

Phenomenology in Medicine

A Reflection on Shared Decision-Making in the Clinical Encounter



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Abstract

Ever since the mid-1990s, the importance of implementing shared decision-making in the medical encounter between a doctor and a patient has been increasingly emphasized. Shared decision-making seems to want to carry out the same goals as found in the tradition of phenomenology in medicine; a better communication with and involvement of the patient in the disease process and the decision-making that comes with it. The question is to what extent it actually succeeds at this? One of the best results shared decision-making could achieve in this light is the appreciation of the impact illness has on a patients' life, not just as a secondary effect of the biological disease but as a primary phenomenon. However, this might be too ambitious for the current state of affairs. The gap between the third and first person experiences of illness is more than just a difference in mutual information and knowledge level that shared decision-making tries to solve. In addition to this, practical matters such as the level of training for doctors in shared decision-making, the costs of the process, as well as a patient's will to actually participate in the process, are not completely resolved. However, if the practical hurdles can be overcome, shared decision-making will be a way to make explicit the assumptions that result in the distortion of meaning on both ends, especially allowing for the patient to provide a detailed account of 'illness as lived'. And this will in turn change the role of the physician from the paternalistic father to perhaps a type of coach, and as such finally putting the patient at centre. The inequality and gap between the patient and physician is inevitable and perhaps even eternal, but realizing the gap is there, discussing the gap and together figuring out a way to come closer, might be the only and true way to have an equal conversation in an unequal setting.



Chapter 1 Prologue

As a medical student I am aware of the challenging nature of the field I want to dedicate my life to. More than my personal academic and clinical development, I look forward to my relationships with my colleagues, patients and their family. Supporting them in difficult times and actually contributing to a greater good seems a splendid way for me to spend my life.

As a philosophy student I have an endless curiosity towards what I like to call ‘the sandcastles’ of life; beliefs, assumptions or rules we have constructed and all seem to oblige by. With a childish enthusiasm I look forward to kicking them down, just to see what will happen or remain. Sometimes I need to conclude that the sandcastle was the truth after all. But just as many times I come to realize that kicking them down was the right thing to do. And this is just when the fun starts; a new castle must be built from scratch, a new philosophical theory, belief or rule to hold together the sand.

Combing the perspective of a medical and philosophy student brings together the best of the two worlds described above. Looking for the sandcastles in medicine in particular has not only proven an enormously interesting and satisfying challenge, but also a very useful one. I have come to passionately believe in the need for sandcastle-kickers in our field and hope and thrive to continue to be one.

In this bachelor thesis I hope to take the first steps towards these goals by reflecting on one of the most ancient and appreciated practices in medicine: the art of conversation between a patient and his physician.



Chapter 2 Introduction

“Nothing about me without me.”¹

Ever since the mid-1990s, the importance of implementing shared decision making in the medical encounter between a doctor and a patient has been increasingly emphasized. Several prominent medical journals have published articles of researchers announcing that shared decision making is ‘the new paradigm’ in medicine, a breath of fresh air compared to the traditional ‘doctor knows best’-mentality².

In 1998, for example, *Health Expectations*, was launched, an international journal entirely devoted to the area of patient and public involvement in health care decision making.³ A year later, the British Medical Journal published a special issue on patient partnership in recognition of the need to further study this ‘paradigm shift’.⁴ It seems, therefore, that a new approach to treatment decision making is advocated, and it is suggested that the notion of ‘shared decision making’ is used “as a deliberate contrast to emphasize the role of the patient.”⁵

Ignoring for now the fact that these statements lead one to believe that there is a clear definition or consensus on what shared decision making exactly entails, these examples show that the incentive of shared decision making is slowly but steadily coming to surface. And this rise, in some sense, seems to carry out the same goals as found in the tradition of phenomenology in medicine; a better communication with and involvement of the patient in the disease process. As stated by Toombs in *The Meaning of Illness: A phenomenological Account of the Different Perspectives of Physician and Patient*:

“In discussing my illness with physicians, it has often seemed to me that we have been somehow talking at cross purposes, discussing different things, never quite reaching one another. [...] Rather than representing a shared reality between us, illness represents two distinct realities- the meaning of one being significantly and distinctively different from the meaning of the other.”⁶

This fundamental discrepancy in perception of illness, according to Toombs, calls for a phenomenological approach. In this essay I will discuss whether and to what extent the incentive of shared decision making is able to grant our ‘phenomenological wishes’. And then, what are the consequences for the future of medicine?

¹ Billingham V., *Through the Patient’s Eyes*, Salzburg Seminar Session 356 (1998)

² Barry M.J., Edgman-Levitan S., *Shared Decision Making- The Pinnacle of Patient-Centered Care*, *N Engl J Med*, (2012), p.780

³ Coulter A. Editorial. Welcome to the inaugural issue. *Health Expect.* (1998), p.1

⁴ Schoefield T, Elwyn G, Edwards A, Visser A. Shared decision-making. *Patient Educ Couns.* (2003), p. 229

⁵ *Ibid.*

⁶ Toombs S.K., *The Meaning of Illness, A phenomenological Account of the Different Perspectives of Physician and Patient*, (1992), p.11



Before looking into this critical phenomenological reflection on shared decision making, we will start this essay by building up a general background knowledge of the two concepts used in our discussion; phenomenology in medicine and the concept of shared decision-making.



Chapter 3 Meet Susan

When considering the workings and functioning of clinical practice, as we partially aim to do in this work, it is easy to get lost in abstract terms far away from the actual reality of the patient-doctor interaction. Terms such as ‘the ill patient’ or ‘the decision’ will lose its meaning and become vague, general concepts if we don’t allow them to take concrete shape. Therefore, before moving any further into this essay, I would like us to jump off that cloud. With both feet on the ground, I would like you to meet Susan S., a real-life anonymized patient, functioning as an example case throughout the rest of this essay.

Susan S. is a thirty year old entrepreneur with her own publishing house. She lives in Amsterdam since last summer, when she moved in with her partner Rob. Rob is a full-time accountant who collects cars in his free time. Rob and Susan have been together for two years now, have never really discussed kids, but Susan keeps the option open. At least, she hopes she still has the option.

Susan was diagnosed with severe aortic valve stenosis almost four years ago in Rotterdam. She has always had issues with her heart, causing her to be out of breath really fast and unable to move around as easily as other women of her age. She tires very quickly, often has chest pains and sometimes lays awake at night afraid to fall asleep due to heart palpitations. An incident three months ago was the last straw; Susan hurried up the stairs too fast to catch a train and collapsed. Not much later Susan ends up in the hospital, where the cardiologist refers her to Dr. H, a senior Cardio-Thoracic surgeon, who tells her it’s time for the operation that will replace her sick aortic valve with a new one. Before the end of the year Susan has a decision to make; what kind of valve will she choose to replace her own with? Will it be a mechanical valve, made of titanium or steel? This valve will probably last a lifetime, but will also require Susan to take blood thinners for the rest of her life and get regular blood tests to ensure her blood count is optimal. In addition, the use of blood thinners will require her to live a regular lifestyle with minimum alcohol consumption and avoiding extreme sports which might initiate bleeding. The blood thinners may also, with a probability, affect a possible pregnancy and give her a general higher risk of bleeding. Mechanical valves make a ticking sound that patients often hear, constantly reminding her of the surgery. Then there is the biological valve, made of organic material (usually pig or cow, or human). This will allow her to stay off the blood thinners and open up the possibility of pregnancy, but it will not last her a lifetime. With her young age, she probably have to be re-operated in 10-15 years due to wear and tear of the valve. And then there is the choice on what kind of biological valve she wants; animal or human? Should she use a human donor valve or replace her sick valve with one of her own, healthy valves⁷?

⁷ Tillquist MN, Maddox TM. Cardiac crossroads: deciding between mechanical or bioprosthetic heart valve replacement, (2011).



Chapter 4 Phenomenology in Medicine

“A true physician should also be a philosopher.”- Galen⁸

In the times of Galen, philosophy as the mother of all sciences, was almost a synonym for medicine. However, as we will discover in upcoming chapters, throughout the course of history the role of the physician changed and so did medicine’s vicinity to philosophy. Nevertheless, this has never stopped philosophers from reflecting on the issues within medicine.

In the early years of the twentieth century the tradition of phenomenology saw the light. Briefly stated, phenomenology ‘examines the encounter between consciousness and the world’⁹:

“It is the science (logos) of relating consciousness to phenomena (things as they appear to us) rather than to pragmata (things as they are).”¹⁰

As such, we could say that phenomenology is not interested in making metaphysical claims. Rather, it focuses on the experiences of thinking and knowing and how phenomena appear to consciousness within these experiences. Phenomenology is also a primarily descriptive science: a practice rather than a system. It is due to this nature that phenomenology has been used in disciplines ranging from film and music to sociology and nursing. Heidegger, one of the founding fathers of the field, might have given one of the most interesting examples of a phenomenological experience, namely that of viewing the painting *Peasant Shoes* by Van Gogh:

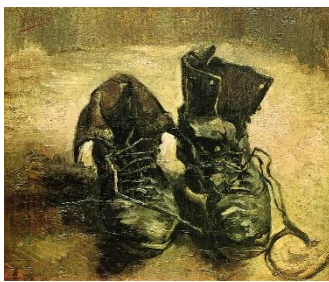


Figure 1 Painting Shoes,
Vincent Van Gogh (1888)

“From the dark opening of the worn insides of the shoes the toilsome tread of the worker stares forth. In the stiffly rugged heaviness of the shoes there is the accumulated tenacity of her slow trudge through the far-spreading and ever-uniform furrows of the field swept by a raw wind. On the leather lie the dampness and richness of the soil. Under the soles slides the loneliness of the field-path as evening falls. In the shoes vibrates the silent call of the earth, its quiet gift of the ripening grain and its unexplained self-refusal in the fallow desolation of the wintry field. This equipment is pervaded by uncomplaining anxiety as to the certainty of bread, the wordless joy of having once more withstood want, the trembling before the impending childbed and shivering at the surrounding menace of death. This equipment belongs to the earth, and it is protected in the world of the peasant woman. From out of this protected belonging the equipment itself rises to its resting-within-itself.”¹¹

Whoever is just a little bit familiar with Heidegger’s work will immediately recognize his style and almost incomprehensible vocabulary. However, this quote does illustrate how phenomenology is about describing experiences against their backgrounds:

“Phenomenology is used to attend to various aspects of our experience, providing a method for discerning and describing human experience. It is particularly useful not only for analysing units of

⁸ As cited in: A History of Medicine, Magner L.N., (2005), p.89

⁹ Carel H., Phenomenology and its application in Medicine, (2011), p.34.

¹⁰ Ibid.

¹¹ As cited in: The Art of Art History : A Critical Anthology, Preziosi D., (2009),p.296



input (e.g., a spoken sentence) but in understanding the particular background against which the input is perceived and interpreted.”¹²

“In order to render this world comprehensible, we interpret it in the light of a meaningful structure which we impose upon the “reality” we encounter. By means of intentionality and directedness of act of consciousness, we attend certain aspects of our experience which are always perceived against a background or horizon which includes a unique biographical situation and stock of knowledge and which incorporates the horizons of past and future.”¹³

This background need not only be a cultural one. Phenomenology is more than just a form of anthropology, but rather a philosophical method looking into the very conditions of the possibility for having a particular experience. From this quote it is not a far stretch to the field of medicine.

Traditionally, phenomenology in medicine has also focussed on the human experiences, and particularly on the discrepancy between that of the patient and the doctor:

“Since all experience represents a correlation between experiencing and that which is experienced, and since the locus of meaning is grounded in the intentional activity of consciousness, the Other’s experiencing is not immediately accessible. Everyone has exclusively his or her own phenomena which only he/she is capable of experiencing quite originally.”¹⁴

Just like in van Gogh’s painting, the shoes are explained against the background of the person owning them, so is the experience of disease explained against the background of the patient. This subjective experience of a disease is, as we will discover later on, significantly differs from the objective disease the doctors sees, examines and tries to treat. Susan *experiences* the disease, and this subjective experience of disease is described as *illness*, a significantly different entity. As in the case of Susan, she experiences the disease against her own background: she is relatively young, just moved in with her partner, might want to have kids and is thinking about the rest of her life with her partner. Dr. H sees Susan’s disease against the background of his own experience in the field, previous patients he helped with this particular disease or a research grant he received to investigate the long-term results of mechanical valve replacements. A clarifying example would be one in the realm of temporality. Imagine Dr. H asking Susan how long it takes for her to recover from an out-of-breath-experience when she hurries up a flight of stairs. Dr. H wants to know whether it was seconds, minutes or hours, in order to differentiate between the numerous diseases he is considering and has seen in his live. Susan, on the other hand, only experiences this one disease, and quite intensely. She is out of breath when she is trying to catch the train. She was out of breath when running after her partner during a fight. And those moments seem endless. As S. Kay Toombs explains in *The Meaning of Illness*:

“Illness as it is ‘live through’ is experienced as an ever-present, enduring consciousness of disorder which resists measurement in terms of objective time”¹⁵

¹² Carel H., Phenomenology and its application in Medicine, (2011), p.34-35

¹³ Toombs S.K., The Meaning of Illness, A phenomenological Account of the Different Perspectives of Physician and Patient, (1992), p.7

¹⁴ Ibid.

¹⁵ Toombs S.K., The Meaning of Illness, A phenomenological Account of the Different Perspectives of Physician and Patient, (1992), p.15



In addition to time, illness is experienced differently by physician and patient in many other domains as well, revealing a systematic distortion of meaning in the patient-physician relationship. Maurice Merleau-Ponty, a French phenomenological philosopher, adds another layer to this acknowledgement of the primacy of perception with his ‘embodied phenomenology’. Merleau-Ponty explains perception as an embodied activity, with the body being the condition of possibility of perception and action. This nature of experience is our foundation of subjectivity. As Havi Carel explains about Merleau-Ponty’s vision in *Phenomenology and its application in medicine*:

“The kind of creatures we are is circumscribed by the types of experiences we have and the kinds of actions we perform, both of which are shaped by our bodies and brains. Any attempt to understand human nature would have to begin with the body and perception as the foundations of personhood.”¹⁶

As such, the body forms the source of subjective feeling for Susan. However, the body is also considered to be a physical thing, an object that can be weighed, measured and described using medical terms by Dr. H. This makes the body a so called ‘subject-object’, a being that can be experienced from both the first and third person point of view. In the everyday experience of a healthy body the objective and first person body seems to be aligned and in harmony. In illness, however, the body loses its ‘transparency’ in some sense. Our experience of it comes to the foreground and our attention is drawn to the malfunctioning part. We suddenly become aware of the things we used to but no longer can do, such as running for the train in Susan’s case¹⁷.

This phenomenological view of (the experience of) disease allows for a reflection on how to shape the patient-physician relationship, the subject of our essay. Although phenomenology as such does not seem to put normative claims on medicine itself, it is often seen as valuable theory to apply to medicine. Carel himself explains in his paper:

“By using the distinction between the objective body and the body as lived, we can expose a potential difficulty in the patient-physician communication. Generally speaking, the clinician understands illness as a biological process, in abstraction from lived experience. For the patient, on the other hand, illness is experienced in its qualitative immediacy, grounded in lived experience. For example, clinical data may be viewed as knowledge to the physician but they are ‘news’ to the patient.”¹⁸

From the same phenomenological point of view which describes this gap between the patient and the physician, we could also look for possible solutions or improvements for the relationship. Carel himself describes a generally accepted suggestion, in which phenomenology could be used as a way to present to the clinician ‘some of the invariant features of illness as experienced, such as bodily change and reduction in ability to perform daily activities.’¹⁹ He also states that ‘phenomenology can be used to examine the nature of the difference between patient and physician understandings make explicit the assumptions that result in the distortion of meaning, and provide a detailed account of illness as lived.’²⁰

¹⁶ Carel H., *Phenomenology and its application in Medicine*, (2011), p.36.

¹⁷ This getting used to performing certain tasks is sometimes described as the ‘Habitual body’ in phenomenology (or the body as lived), explaining how in illness the relationship to an environment and to a set of abilities is no longer available.

¹⁸ Carel H., *Phenomenology and its application in Medicine*, (2011), p.42.

¹⁹ Ibid.

²⁰ Ibid.



With this phenomenological analysis of the patient-doctor relationship made clear, as well as the possible improvements we could deduct from it, we can move forward towards the next chapter in answering the question whether shared decision-making lives up to these phenomenological expectations.



Chapter 5 The Clinical Encounter in Historical Context: An Impression

‘Medicine is an interpretive meeting, which takes place between two persons (the doctor and the patient) with the aim of understanding and healing the one who is ill and seeks help. Clinical medicine [...] is thus first and foremost a practice and not a science.’²¹

As described in the introduction, the incentive of shared decision making is causing a new paradigm in the clinical encounter. However, to understand this new paradigm and the shift it claims to cause, it is necessary to discover the old paradigms it tries to shift away from. This chapter will be devoted to just that; giving a sketch of the clinical encounter in the Western history.

The Father and Founder- Hippocrates

Seen as the father of Western Medicine and the name all doctor’s still oath by, we will start our sketch with Hippocrates. His way of medicine is what historians describe as a handicraft- an art and practice- aimed at curing the patient through the doctor’s skills.

The Hippocratic physician considered his patient as placed in a *kosmos* or world order, which mirrored the order *within* each individual. Illness was essentially an imbalance, and the physician’s task was to find what this imbalance consisted of through experience and argument. This made the Hippocratic physician more than anything, a craftsman, according to German historian Ludwig Edelstein:

‘While the modern doctor, in spite of the payment he receives, is not on the same social level as the other craftsmen, who, like him, are paid for their services, the ancient physician is the equal of the other craftsman and thereby occupies a low position in society. [...] to the patient the physician is craftsman who must prove that he knows his business and that he is just as eager to do his work well as to earn money.’

Other historians claim the patient-doctor encounter in Ancient Greece was based more on an urge to help and understand; a form of *medical philia* or friendship as the Greek called it, coming from both the patient and the doctor. As Plato states in the *Lysis* (217a) ‘The sick man loves the physician because he is sick’.

Pre-modern Medicine

Talking about modern medicine right after Hippocrates, means skipping more than a thousand years of history. Nevertheless, this jump seems to be justified, as most historians claim that during the time in between no essential medical progress was made up until

²¹ Svenaeus F., *The Hermeneutics of Medicine and the Phenomenology of Health*, (2000), p.11. Much of the remainder of the chapter is based on this reference.



around 1600, with the scientific revolution. What happened in these 'Dark Ages' was mostly based on works of Hippocrates or Galen of Pergamum (who established Hippocrates as the father of medicine), the two men who formed the corpus of the medical literature in medieval Europe. With the rise of Christianity, illness was interpreted in the context of punishment and sin, considering any attempt by a physician to cure illness as a rebellion against the will of God- and therefore sinful as well. This, however, did not keep patients from seeking medical help and doctors from working, be it not in high esteem. Also, religion and medical activity seemed to merge, in contrast to the non-intervention religious beliefs, in the form of the 'priest physician' taking care of the poor and ill in the first types of primitive hospitals. In these limited patient-doctor encounters, the emphasis of the tasks of the physician lay on the care of the soul, more than any limited bodily suffering. Spiritual conversation and guidance was therefore the physician's obligation.

With the years progressing, around the 1100 hundreds the old Greek texts revived and returned by way of the Islamic medical tradition. With this and the rise of universities, arts like that of dissection came springing up. Medical licensing found its birth, creating university-trained doctors as 'elite physicians'.

With the rise of the Renaissance and its players such as Vesalius, the domain of medical practice is regained from the Church and the first advances are made; ancient theories are proven wrong and the spirit of enquiry is born. With the mechanistic philosophy of thinkers like René Descartes and Francis Bacon the scientific revolution was founded, as well as its repercussions for medicine.

When looking at the consequences for the patient-doctor relationship itself, however, not much has changed. The doctor still had three accounts to rely on:

- 1) the patient's statement in word
- 2) the physician's observations
- 3) the physician's manual examination of the patient's body

The focus, however, was clearly on the first account. Examinations of the body were rare occasions in these times; not only was religious chasteness a key factor, but the examination was considered of less importance. Besides the occasional look at the eyes and tongue, smelling of the breath or urine, bodily examination was close to no help. The most important aid in making a correct diagnosis, however, was the patient. Only he had direct access to his own symptoms, making the patient's own feelings and thoughts upon his disease the centre of pre-modern medicine; a focus on the patient as a person, rather than an object. Considering the low esteem of doctors in that time (especially the ones not affiliated with a university) one could consider the influence of a patient in the medical meeting, especially a wealthy aristocratic one, quite large. The establishing of a diagnosis was sometimes a negotiation between the doctor and the patient, with the patient making suggestions which the doctor would then have to confirm.

Although this seemingly patient-centeredness is a different sound in comparison to some of the modern medical practice we will touch upon later on, one must not mistake this with



the individuality of the patient. As most accounts show, simple rights such as privacy during a medical meeting were not yet common. Medical visits would happen in the midst of friends and family. In addition, it often happened that physicians would diagnose and prescribe remedies on the basis of a written account, without having seen the patient. The idea of the patient as an autonomous self instead as a part of a grand design is one that we will have to wait and see in the modern era, transforming the medical meeting once again.

The Birth of Modern Medicine

‘Before the end of the eighteenth century, *man* did not exist’- Michel Foucault²²

If we are to believe Michel Foucault, and other historians who agree with him, modern medicine as we know it was born in post-revolutionary Paris, where the medical clinic became unified with pathological anatomy. After the closing down of the universities in post-revolutionary France, medicine was more and more taught in hospitals, in the style of bedside teaching. A new focus on systematic empirical studies of the body arose, both in living and deceased form. The body of the patient was looked upon as a functional space where the disease resided. This, as we can somehow feel, touches upon the new ways of medicine as mentioned in the introduction. What did this shift do to the relationship between a doctor and the patient?

This is a point where historians seem to divide. On the one hand we have the view of historians who claim that medical history advances progressively and cumulatively, one discovery after another, and the role of science in this being the provider of these increasingly significant theories and techniques, with which medicine is allowed to grow. Foucault, on the other hand, claims the epistemic view, which discards the idea of progression, but rather depends on epistemological shifts in discourse. His notion will serve as a jumping board towards more insight into the patient-doctor relationship that resulted from modern medicine.

According to Foucault, the difference between classical and modern medicine is not a progression in a history of medicine, but a difference in the *episteme* or grid that predetermines the knowledge we have. Classical medicine was a representational phenomenon. Physicians of that time would come up with a taxonomy, tables filled with diseases and descriptions, signs as they manifested themselves on the surface of the patient, thus representing the disease. Foucault claimed that these systems left no room for the patient or the doctor as human beings, as they were seen as disturbances in the bigger representational system of disease:

‘In the rational space of disease, doctors and patients do not occupy a place of right; they are tolerated as disturbances that can hardly be avoided: the paradoxical role of medicine consists above all in neutralising them, in maintaining the maximum difference between

²² As cited in; Svenaeus F., *The Hermeneutics of Medicine and the Phenomenology of Health*, (2000). P.308.



them, so that, in the void that appears between them, the ideal configuration of the disease becomes a concrete, free form, totalized at last in a motionless simultaneous picture, lacking both sensity and secrecy, where recognition opens of itself onto the order of essences.'

In modern medicine, Foucault claims, we are for the first time allowed to see man as man; an integrated functional object with a depth, not just a surface upon which diseases are read and classified.

As you can imagine, these claims of Foucault seem to bypass the patient-centeredness of classical medicine we so clearly claimed in the previous paragraphs. What Foucault then perhaps tends to forget is the practical aspect of medical practice - the meeting between doctor and patient - an aspect which persist throughout the changing theoretical works of scientists.

However, if we were to conclude this paragraph with one important thing we can learn from Foucault's line of thought, it is that the birth of modern medicine is not only a liberating success of science which the progressive view claims. The patient in modern medicine also runs the risk of being reduced to an object, a case in the records, disappearing as a person, the meeting of a doctor and patient turning into a scientist examining his object. This 'object', the patient, however, at the same time never ceases to be a person. And as such we see the rise of a conflict.

This conflict was only further emphasized in the years following 1800. With the rise of medical technology, this distance only enlarged. With the invention of the stethoscope, for example, the physician was able to listen to the patient without making any inquiries about his symptoms, thoughts and feelings. The body spoke an exact and objective language, making the patient's description of minor importance. And as such, objectivity became more and more important. With the laboratory revolution and the uprising of instruments that allowed a physician to measure, the patient is quantified. Projected on the first prototypes of screens, the eyes of the physicians turned to the variables, rather than the patient attached to it. As Gadamer states in *The Enigma of Health*:

"We have for example, the disintegration of the person. This happens within medical science when he individual patients objectified in terms of multiplicity of data. This means that the patients assembled as through a card index in the clinical examination of today. If this is done correctly all data (Werte) belong to the individual patient. But the question still remains whether the value of the individual (Eigenwert) is recognized in this process."²³

²³ Gadamer H-G, *The Enigma of Health* (1993), p.108



The last of these developments seems to be the computer-assisted diagnosis we seem to touch upon in the current practice. Not only is the voice of the patient in danger, but the computer, currently used as a tool, might also threaten the voice of the doctor himself; making the *meeting* between doctor and patient obsolete. More about that later on.



Chapter 6 Current Decision-Making Approaches in the Clinical Encounter

After our brief journey through history, be it progressive or epistemological, we have arrived at present day. In this chapter we will look at an overview of the current models of the patient-doctor relationship and the research done into this field. This chapter will provide our final piece of information before moving onto the next chapter, where we will look deeper into the incentive of shared decision-making, the main subject of this essay.

What is decision-making?

As we will now look at the current approaches to decision-making in the patient-doctor encounter, it becomes even more relevant to look at one of the concepts we have been using without a clear definition; ‘decision-making’. What do we mean by that? We need to get this concept straight before we can even look at what kind of decision-making is practised today and how this could be ‘shared’.

Tentatively, we could state that decision-making in the context of this essay takes place in every consultation a patient undergoes for a certain problem. Although every case is different, and some problems allow for more therapeutic options than others, there is always the decision to do nothing instead of something, which automatically implies a decision. Decision making is always in the context of the consultation²⁴. A generally accepted view of the process of a consultation is the consultation theory by Byrne and Long (1976)²⁵. After analysing over 2000 consultations they were able to identify a general structure of most medical consultations. In the example of Susan and Dr. H the following would be possible:

1. Establishing of the relationship

On the first encounter between doctor and patient the so called ‘establishment of the relationship’ takes place. Why, on this occasion, has the patient decided to visit this particular doctor? Is the patient referred? Has the patient visited a doctor before for this particular complaint? And if so, what has been discussed in the previous consultation and what will be discussed now? In the case of Susan and Dr. H, the following would be a possibility:

“Hello Susan, my name is Dr. H, senior cardio-thoracic surgeon in the Erasmus MC. Your general practitioner referred you to my service”.

2. Determining the reason for attendance

In this phase patient and doctor further zoom into the particular complaint or set of complaints the patient has. Sometimes, a complaint is just a cover-up for an underlying

²⁴ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, British Journal of General Practice (1999)

²⁵ Byrne P.S., Long B.L., Doctors talking to patients, HMSO, (1976)



issue. Regardless, in this stage the doctor tries to bring to light or further explore the particular reason of attendance. In the case of Susan and Dr. H, where part of Susan's complaints are already known, we could expect the following:

"I have read the letter of your general practitioner explaining that you are experiencing shortness of breath. Could tell me more about your complaint?"

3. Conducting a verbal/physical examination

"Susan, I would like to conduct a physical examination, especially of the heart, to check your current health. Is that alright?"

Apart from the strictly medical questions, this part of the consultation also allows room for the patients ideas, concerns and expectations. Some complaints and disease, however, are more fit for his approach than others. In the case of Susan and her heart disease, the condition might run in the family, which is something that could be discussed in the consultation, both from a physical and a psychological point of view. Dr. H could for instance ask Susan:

"When you first experienced the shortness of breath, was there a particular disease you were perhaps thinking of or fearing?"

4. Consideration of the patient condition

Now the doctor needs to think and relate all of the patient's symptoms to cases seen previously and to his general medical knowledge. After having come up with the possible diagnosis, it is important to communicate this with the patient. Often, however, the diagnosis is not completely clear from verbal and physical examination and further tests are needed:

"Looking at the outcome of the physical examination and the information I received from your general practitioner, I believe you most likely have something related to a heart valve. However, I will need to run more tests to be more certain."

5. Detailing treatment or further investigation

When possible diagnosis are communicated, the next stage is to discuss how to move forward from this. Is there a treatment available, and if so, what are the options? Or is further investigation needed to make the diagnosis more certain, and if so, what are the consequences for the patient?

"Susan, we have discussed the possibility of a heart-related issue. However, in order to differentiate between the different conditions I am considering at the moment, I would like to make an ultrasound of the heart and your heart valves in particular. Would you agree to that?"

6. Terminating consultation

When all of the previous has been discussed, the final part of the consultation arrives, the actual termination. In this phase the doctor wants to summarize what has been discussed,



as well as anticipate future consultations. In our case, Dr. H could terminate with the following:

“Well, then we agree to see each other in two weeks, to discuss the outcomes of the tests. Do you have any questions before we end the consultation?”

The first half the conversation is clearly, if not solely focussed on gathering information about the patients problem. A lot of emphasis is placed on this stage of the consultation in medical education and literature. Of course, we could state that this stage is crucial for how beneficial the rest of the consultation will be²⁶.

The decision-making we are talking about, however, takes place in the context of the fourth and fifth stage of the consultation. In this stage the physician enters a conversation with the patient about his conditions as well as the possible therapeutic options. Byrne and Long found that a discussion of the patient’s condition occurred in less than 25% of consultations, and patients have been found to be dissatisfied with the explanations of their condition and the information they receive²⁷. It is exactly this part of the consultation that shared decision-making tries to tackle, by giving both the patient and the doctor the means to enter in a conversation and not only discuss the patient’s condition, which could be considered to be a fundamental right, but also the various therapeutic options.

When looking into the literature, a quartet of decision-making approaches in the clinical encounter seems to be at the forefront^{28,29,30}.

- 1) Paternalism
- 2) Informed Decision-making
- 3) The profession-as-agent-model
- 4) Shared Decision-making

Paternalism- ‘Doctor knows best’

Often viewed as an old-fashioned way of constructing a clinical encounter, paternalism focuses on what the physician considers best for the patient, without eliciting the latter's preferences³¹. The patient requests professional help and is willing to comply with the medical regimen. In this way, the physician dominates the medical encounter and uses his skills and experience to diagnose, test and treat the patient.

In the extreme case, "the physician authoritatively informs the patient when the intervention will be initiated"³². In the less extreme, the physician will give the patient *selected* information and will encourage the patient to consent to what the physician

²⁶ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, British Journal of General Practice (1999)

²⁷ Byrne P.S., Long B.L., Doctors talking to patients, HMSO, (1976)

²⁸ Charles C. et al., Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model (1999)

²⁹ Frosch D.L., Shared Decision Making in Clinical Medicine: Past Research and Future Directions (1999)

³⁰ Emanuel E.J. and Emanuel L.L., Four models of the physician-patient relationship, Journal of the American Medical Association (1992)

³¹ Charles C. et al., Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model (1999)

³² Emanuel E.J. and Emanuel L.L., Four models of the physician-patient relationship, Journal of the American Medical Association (1992)



considers best³³. The role of physician depicted in this model is to be the guardian of the patient's best interest.

In the case of our patient Susan S., this would mean that the physician would for example strongly recommend Susan to go for a biological valve:

'Mrs. S., the mechanical valve would in our opinion be the best option for you. We have extensive experience with the surgical placement of these valves and hear only successful stories from all the patients we treat. Besides that, a trial we are currently working on seems to predict the same.'

As we can see in this case, patient involvement (if there is any) is limited to providing consent to the treatment advocated by the physician. In this paternalistic approach, one can imagine, we therefore also find a way to confirm the status difference between the doctor and his patient. As Elwyn et al. (1999) state in *Shared decision-making in primary care: the neglected second half of the consultation*:

*"By keeping the patient as passive recipient of the doctor's 'expert' advice, it clearly has the superficial attraction of maintaining the professional's status."*³⁴

Paternalism, however, has been the most prevalent approach in the clinical encounter for quite some time, and not up until the 1980s did a change come about^{35,36}. What were the assumptions that founded this approach for so long? According to Charles et al. (1999) the following four assumptions underlie the approach of paternalism:

- 1) For most diseases, a single best treatment exists and physicians generally would be well versed in the most current and valid clinical thinking.
- 2) Physicians would not only know the best treatments available, they would consistently apply this information when selecting treatments for their own patients.
- 3) Because of their expertise and experience, physicians were in the best position to evaluate trade-offs between different treatments and to make the treatment decision.
- 4) Because of their professional concern for the welfare of their patients, physicians had a legitimate investment in each treatment decision.³⁷

And precisely these assumptions can help us explain why during the 1980s and beyond, the credibility of paternalism began to be questioned.

³³ Ibid.

³⁴ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, *British Journal of General Practice* (1999)

³⁵ Charles C. et al., Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model (1999)

³⁶ Barry M.J., Edgman-Levitan S., Shared Decision Making- The Pinnacle of Patient-Centered Care, (2012)

³⁷ Charles C. et al., Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model (1999)



First and foremost, both patient and doctor began to discover that for a numerous amount of diseases, there was not just one best treatment, towering above all other treatments. A more murky and complex decisional context evolved where different treatment had different types of trade-offs between benefits and risks. Since the patient rather than the physician would have to live with the consequences of these trade-offs, the assumption that physicians were in the best position to evaluate and weigh these was increasingly challenged³⁸.

At the same time, research into the quality of medical care began to focus on the effectiveness and appropriateness of a wide range of services delivered by physicians³⁹. Research showed, for example, that physicians' treatments of one and the same disease differed significantly, regardless of the patient population or location of the institution^{40,41,42,43}. Variations in treatment patterns were also found for diseases for which clinical guidelines had been developed on best practices⁴⁴.

But there is more. Rising health care costs in both Canada and the United States was another health policy issue focusing attention on the medical profession⁴⁵. The joining together of cost and quality concerns resulted in recommendations to make physicians more explicitly accountable to patients and incorporating a larger role for patients in the decision-making process⁴⁶. 'A dollar once spent cannot be spent again', and therefore doctors in the new health care system are not only concerned with their patient well-being, but also with finding the most sustainable way of providing health care to all. In this process of finding the right balance, the patient is more and more involved and asked to be considerate.

Informed Decision making

In reaction to paternalism, a number of new approaches to decision making in the clinical encounter arose, Informed Decision-making being one of them. Both the informed as well as the profession-as-agent model mostly recognize and try to tackle the asymmetry in information between patient and physician. As Hurley et al. (1992) explain:

³⁸ Charles C. et al., Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model (1999)

³⁹ Ibid.

⁴⁰ Roos N.L. , Hysterectomy: variations in rates across small areas and across physicians' practices, (1984).

⁴¹ Chassin et al., Variation in the use of medical and surgical services by the medicare population, (1986).

⁴² Wennberg J.E. et al., Are hospital services rationed in new haven or over-utilized in Boston, (1987).

⁴³ Leape et al., The appropriateness of use of coronary artery bypass graft surgery in New York State, (1993).

⁴⁴ Lomas J. et al., Do practice guidelines guide practice? The effect of a consensus statement on the practice of physician, (1989)

⁴⁵ Katz S.J. et al., Shooting inward as the circle closes, (1997).

⁴⁶ Svenaues F., The Hermeneutics of Medicine and the Phenomenology of Health, (2000)



"The crux of the information problem is that while the health care provider possesses better knowledge regarding the expected effectiveness of health care in improving health status, the individual knows best how improvements in health status affect his or her well-being."⁴⁷

In the case of Susan we could say that Susan and Dr. H are drifting on two different islands. Dr. H's island contains the bigger picture and the technical knowledge; not only Susan but also his previous patients, their decisions and outcomes are all present on that island. Cindy for example, the woman he treated four years ago with a biological valve, who was extremely content. But also Jack, the single businessman who received a mechanical valve ten years ago and died on Dr. H's operating table. But also Dr. H's own preference for treatments, his/her (surgical) experience and expertise, what he was thought by his mentor and peers, his knowledge of the latest research and the statistics and numbers going hand in hand with that, play a role. For Dr. H., Susan is one of many patients categorized with the same disease.

Susan's island is mostly filled with her own illness, as well as her ideas, fears, wishes, preferences and ambitions influenced by that given fact. Susan just moved in with Rob in Amsterdam, how is this going to affect their relationship? Will she be able to have children, even with her condition? And how long will she then live?

In order to build a bridge between these islands, the informed decision making model tries to increase the patient's knowledge of the possible risks of alternative therapeutic options and their clinical effectiveness. In our case, this would mean that Dr. H would explain what options Susan has, and what the consequences, risks and benefits would be of each of the options:

"Susan, in addition to the biological valve I just told you about, we also have the mechanical valve. This mechanical valve will probably last you a lifetime, so the chances of re-operation are a less than with the biological valve. However, you will have to take blood thinners if you decide for this valve; there is namely a possibility of blood clots forming around the valve, which we should minimize. The blood thinners, in their turn, will thin your blood not only near the valve, but in your whole body. This mean you will bruise and bleed quicker."

In this way the patient is allowed to overcome the information deficit and can make decisions that reflect both their preferences and the best scientific knowledge available. Theoretically, in this model, an informed patient no longer needs to share the treatment decision-making process because she now possesses both components (information and preferences) viewed as essential to the task. In this model, treatment decision-making control is clearly seen to be vested in the patient. The physician's role is limited to that of

⁴⁷ Hurley, J., Birch, S. and Eyles, J. Information, efficiency and decentralization within health care systems. CHEPA Working Paper 92-21., (1992).



information exchange, communicating the needed technical or scientific knowledge to the patient, without stating a preference⁴⁸. As noted by Emanuel and Emanuel (1992):

“The physician is proscribed from giving a treatment recommendation for fear of imposing his or her will on the patient and thereby competing for the decision-making control that has been given to the patient.”⁴⁹

Eddy et al. (1990) states the same in the context of breast cancer:

“..the people whose preferences count are the patients, because they are the ones who will have to live (or die) with the outcomes. ...Ideally, you and I are not even in the picture. What matters is what Mrs. Smith thinks.... It is also quite possible that Mrs. Smith's preferences will differ from Mrs. Brown's preferences. If so, both are correct, because 'correct' is defined separately for each woman. Assuming that both women are accurately informed regarding the outcomes, neither should be persuaded to change her mind.”⁵⁰

In other words, the physician's treatment preferences for the patient do not enter into the decision-making process. Instead, the informed decision making model tries to ‘empower’ the patient with information toward a more autonomous form of decision-making. Without immediately sticking a normative conclusion to this fact, we can state that where the paternalistic model leaves the patient out of the picture, the informed decision model reduces the role of the physician to that of ‘information transfer’. Here, an interesting discussion point surfaces; with the growth of knowledge, the patients responsibility towards the decision seems to grow as well. Research has shown, however, that while patients typically express high preferences for information about their illness and its treatment^{51,52,53}, their preferences for participation in treatment decision-making are much more diversely distributed^{54,55,56}. In other words, patients want information about their medical condition and treatment options without necessarily being responsible for making treatment decisions^{57,58,59}.

Another side note to this model is the question to what extent the gap between patient and physician can actually be bridged. Some argue that even though within this model information is gapped when the physician explains to the patient what the disease and the

⁴⁸ Hurley, J., Birch, S. and Eyles, J. Information, efficiency and decentralization within health care systems. CHEPA Working Paper 92-21., (1992).

⁴⁹ Emanuel E.J. and Emanuel L.L., Four models of the physician-patient relationship, (1992), p.2225

⁵⁰ Eddy D.M., et al., Anatomy of a decision, Journal of the American Medical Association (1990)

⁵¹ Cassileth, B., Zupkis, R. V. and Sutton-Smith, K.et al., Information and participation preferences among cancer patients, (1980).

⁵² Lerman, C. E., Brody, D. S. and Caputo, G. C.et al. Patients’ perceived involvement in care scale: Relationship to attitudes about illness and medical care., (1990).

⁵³ Beisecker, A. E., Aging and the desire for information and input in medical decisions: Patient consumerism in medical encounters. (1988).

⁵⁴ Vertinsky, I. B., Thompson, W. A. and Uyeno, D. Measuring consumer desire for participation in clinical decision making, (1974)

⁵⁵ Strull, W. M., Lo, B. and Charles, G. Do patients want to participate in medical decision making?, (1984).

⁵⁶ Pendleton, L. and House, W. C., Preferences for treatment approaches in medical care. Medical care 22 (7), 644, (1984)

⁵⁷ Ende, J., Kazis, L. and Ash, A.et al., Measuring patients' desire for autonomy: decision making and information seeking preferences among medical patients., (1989)

⁵⁸Beisecker, A. E. and Beisecker, T. D. Patient information-seeking behaviors when communicating with doctors. (1990).

⁵⁹ Ryan, M. The Economic Theory of Agency in Health Care: Lessons from Non-Economists for Economists. (1992).



treatment might entail, the 'knowledge gap' remains present. The patient does not possess the knowledge a physician has in general. One could wonder, therefore, how much the information gap will actually mean for the patient.

With this in mind, we move onto the next possible approach to decision making in the clinical encounter and will come back to the information and knowledge gap later on,

The-physician-as-agent model

With the physician-as-agent-model we will find a clear contrast with the informed-decision-making model. Although the physician-as-agent model tries to solve the same informational asymmetry as the informed decision making model, it decides to reach that goal by informing the physician instead of the patient:

"the professional-as-agent assumes responsibility for directing the health care utilization of the patient ...as an agent trying to choose what the patient would have chosen, had she been as well-informed as the professional"⁶⁰.

In other words, in this model, the physician makes the treatment decision, either assuming that he knows, or having elicited the patient's preferences for future health states, lifestyle choices etc. Both components (information and preferences) then reside in the physician, rather than the patient, and the former becomes the sole decision-maker:

"Mrs. S, looking at the surgical expertise in this centre, and what you told me about your possible wish to have children, I would recommend the biological valve. We know how to place those valves and how to get the best results, and the absence of the necessity to take blood thinners makes a future pregnancy possible."

This approach, clearly, has its own issues. Besides the fact that, legally, some form of minimal informed consent is necessary, we again see that one of the agents in the encounter, the patient, is more on the side-line. Then again, we could argue, that the patient, is indeed represented, namely in the physician. Through transferring the patient's wishes and preferences, the physician would be able to think for both.

Although we might be jumping ahead by already involving phenomenology, from the point of view of this theory the statement above would be an impossible one. As Merleau-Ponty's 'embodied experience'-theory tells us, Dr. H's attempt to take into consideration Susan's preferences and deciding for her would be a futile attempt to make the third person view into a first person one.

⁶⁰ Evans R. G., *Strained Mercy: The Economics of Canadian Health Care.*, (1984), p.75.



Chapter 7 The Incentive of Shared Decision-Making

“An intervention should be considered a “standard” only if there is “virtual unanimity among patients about the overall desirability [...] of the outcomes.”⁶¹

After having discussed some different models of decision-making in a medical context, we have finally arrived at the shared decision-making approach. In this chapter we will look into this approach which forms the centre of the essay. How did shared decision-making come about? What are its goals? How are we to reach those goals? And what has research taught us so far about its results?

The birth of a new style- What is a shared decision?

As explained in the previous paragraph, for many years the decision for treatment was that of the doctor, the patient following the dominating doctor in his decision. However, times have changed and so has the patient-doctor encounter. Patients have become more present in the encounter and the patient’s autonomy has become a more prominent issue. The right to informed consent, for example, has resulted in the fact that treatment should occur only after a patient is thoroughly informed about the implications of the choice and has agreed to the procedure on the basis of this information. The internet has empowered patients, allowing for patients to obtain information about medical problems and treatments as well as about alternatives to traditional medicine. Shared decision-making represent the birth of a new style in this context.⁶²

In 1999, Coulter et al.⁶³ proposed a definition of a shared decision based on articles by authors such as Szasz and Hollender⁶⁴ and Emanuel and Emanuel⁶⁵, who were among the first authors to develop the concept of patient participation in medical decision making:

“In SDM, the intention is that patients and health professionals share both the process of decision-making and ownership of the decision made. Shared information about values and likely treatment outcomes is an essential prerequisite, but the process also depends on a commitment from both parties to engage in the decision-making process. The clinician has to be prepared to acknowledge the legitimacy of the patient’s preferences and the patient has to accept shared responsibility for the treatment decision.”⁶⁶

Beyond presenting the patient with facts about a procedure, shared decision making is a process by which doctor and patient consider available information about the medical problem in question, including treatment options and consequences, and then consider how

⁶¹ Eddy D.M., et al., Anatomy of a decision, Journal of the American Medical Association (1990)

⁶² Dominick L. et al., Shared Decision Making in Clinical Medicine: Past Research and Future Directions, (1999)

⁶³ Coulter A., Welcome to the inaugural issue. Health Expect. 1998;1:1–2.

⁶⁴ Szasz TS, Hollender MH. A contribution to the philosophy of medicine, (1956).

⁶⁵ Emanuel E.J. and Emanuel L.L., Four models of the physician-patient relationship, Journal of the American Medical Association (1992)

⁶⁶ Coulter A., Welcome to the inaugural issue. Health Expect. 1998;1:1–2.



these fit with the patient's preferences for health states and outcomes. After considering the options, a treatment decision is made based on mutual agreement⁶⁷.

The shared decision-making process is therefore characterized as follows⁶⁸:

- Shared decision-making involves at least two participants — the doctor and the patient — and often many more (their respective networks of family or professional colleagues).⁶⁹
- Both parties (doctors and patients) take steps to participate in the process of treatment decision-making.
- Information sharing is a prerequisite to shared decision-making.
- A treatment decision (which may be to do nothing) is made, and both parties agree to the decision.

We could say that some conditions need to be met in order for a decision to be shared. First, the atmosphere must be conducive to active patient participation. The attending physician must make patients feel that their contributions are valued. Patients in turn need to be frank about their preferences and goals for treatment. The physician then helps the patient determine how these goals and preferences fit with the available treatment options and a shared decision is reached. However, each of these condition, in turn, could turn out to be an obstacle in the road towards a shared decision. More on this later on.

How to reach a shared decision?

As we have seen, informed decision making consists of both information exchanges (from the doctor to the patient and vice versa), as well as a conjoint deliberation process leading up to a joint decision.

Given the importance of information transfer from physician to patient, it is not surprising that various sorts of decision-aids have been and are being developed to help physicians communicate treatment information to patients. Treatment decision aids are a form of educational intervention. As Llewellyn-Thomas (1995) notes:

*"A distinguishing feature of a decision aid is the inclusion of exercises designed to promote clarification of the patient's values regarding what is at stake and what it is that he or she is trying to achieve as a result of treatment."*⁷⁰

⁶⁷ Dominick L. et al., Shared Decision Making in Clinical Medicine: Past Research and Future Directions, (1999)

⁶⁸ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, British Journal of General Practice (1999)

⁶⁹ With the rise of multidisciplinary teams, patients are often involved and talking to more than one physician. Interesting to ask in this context is whether the patient is sharing a decision with all or just one of them, the 'main' physician? And is this what we are seeing in practice or are we risking that the patient is actually sharing a little bit of the decision with every physician and in effect with no one? Lonely in a crowd?

⁷⁰ Llewellyn-Thomas, H. A. Patients' health-care decision making: A framework for descriptive and experimental investigations., (1995) p.104



These aids range from high technology interactive videos to low technology charts with audio tapes^{71,72}. There are also decision aids which present scientific information to patients about treatment benefits and risks. These are developed to create more informed patients and to encourage evidence-based decision-making. This approach assumes that if only physicians knew how to transfer scientific information to patients in an accurate and unbiased way, the latter could be filled up (like an empty glass) with new knowledge and thereby transformed into informed and willing decision-makers⁷³. The asymmetry in knowledge between a doctor and patient in this way could then be lifted.

In our patient Susan's case, www.hartklepkeuze.nl⁷⁴, a recently launched Dutch online Decision Aid by the Dutch Society for Cardiothoracic Surgery, could be a realistic tool that dr. H could suggest in the shared decision making process.



Figure 2 Homepage Decision Aid Tool

The site consists of two parts; one in which the patient can read general information about the two types of heart valves. The other consists of a decision aid tool, in which the patients answer questions both on their own preferences and values with regards to the valve, as well as general knowledge questions to test their level of knowledge on the subject. The scores of these tests can be downloaded and the site advises the patient to take the scores as well as any remaining questions with them to the doctor during the appointment.

⁷¹ Barry MJ, Fowler FJ, Mulley AG, Henderson JV, Wennberg JE. Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. (1995)

⁷² <https://decisionaid.ohri.ca/ip-sdm.html>

⁷³ Dominick L. et al., Shared Decision Making in Clinical Medicine: Past Research and Future Directions, (1999)

⁷⁴ www.hartklepkeuze.nl



Figure 3 Questionnaire on personal attitude towards the two different types of valves
In this way the Decision Aid forms a first step in the decision making process. During the following appointment(s) patient and doctor further deliberate the decision to be made. As you can see in Figure 4, the decision aid also goes as far as to give semi-personal (based on age) risk percentages.

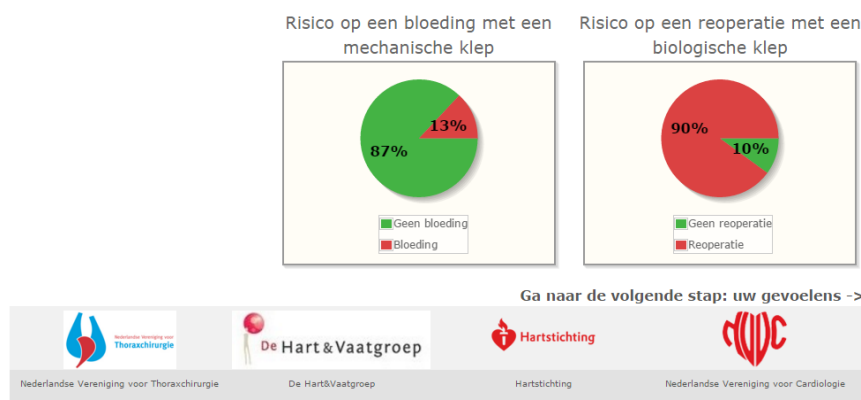


Figure 4 Examples of percentages as presented in the Decision Aid Tool ('Risk of bleeding with a mechanical valve' and 'Risk of reoperation with a biological valve' respectively). With a change in the patient's demographic data put into the Decision Aid, the results presented in the graphs will change.

Of course there is the question on how to communicate numbers and risks with patients. Medical science is a paradox; although doctors treat individual patients, they make use of larger populations to gain information and insights on success rates of treatments, adverse effects, risks of treatment and so on. This means that a lot of numbers are actually statistics, giving risk percentages. As it is even hard for some doctors to interpret these percentages in some cases, we can easily imagine the struggle of patients to understand numbers and risks



as represented in these decision aids, or in medicine in general⁷⁵. Doesn't the patient see just a population of one, namely him or herself? More on this in the upcoming reflective chapters.

Why would we want a shared decision?- What research has thought us (so far)

For now, let's answer this question with a more medical than phenomenological perspective, since the latter will be discussed extensively in the next chapter.

Research in the field of shared decision making is still limited and complicated, since a wide range of definitions is used across researchers, making general conclusions difficult⁷⁶. However, we can state that from a strictly medical perspective, shared decision-making could form the answer to a number of problems. One longstanding problem is that of non-adherence to therapy, advice, or other management plans⁷⁷. Just think of the diabetic patient not taking it's insulin on time or in the right doses, the heart patient not taking on exercise to lose weight or the asthmatic patient continuously smoking. There is a growing body of evidence that these problems occur owing to poor communication between doctors and patients. This is where a shared decision may come in handy. The benefits of effective communication on patient satisfaction, in their turn, have also been identified in research. Stewart (1997)⁷⁸, for example, reports that where patient perceive that they have achieved 'common ground' with physicians, there are fewer demands on laboratory and referral services. Her review concluded that four key dimensions of communication were related to positive outcomes:

- the provision of clear information,
- questions from the patient,
- willingness to share (discuss) decisions
- agreement between patient and doctor about the problem and the plan

According to the latest Cochrane review of 86 trials, the use of patient decision aids for a range of preference-sensitive decisions led to increased knowledge, more accurate risk perceptions, a greater number of decisions consistent with patients' values, a reduced level of internal decisional conflict for patients, and fewer patients remaining passive or undecided. The use of decision aids is also associated with patients' choosing prostate-specific-antigen tests for prostate-cancer screening and major elective surgery less often, which suggests that shared decision making could be a tool to help address the problems of overdiagnosis, overtreatment and treatment variation.

⁷⁵ Gigerenzer et al., *Helping Doctors and Patients Make Sense of Health Statistics* (2008)

⁷⁶ Elwyn G. et al., *A shared decision-making in primary care: the neglected second half of the consultation*, *British Journal of General Practice* (1999)

⁷⁷ Ibid.

⁷⁸ Stewart M., *The impact of patient-centred care on patient outcomes in family therapy* (1997)



So far, we seem to have only heard words of praise for this incentive. However, if we look at the implementation of shared-decision making in practice, there do not seem to have been any significant changes since the mid- 1990s⁷⁹. What is standing in the way? Why would some doctors, perhaps cynically, argue that that information sharing does not necessarily lead to a sharing of the treatment decision-making process? More on this in the following chapters.

⁷⁹ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, British Journal of General Practice (1999)



Chapter 8 On a Cynical Note (and Beyond)

With everything that is new, comes a little resistance. The key is to figure out if and to what extent this resistance is valid and could work as constructive feedback. Before moving on to the next chapter, in which all previous chapters will be merged to a conclusion and reflection, we will first try to address and discuss some of the most important counterarguments against shared decision-making. We will not refrain from discussing the most negative, destructive or even cynical points of view. This with the ambition of opening up the conversation completely in order to reach a fair and useful conclusion on the incentive.

Who is going to pay for this?

In the current health care system we find more and more emphasis on the costs of health-care, and especially the cost-effectiveness of health care. In the Netherlands, for example, general practitioners are given limited consultation time per patient, which is already considered to be insufficient⁸⁰. Therefore, a pessimist might ask whether it is possible or even desirable to push the limits even further.

Firstly, we must factor in the possible benefits of the shared decision-making as well. A breadth of evidence has accumulated about the benefits of this 'effective' communication on patient satisfaction⁸¹ and on patient adherence to treatment⁸². These benefits will weigh in on the costs and might eventually improve them⁸³. Secondly, as we have seen in the previous chapters, the process of shared decision-making does not need to take place completely during consultation. As more and more online decision aid tools are constructed and tested, a lot of the preparation for the conversation might be done at home by reading and filling out questionnaires.

Nonetheless, we must realize that 'budgeting' on shared decision-making is a delicate subject and might even render the positive results obsolete when done poorly or hastily:

"Savage and Armstrong⁸⁴ randomized 359 patients to receive 'directive' and 'sharing' consulting styles, verified by assessing a subsample of 40 recordings. The 'directing' style had a better effect on satisfaction levels but only in those with self-limiting illness or chronic conditions, echoing similar work by Thomas.⁸⁵ These results appear to indicate that if the 'sharing strategies' are followed mechanically or ritualistically then they are insensitive to the situational context and will not produce improved health outcomes."

Isn't it threatening to the 'power' relationship between doctor and patient?

Supporters of the current decision making models might argue that the shared decision-making process will kick the doctor of his throne. Are patients really ready for a doctor to share their decision with them? Are they not better off or even asking for a doctor to take the lead and make the decision? Won't it make doctors look uncertain?

Although these notes are quite understandable, they seem to argue from the old paradigms such as the previously described paternalistic view. As we will discuss later on, the previous statements may

⁸⁰ Oxtoby K, Consultation Times, (2010), http://careers.bmj.com/careers/advice/Consultation_times

⁸¹ Stewart M. Studies of health outcomes and patient-centered communication, (1995)

⁸² Young M, Klinge RS. Silent partners in medical care. A cross-cultural study of patient participation., (1996)

⁸³ With the current state of shared decision-making being a not yet completely accepted one, numbers on the actual cost-effectiveness are scarce.

⁸⁴ Savage R. Effect of a general practitioner's consulting style on patient satisfaction: a controlled study., (1990)

⁸⁵ Thomas KB. The consultation and the therapeutic illusion. (1978)



be true for some types of patients who might not instantly feel comfortable with the idea of sharing the decision they would want the doctor to make. However, the patient population is changing. And when the population growing up with internet and online sources starts to take over the waiting room, we might find more involved patients demanding a say. Will that then diminish the 'respected' position as doctors?

We could perhaps even argue the contrary. Research has shown that shared decision-making might play an important role in the development of a positive relationship between a physician and patient. Charles et al. (1999)⁸⁶ reported:

"In our current study of women with early stage breast cancer, for example, we found that women stressed the importance not only of finding a physician they could trust, but also one who would treat them as individuals. Patients' assessments of these physician attributes rested, in large part, on their perceptions of the physician's ability and willingness to contextualize the decision-making process by framing the discussion in terms of each unique background, characteristics and life experience"

In this sense we could even say that the doctor in the shared decision-making model might even gain more respect and persuasiveness than in the previous models.

Is every doctor even skilled in 'sharing' and 'involving' patients?

Of all the 'cynical notes', this might be the most valid one. Up to now we have mainly talked about shared decision-making as a process in which both the patient and doctor engage for mutual benefit. However, this process has partially remained a black box. It is therefore important to realize that a lot of doctors currently lack skills such as those to convey information about risks and benefits in the shared decision-making process, seeing that they have been used to other models. In addition, these skills are currently not trained properly in medical school either. These skills, however, are necessary in order for the process to succeed.

Difficult with these kind of points is to distinguish between *impossible* and *not yet possible*. Decades ago the idea of informed consent was in the stage that shared decision-making is today. Back then, doctors were in the same kind of position and a new skill had to be not only taught but also learnt. With shared decision-making, I feel this would not be any different. Perhaps not every doctor is currently skilled in the process of share decision-making. However, not every doctor has been taught these skills. If attitudes towards shared decision-making change, if the incentive gains more momentum and support, the medical training will follow.

What if there is no real decision to make?

For some decisions, there seems to be one clearly superior path: a fractured hip needs repair, acute appendicitis needs surgery, and bacterial meningitis requires antibiotics. In these cases, you might say, patient preferences play little or no role⁸⁷. There really is no decision to make, except perhaps, for the often forgotten decision to do nothing.

In contemporary times, however, for most medical decisions there seems to be more than one reasonable path forward. This includes options like doing nothing, doing something but not now, doing something but not here and so on. All these different paths have their own effects and side-effects. Decisions about therapy for early stage breast cancer or prostate cancer, for example, lipid-lowering medication for the primary prevention of coronary heart

⁸⁶ Charles C. et al., Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model (1999)

⁸⁷ One could also argue that even in the cases that there seems to be no decision to be made, that the patient should still be involved in the process.



disease, and genetic and cancer screening tests or heart valve surgery as is the case in this essay, are some examples.

Do patients even want to participate in shared decision-making?

In literature on the subject of shared decision-making examples have been described of patients reacting badly to the process of shared decision-making. **Figure 5** shows an example as described by Elwyn et al. (1999)⁸⁸

An elderly lady (aged 82) has been suffering from right upper quadrant pain for some two years and eventually consults her family doctor. He refers her to a surgeon who, with the aid of ultrasound findings, confirms a diagnosis of cholecystitis. The surgeon then suggests that cholecystectomy is an option, and that he would be happy to do this if the patient is agreeable. This situation of contributing to the treatment decision is completely novel to this lady — she has been used to being told ‘what treatment she should have’ — and she now feels highly uncertain and anxious. She chooses to discuss the situation with her family doctor again who has more of an understanding about her expectations for involvement in decision-making, and is more positive about opting for cholecystectomy. She then informs the surgeon that she will have surgery.

Figure 5 Example Case

In this case of the elderly lady it is clear that involvement in the decision-making process threw her off her feet. It illustrates how a long-term context of involvement in decision-making is important, and how it cannot be imposed out-of-the-blue or with everyone. In the case of the elderly lady it might even be her preference to have the doctor choose. How then should the incentive of shared decision-making deal with this?

The key answer in his case seems to be to inform and then ask the patients what they would prefer. Recent work has shown that⁸⁹ doctors are often unaware of patients’ view on treatment. Decisions about prescribing antibiotics, for example, were shown to be guided by a physician’s perception of patients expectations rather than the actual expectation. A study⁹⁰ that followed up 425 women who consulted their general practitioner with menorrhagia (the symptom of abnormally heavy bleeding during menstruation) found that half the doctors were unaware of their patients’ views. And these are just a few examples. As a physician, therefore, you need to find out the specific patient’s preference by actually informing, rather than concluding beforehand. In addition to this as a concluding point I would like to argue that it is of course also important how physicians ask their patients if they want to participate in shared decision-making. Recent work has demonstrated that patients, perhaps because they feel their doctors are not interested, rarely make demands for information or for increased involvement. It seems, therefore, that ‘assumptions and generalizations clearly cannot be made, and the literature points to the need to ascertain involvement preferences within consultations and for the need to develop ways of accurately assessing preferred levels of participation.’⁹¹

⁸⁸ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, *British Journal of General Practice* (1999), p.479

⁸⁹ Ibid.

⁹⁰ Coulter A, Peto V, Doll H. Patients’ preferences and general practitioners’ decisions in the treatment of menstrual disorders. (1994).

⁹¹ Elwyn G. et al., A shared decision-making in primary care: the neglected second half of the consultation, *British Journal of General Practice* (1999), p.479



Chapter 9 A Reflection on the future of Shared Decision-Making

So far we have looked at the incentive of shared decision-making in historical and contemporary context. Also, we have looked at the field of phenomenology and in particular its application in medicine. In this chapter we will bring together both by reflecting on shared decision-making and deciding to what extent it is able to grant the phenomenological wishes.

In order to truly reflect, we also need to bring back in the picture both Susan and Dr. H. As discussed previously, from the phenomenological standpoint Susan and Dr. H experience different realities. Susan's illness, and the decision she will have to make about the treatment of that illness, are explained differently against the background of Susan's life and that of Dr. H: we could even speak of the previously mentioned systematic distortion of meaning in the patient-physician relationship.

Shared decision-making seems to be an attempt at bridging the gap between patient and physician. One of the best results shared decision-making could achieve is the appreciation of the impact illness has on a patients' life, not just as a secondary effect of the biological disease but as a primary phenomenon⁹². Instead of seeing the patient's experience as a thin layer over the objective reality of the disease, we will allow for the patient's experience to represent the actual reality in the medical encounter. After all, the phenomenology teaches us that this *is* in fact the patient's reality⁹³.

However, we must also realize that the bridge will not reach the other side completely. Although Susan can explain to Dr. H what is on her mind when it comes to the decisions, Dr. H will never actually experience what Susan experiences. It might be easier for Dr. H to take into account Susan's personal preferences and needs when there is room and ample means for Dr. H to hear and take into account Susan's preferences. But it might be a bridge too far to say that this exchange of information will allow Dr. H to understand Susan's experiences. What will Dr. H actually understand or experience of what it will mean for a woman, and in particular Susan, to maybe have to postpone or forget about a pregnancy? Even when she explains to him how becoming a mother is something she has always wanted? What it will mean for her to hear the valve tick in her body at night? And the same goes for Dr. H. When Dr. H finally reaches the summit of his ability to explain risks and benefits to his patients and especially Susan, we could argue to what extent this will actually bridge the gap. Susan might understand the information provided quite quickly, which will narrow the information gap. She could even understand what it means to have a 10% risk of bleeding after surgery or to be at low risk for an allergic reaction. But nevertheless, the knowledge gap remains present. If Susan sees 10 red coloured puppets and 90 black ones (**see Figure 6**), she will not see what Dr. H sees. As Dr. H is wondering how to categorize the 10 red coloured patients, how to identify and inform them, Susan is wondering which one of the puppets she will be. What it will mean for her to be a red or blue puppet? Although the mutual deliverance and exchange of information tries to search for an even playing field, we must realize that these two fields are in different dimensions.

The gap between the third and first person experiences of illness is more than just a difference in mutual information and knowledge level that shared decision-making tries to solve, but rather a

⁹² Care h.l, Phenomenology and its application in Medicine, Theor Med Bioeth (2011) p.42

⁹³ This is where the previously mentioned distinction between disease and illness comes in again.



fundamental difference in approach to illness. Illness represents two distinct realities⁹⁴ between patient and physician and it is hard to figure out a way to bridge two realities.

So what is the conclusion we have to draw? Good try but not good enough? Best try but it won't get any better? As we can read in the medical literature described in the previous chapters, medicine seems to have high hopes for shared decision-making. It is the modern man's dream clinical encounter, a way to overcome paternalism and put the patient in the centre of attention. Shared decision-making advocates are optimists; about the skills the doctors will need to develop to actually accomplish a shared decision, about the costs that will be avoided by having better complying and more satisfied patients and about the willingness of patients to participate. However, the actual largescale implementation, catering to the needs of every patient individually, is lacking, which makes these ideas more a vision than a solid practice. What phenomenology would tell us, in my opinion, is to nevertheless keep on going. With shared decision-making we finally reach an era in which physicians are more 'phenomenologically-minded', an era in which they are made aware of the possibility to examine *the nature* of the difference between patient and physician understandings. Shared decision-making will be a way to make explicit the assumptions that result in the distortion of meaning on both ends, especially allowing for the patient to prove a detailed account of illness as lived. And this will in turn change the role of the physician from the paternalistic father to perhaps a type of coach. Instead of asking 'What is the matter?', we might start asking 'What matters to you?' And even though I believe that phenomenology tells us that patients and physician are speaking from two different islands in two different realities, shared decision-making seems to be a fruitful attempt to see a reflection from the others side, as one would in the mirror. This reflection might be enough for a patient to feel included and involved, appreciated and seen. Although shared decision-making has a long way to go, we must not fear away from turning the rhetoric into reality. Patients should be educated about the essential role they play in decision making and be given effective tools to help them understand their options and the consequences of their decisions. They should also receive the emotional support they need to express their values and preferences and be able to ask questions without censure from their clinicians. The inequality and gap between the patient and physician is inevitable and perhaps even eternal, but realizing the gap is there, discussing the gap and together figuring out a way to come closer, might be the only and true way to have an equal conversation in an unequal setting.

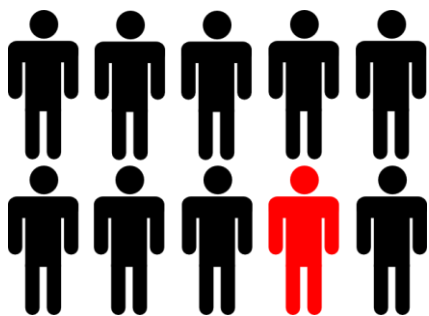


Figure 6 Possible figure to explain risks to a patient in a shared decision-making setting.

⁹⁴ Toombs S.K., *The Meaning of Illness, A phenomenological Account of the Different Perspectives of Physician and Patient*, (1992), p.25



Chapter 10 Epilogue

Jimi Hendrix, a guitarist and musician from the '60s, once sang about the sandcastles I mentioned in the prologue:

“And so castles made of sand fall to the sea, eventually.”⁹⁵

As I explained, philosophy, and especially the application of philosophy in my field of medicine, feels like kicking down sandcastles and building new ones. The clinical encounter between physician and patient might be one of the most ancient sandcastles in medicine, having already undergone countless reconstructions throughout history. In this bachelor thesis I have reflected on a new suggestion for a remodelling: shared decision-making.

By looking at the aims and views of phenomenology, as well as the ambitions and current state of shared decision-making I have been able to critically reflect on the practice. Although we are still far away from the actual, widespread application of the theory, it might not be too forbearing to judge whether I myself would be an advocate of the approach. With the limited practical experience I have, I hesitate to make a general judgement, but I am positive. Having seen the process of illness up close, I have realized how for some patients the lack of contribution to the process can be equally traumatizing as being ill in the first place. I believe, I as a physician should and could contribute to minimizing this pain. I see it as a challenge, to reach my patient in such a way as that we could be equals, even in inequality.

I wonder what will actually come from these ambition, but for now I am grateful I have been given the opportunity to keep the sandcastle upright a little longer, contrary to what Hendrix might have preached.

⁹⁵ *Castles made of Sand*, Jimi Hendrix, 1967.



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