable, dependent and socially context of illness—may be experienced guilt. Our analysis of the experiences of medical ethicists, doctors and nurses as patients points out that patient-centeredness requires a logic of care to supplement the predominant logic of choice. Two strategies may help to integrate a logic of care into shared decision making.

In the first place, our analysis underlines the importance of understanding the messiness of lived experiences of people who have to deal with serious illness and supports the growing attention for research with qualitative methods to explore how individuals experience illness in real-life contexts. In accordance with this, Dresser argues for a first-person bioethics that better appreciates the existential, psychological and social context of illness.

Second, promoting a logic of care should be integrated in medical education. Doctor-patients describe a considerable difference between their intellectual and experiential knowledge. More awareness of this gap seems to be imperative, just as a better balancing of principle-based ethics and care ethics in medical and nursing education. Narrative medicine is one way to widen trainees’ points of view. Another way is the creation of a pedagogical context in which good care can be taught and cultivated. Personal portfolios and self-reflection may provide such a context, just as a ‘care-ethics lab’ in which patienthood can be simulated in exercises and ethical reflection on good care and what it means to be a patient can be stimulated.

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