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Using Patient Knowledge in Patient Participation

Can a capabilities approach provide an equitable design for patient participation and avoid epistemic injustice?

Master's thesis submitted in fulfilment for the degree of

Master of Applied Ethics

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Place and date: June 16, 2022, Utrecht

Word count: 15.083

Acknowledgements

First of all, I would like to thank Prof. Hans van Delden and Dr. Jos Phillips for providing me the opportunity to continue doing research for the project of Patient Participation at the Julius Center. I would particularly like to thank my supervisor Prof. Hans van Delden for making time to guide me through the process of writing my master's thesis and putting in the effort to take my needs into account and for thereby personalising his guidance. He truly made this a pleasant, interesting and intellectually challenging project.

Abstract

This thesis provides an epistemological and ethical analysis of the use of the concepts ‘experience’, ‘experiential knowledge’ and ‘experiential expertise’ within patient participation in The Netherlands. It shows how the use of these concepts can provoke epistemic injustice being done to patients by creating hierarchies of epistemic positions and by exclusion of marginalised groups. It is argued that instead of experiential knowledge, we should start using the term ‘patient knowledge’. In order to do this it is examined whether a capabilities approach could be a suitable theoretical framework to involve patient knowledge into care in a morally just way. Therefore, three arguments in favour of– and against– a capabilities approach are introduced, exploring if it can provide an equitable design for reshaping patient participation policies within The Netherlands. It was concluded that an essentialist capabilities approach can provide an equitable framework for patient participation on an institutional (macro) level. At an individual (micro) level, it can provide a starting point for the conversation between physicians and patients, but leaves the freedom to interpret the framework to the patient and the physician. The task of the physicians is to create the space for good communication, by, for instance, using tools as a prelude for the conversation or by the acquisition of both moral and epistemic virtues.

Key words: healthcare field, patient participation, experiential knowledge, patient knowledge, epistemology of institutions, epistemic virtues, epistemic injustice, capabilities approach, Aristotelian ethics, epistemic responsibility

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Introduction

Within the Dutch healthcare field, patient participation¹ has become an often heard term. We want patients² to participate within biomedical research or their own individual care, with the aim to enhance the quality of healthcare³ and to empower patients. For this purpose, Dutch patient associations and healthcare institutions deploy patients as experiential experts to share their experiences and their knowledge. Within these institutions, a threefold distinction between ‘experience’, ‘experiential knowledge’ and ‘experiential expertise’ is commonly used. However, not every patient possesses experiential knowledge or can be an experiential expert: there are certain requirements to gain experiential knowledge and to become an experiential expert. When patients want to participate in contexts such as biomedical research, policy-making or within patient associations, they need to meet these requirements through, for instance, special training. This creates a hierarchy between patients and excludes certain groups, and sometimes eventually even provokes epistemic injustice being done to patients. In order to avoid this problem, I have argued elsewhere⁴ that we should replace the term ‘experiential knowledge’ for the term ‘patient knowledge’. In this thesis I want to examine what would be the best way to use patient knowledge in practice. For this purpose, I focus solely on the way healthcare institutions are shaped in The Netherlands, in order to avoid making generalisations about the way these institutions are shaped elsewhere. I note, however, that the issue addressed here may be prevalent within (healthcare) institutions in other countries too. The aim of this research is to find a way to introduce patient knowledge into practice by not expecting every patient to participate in the same way, without excluding patients from participation and at the same time respecting people who do not want to participate. When looking at applicable theories that might be helpful in this context a ‘capabilities approach’ seems to be a plausible candidate. Moreover, when thinking about how to approach patients as people with possibilities instead of defects, this strategy has also

¹ In the UK this is often referred to as ‘patient involvement’ and in the US it is referred to as ‘patient engagement’. See e.g. Solbjør & Steinsbekk (2011), Vahdat et al. (2014) and Higgins et al. (2016).

² When referring to “patients” I mean people who have certain physical conditions that make them encounter any event within a hospital. Taking into account patients with mental illness is outside the scope of this thesis.

³ Throughout this thesis I make a distinction between the terms “health care” and “healthcare”. I use the term health care to refer to the set of actions by a person to maintain or improve a patient’s health and the term healthcare when referring to an institution offering medical services or the set of medical services that an organisation or country provides.

⁴ Van Wijck, N. (2022). Taking into account patients’ knowledge in medical practice: An epistemic and ethical analysis of the concepts ‘Experience’, ‘Experiential knowledge’ and ‘Experiential expertise’. *Julius Center, UMC Utrecht*, 1–23.

been used by many other researchers.⁵ For instance, Entwistle et al. (2012), have argued that “experiences of healthcare delivery matter because they shape and represent capabilities that are key to how well people’s lives can go.”⁶ In addition, the currently very popular ideas of ‘positive health’ and ‘person-centred care’ could also be interpreted as approaches that originate in a capabilities approach, as they are focused on strengthening what people can do, but also looking at what people find important. An understanding of positive health without taking into account patients’ experiences is unthinkable. Therefore, I will explore whether a capabilities approach offers tools for an equitable design of patient participation and can take into account patient knowledge. I particularly focus on Martha Nussbaum’s capabilities approach, because it provides a clear essentialist framework that is particularly concerned with fighting entrenched social injustices, which could potentially be useful for the reshaping of patient participation I argue for in this thesis. For this purpose, I will take into account all forms of patient participation: on both a macro level (biomedical research, policy within the hospital or educational organisation) and a micro level (the care of the individual patient).

This thesis is structured as follows: In chapter 1, I start off by clarifying the problem by explaining how patient participation is currently shaped in The Netherlands, and set out the epistemological and ethical implications of this system. In chapter 2, I introduce the theoretical framework of a capabilities approach and draw specific attention to the capabilities approach advocated for by Martha Nussbaum, and examine if – and in what shape – it could be beneficial for patient participation on both an institutional and individual level. In chapter 3, I demonstrate that applying a capabilities approach within the healthcare field has multiple advantages for enhancing patient participation, based on the following three arguments: first, a capabilities approach can make use of individual patients’ strengths and capabilities without expecting them to participate in the exact same way or to the same extent as other patients. Second, a capabilities approach can enhance diversity and inclusivity within the healthcare field. Third, a capabilities approach can avoid epistemic injustice. Then, I bring forward three counter-arguments to applying a capabilities approach to shape patient participation, and reply to these criticisms. Finally, after having considered all the arguments, I present concluding remarks and implications.

⁵ E.g. see Entwistle et. al (2012), Simon et al. (2013) and Mitchell et al. (2017)

⁶ Entwistle, V., Firnigl, D., Ryan, M., Francis, J., & Kinghorn, P. (2012). Which Experiences of Health Care Delivery Matter to Service Users and Why? A Critical Interpretive Synthesis and Conceptual Map, p. 72.

Chapter 1 Patient participation and patient knowledge

1.1 Patient participation in the Netherlands

Nowadays in the Netherlands, more and more attention is drawn to making institutions inclusive, accessible to everyone and built on collaboration. Through Open Science community members can collaborate with scientists on research to bridge the gap between society and science, within psychiatry ex-clients can share their experiences to help other clients and within medicine patients can participate by sharing their experiential knowledge. All of these initiatives have one thing in common: ‘lay people’ can share their experiential knowledge in order to enrich the communal body of knowledge. In recent years, the concept of experiential knowledge has increasingly been used to characterise the contribution patients make to healthcare. What has been referred to as ‘lay health beliefs’ has gradually evolved into ‘lay knowledge and expertise’. This specific form of knowledge is related to patient participation. Within the medical practice, patient participation serves to enhance the quality of healthcare in general. Where patients were expected to be passive subjects, they are currently expected to be an active participant in their own care. This active participation is often referred to as patient participation, patient involvement or patient engagement. Patient participation is a broad concept, which is defined in multiple ways in the relevant literature. Eriksson (2001) describes patient participation as “being involved in decision-making or expressing one’s views on different treatments. It includes sharing information, communicating feelings and symptoms.” Eldh et al. (2004) have defined it as follows: “[patient participation is] to be confident, and to comprehend, seek and maintain a sense of control and recognition of one’s own responsibility as a patient.”⁷ Patients can participate on two different levels: on an institutional level and on an individual level. Patients can, for instance, on an institutional level be deployed as ‘experiential experts’ who share their knowledge and experiences within patient associations, self-help groups, biomedical research

⁷ Eldh, A. C., Ehnfors, M., & Ekman, I. (2004a). The Phenomena of Participation and Non-Participation in Health Care—Experiences of Patients Attending a Nurse-Led Clinic for Chronic Heart Failure. *European Journal of Cardiovascular Nursing*, 3(3), 239–246. <https://doi.org/10.1016/j.ejcnurse.2004.05.001>, p. 239.

or policy-making. Patient participation can also occur on an individual level, within the confines of a doctor's office.

In order to advocate for patient participation in The Netherlands, I start off by demonstrating why an equitable design of patient participation is valuable. Currently healthcare in The Netherlands is shaped according to the ‘biomedical model’, which originates from Rudolf Virchow’s conclusion that all disease results from cellular abnormalities.⁸ The biomedical model is often associated with medical reductionism and contrasts with medical holism which recognises that psychological and social factors are also a major part of a patient’s well-being and health.⁹ I have argued elsewhere that by embracing the biomedical model and its reductionism of disease to mere “abnormalities in the body”, the focus on the moral dimension of disease fades into the background.¹⁰ Because of the fact that a disease can be caused by multiple factors, at multiple levels, and working together in complex ways, the healing process consists of more than just healing a disease: the patient’s experiences with the disease in question can also be taken into account. Naturally, medical intervention is an indispensable part of the generic medical practice, but the epistemic and moral aspects of the contact between professional and patient within the healthcare field also play an important role. Within a biomedical framework, medical practice is often task-based rather than patient-focused, thereby closing down opportunities for establishing sustained contact between healthcare professionals (e.g. physicians or nurses) and individual patients, and for the rich forms of communicative relationship that might facilitate the recognition and cultivation of patients’ ability to contribute to the epistemic aspects of their care.¹¹ This can consist, for instance, of time pressure, short consultations, and use of standardised protocols that leave little room for personal needs and values that are prominent characteristics of modern healthcare institutions.¹² Therefore, I believe a fair design should be made for patient participation, in which patients’ experiences and knowledge can be taken into account in such

⁸ Wade, D. T., & Halligan, P. W. (2004). Do biomedical models of illness make for good healthcare systems? *BMJ*, 329(7479), 1398–1401.

⁹ A modern work on holism about disease is Michael Marmot’s Status Syndrome, in which he argues that health and longevity are intimately related to position in the social hierarchy. The lower the status, he states, the higher risk of illness and death, and consequently the shorter the life expectancy. See Marmot (2004): 150–154.

¹⁰ Van Wijck, N. (2021). The Healing Factor of Virtue in Medicine: Why physicians should apply virtue ethics to best fulfil their professional role. *Universiteit Utrecht*, 1–27.

¹¹ Kidd, I. J., & Carel, H. (2016). Epistemic Injustice and Illness. *Journal of Applied Philosophy*, 34(2), 172–190. <https://doi.org/10.1111/japp.12172>, p. 176-177.

¹² I acknowledge that the standardisation of healthcare is not necessarily bad in itself. A certain extent of standardisation can be desirable if we want to keep the extensive, and sometimes complicated healthcare system in The Netherlands afloat.

a way that patients can put to use their strengths and capabilities, but also to enhance healthcare in general. Patient participation has multiple advantages, for both the patient and the healthcare institutions themselves. Governments and patients associations make a plea for active participation in biomedical research processes, because patients can contribute to the relevance and quality of biomedical research by contributing their experiential knowledge.¹³ On an individual level, patient participation is known to reduce stress and anxiety and increase patient's motivation and satisfaction with received care.¹⁴ In addition, patient participation can enable patients to maximise their potential for comfort.¹⁵ These positive outcomes have been found in several studies and summarised by Sahlsten et al. (2008), for example, increased satisfaction with care and hospital stay, treatment, influence, and access to information, better treatment results, patient empowerment, a sense of comprehending and being confident, better adjustment to the situation, and decreased vulnerability. By arguing for enhancing patient participation, I take into account that not every patient might desire to participate. I will elaborate on this concept of 'non-participation' in chapter 4.

1.1.1 The concepts of knowledge and experience within patient participation

Within patient participation in The Netherlands, a distinction is often made between different kinds of knowledge and experiences patients and professionals possess, and the time and place where the contribution of these sorts of knowledge is most desirable. Firstly, a distinction is made between the three concepts: 'experience', 'experiential knowledge' (lay knowledge) and 'experiential expertise' (lay expertise). Secondly, a distinction is made between experiential knowledge and professional knowledge (or medical/scientific knowledge). I have examined multiple studies and came across this threefold division both in international scientific research papers and in publications of Dutch patient associations (e.g. Patiëntenfederatie Nederland) and healthcare (innovation) organisations (e.g. ZonMw and PGO Support). These institutions also use the concepts in the context of patient participation. For instance, ZonMw states five common positive effects of deploying experiential experts: first, the input of expertise by experience is important for entrepreneurs, organisations,

¹³ Caron-Flinterman, J. F., Broerse, J. E., & Bunders, J. F. (2005). The experiential knowledge of patients: a new resource for biomedical research? *Social Science & Medicine*, 60(11), 2575–2584. <https://doi.org/10.1016/j.socscimed.2004.11.023>, p. 2576.

¹⁴ Sahlsten, M. J. M., Larsson, I. E., Sjöström, B., & Plos, K. A. E. (2008). An Analysis of the Concept of Patient Participation. *Nursing Forum*, 43(1), 2–11. <https://doi.org/10.1111/j.1744-6198.2008.00090.x>, p. 2.

¹⁵ Sahlsten, M. J. M., Larsson, I. E., Sjöström, B., & Plos, K. A. E. (2008). An Analysis of the Concept of Patient Participation, p. 3.

governments and researchers. Second, they help professionals to gain access to the target group they work with. Third, it allows patients to be supported more effectively. Fourth, experts by experience can contribute to innovations and cost savings. Fifth, patients themselves can benefit from a more inclusive view and their commitment empowers them and gives them a chance to find work.¹⁶ However, not every patient is automatically an experiential expert. For authentic experience to become experiential knowledge, and for a patient who possesses this experiential knowledge to become an experiential expert, several requirements are mentioned. There seems to be little consensus about these requirements, about what the concepts mean nor about what distinguishes them from each other. Therefore, I will first provide an overview of how the concepts are currently being defined and used.

1.1.2 Experience

Experience within the healthcare field is about diverse individual experiences of patients. In their article, Entwistle et al. (2012) provide a conceptual map that demonstrates why experiences of health care are important. Multiple meanings of the term ‘experience’ are acknowledged: first, experiences can be reports of health care events that patients were involved in, such as what health services and professionals are like. Patients comment on the functioning of the systems and how staff behave, particularly in terms of relating and responding to patients and family members.¹⁷ Second, experiences can be reports of how people were affected by these events, including what they thought and how the events made them feel. So, how patients or family members feel as a result of what services and staff are like and do, and what they consider themselves enabled (or not) to be and do.¹⁸ Based on these two characteristics of patient experiences, the authors argued that “the characteristics and actions of healthcare services and staff, and the ways they relate to patients, have implications for patients’ experiences of being enabled (or not) to feel, be and do what they value feeling, being and doing – in the course of their health care contacts and beyond”.¹⁹ Here, we already see that capabilities can be a good indicator of assessing patients’ experiences with health care. In addition, not only patients can gain experience and

¹⁶ Ten Haaft, G. (2020, maart). *Ervaringsdeskundigheid een stap verder*. ZonMw. https://publicaties.zonmw.nl/fileadmin/zonmw/documenten/Corporate/Participatie/rapport-signalement_opgemaakt_definitief.pdf, p. 11.

¹⁷ Entwistle, V., Firnigl, D., Ryan, M., Francis, J., & Kinghorn, P. (2012). Which Experiences of Health Care Delivery Matter to Service Users and Why? A Critical Interpretive Synthesis and Conceptual Map, p. 73.

¹⁸ Ibid.

¹⁹ Ibid.

experiential knowledge: healthcare professionals can too. In their paper “Experiential knowledge in clinical medicine: use and justification”, Mark Tonelli and Devora Shapira argue for the value and utility of knowledge gained from primary experience for the practice of medicine. They state that primary experience provides knowledge necessary to diagnose, treat, and assess response in individual patients.²⁰

1.1.3 Experiential knowledge

Experiential knowledge is knowledge that derives from personal experience. In medical contexts, experiential knowledge is often ascribed to patients, where medical knowledge is ascribed to healthcare professionals. Patients can possess experiential knowledge as a result of experiences with their illness or with interventions used to treat these illnesses.²¹⁻²² Experiential knowledge is described as a form of practical knowledge, which is often referred to as ‘*phronesis*’, ‘practical wisdom’, or ‘tacit knowledge’.²³ However, in order to gain this form of knowledge, just having had certain experiences (raw experience) does not seem to be sufficient: in most of the relevant literature I have found that there are different requirements for having experiential knowledge. These require a patient to reflect on their experiences, which can include both the events that took place in a patient’s life and the way these affected them. Sometimes it is even argued that the reflection should also involve other patients’ experiences (collective knowledge).²⁴⁻²⁵ For example, experiential knowledge can arise when patients’ experiences are consciously or unconsciously transformed into a personal insight that enables them to cope with their disease or disability. Put differently, experiential knowledge is not solely experience: it requires both the processing of experience and the contextualising of the experiences within an appropriate and applicable context.²⁶ In addition, a hierarchy seems to be established between professional knowledge related to Evidence Based Medicine (EBM) on the one hand, and experiential knowledge on the other hand. In

²⁰ Tonelli, M. R., & Shapiro, D. (2020). Experiential knowledge in clinical medicine: use and justification. *Theoretical Medicine and Bioethics*, 41(2–3), 67–82. <https://doi.org/10.1007/s11017-020-09521-0>, p. 67.

²¹ Caron-Flinterman, J. F., Broerse, J. E., & Bunders, J. F. (2005). The experiential knowledge of patients: a new resource for biomedical research?, p. 2575.

²² Tonelli, M. R., & Shapiro, D. (2020). Experiential knowledge in clinical medicine: use and justification. *Theoretical Medicine and Bioethics*, p. 69.

²³ Ibid.

²⁴ Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2018). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory & Health*, 17(3), 307–330. <https://doi.org/10.1057/s41285-018-0081-6>, p. 7.

²⁵ Ten Haaft, G. (2020, maart). *Ervaringsdeskundigheid een stap verder*, p. 6.

²⁶ Tonelli, M. R., & Shapiro, D. (2020). Experiential knowledge in clinical medicine: use and justification, p. 74.

in the literature, experiential knowledge is commonly defined as “unsystematic clinical experience” or “anecdotal evidence”.²⁷ Professional knowledge, on the other hand, is considered a stable form of knowledge which constitutes the foundation of our information in the sciences and medicine.²⁸ This paradigm stems from currently dominant ideas about what science is and how science should be conducted, which influences the way patients’ experiences are seen. Experiential knowledge is thus often said to be complementary to professional knowledge.^{29 30}

1.1.4 Experiential expertise

Sociologist Thomasina Borkman (1976) was the first person to theoretically clarify the concepts ‘experiential knowledge’ and ‘experiential expertise’ in the context of healthcare, specifically within patients’ self-help groups. She distinguished these concepts by stating that experiential knowledge is truth learned from personal experience with a certain phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others. Experiential expertise, according to Borkman, is the competence or skill in handling or resolving a problem through the use of one’s own experience.³¹ Other authors also refer to experiential experts in medical contexts as ‘expert patients’, ‘trained patients’, or ‘peer counsellors’.³² The term is often made interchangeable with the term ‘lay expertise’, ‘patient expertise’, or ‘peer support’.^{33 34} To be an experiential expert, patients are often expected to meet certain requirements: they have to possess certain skills, competencies and attitudes.^{35 36} Castro et al. (2018) describe how, through a specific training or learning path,

²⁷ Tonelli, M. R., & Shapiro, D. (2020). Experiential knowledge in clinical medicine: use and justification, p. 70.

²⁸ Ibid.

²⁹ Caron-Flinterman, J. F., Broerse, J. E., & Bunders, J. F. (2005). The experiential knowledge of patients: a new resource for biomedical research?, p. 2576.

³⁰ Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2018). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis, p. 9.

³¹ Borkman, T. (1976). Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups. *Social Service Review*, 50(3), 445–456. <https://doi.org/10.1086/643401>, p. 447.

³² Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2018). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis, p. 1.

³³ Thompson, J., et al. 2012. Credibility and the “professionalized” lay expert: Reflections on the dilemmas and opportunities of public involvement in health research. *Health: An Interdisciplinary Journal for the Social Study of Health Illness and Medicine* 16 (6): 602–618. <https://doi.org/10.1177/1363459312441008>.

³⁴ Civan, A., McDonald, D. W., Unruh, K. T., & Pratt, W. (2009). Locating patient expertise in everyday life. Proceedings of the ACM 2009 International Conference on Supporting Group Work - GROUP ’09. doi:10.1145/1531674.1531718, p. 297.

³⁵ Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2018). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis, p. 2.

³⁶ Ten Haaft, G. (2020, maart). *Ervaringsdeskundigheid een stap verder*, p. 4.

patients can obtain the appropriate attitudes, skills, and knowledge to put their experiential knowledge into practice. They continue that “the purpose of this training is to deploy experiential knowledge in an expert and ethical manner and to give future experts by experience sufficient self-confidence when they become an actor in a healthcare context which is merely dominated by medical technical knowledge.”³⁷ Obtaining these competencies is considered important because experiential experts are often deployed to support others in their lives, (professional) practice or for contributing to policy making, education or research.³⁸ In the Netherlands there are multiple organisations that offer courses to enhance patient participation. For instance, The Dutch knowledge and consultancy organisation PGO Support fulfils an advisory role for medical institutions and offers several courses to learn how to best put patients’ experiential expertise into practice. On their website, they write that one of their courses teaches the patient about the basic concepts of the patient perspective, to identify the concepts experiential knowledge, experiential expertise and participation, the field of work of client organisations in which the client's perspective is asked with the purpose of improvement of care, policy and research, the roles in which the volunteer or professional can represent the patient’s perspective, what an advisory process looks like and how to properly implement this advice.³⁹ These courses are meant for employees and volunteers of organisations that, as a representative of the patient’s perspective, want to improve the quality of care and life for their supporters. The European Patients’ Academy on Therapeutic Innovation (EUPATI), which can be considered the European variant of PGO Support, offers courses to stimulate patient engagement as well. Together with PGO Support, EUPATI “has been providing special training for experienced patient representatives who want to be a fully-fledged discussion partner for parties involved in the development of medicines”.⁴⁰ The aim of using experiential expertise in medical contexts is often said to improve the quality of life of patients and healthcare in general.⁴¹ However, these courses seem to aim for this by making patients acquainted with the discourse of healthcare professionals. In the next section, I will explain how the aforementioned forms of knowledge are interrelated.

³⁷ Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2018). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis, p. 8.

³⁸ Ten Haaft, G. (2020, maart). *Ervaringsdeskundigheid een stap verder*, p. 4.

³⁹ Cursus Aan de slag met je ervaringsdeskundigheid | PGOsupport. (2022). PGO Support. Retrieved 1 June 2022, from <https://www.pgosupport.nl/cursussen/aan-de-slag-met-ervaringsdeskundigheid>

⁴⁰ PGO Support. *Medicijnontwikkeling EUPATI Nederland*. (2019). Retrieved 9 June 2022, from <https://www.pgosupport.nl/dossiers/medicijn-ontwikkeling/eupati-opleiding-toolbox>

⁴¹ Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2018). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis, p. 1.

1.1.5 Relatedness of the concepts

Hitherto, we have seen that the three concepts are often used interchangeably and that different criteria are set for gaining experiential knowledge and becoming an experiential expert. Because of these requirements, I argue that the tripartite between experience, experiential knowledge and experiential expertise is hierarchical: the first step is gaining experience, the second step is gaining experiential knowledge and the last step is becoming an experiential expert. Solely having had experiences with healthcare is insufficient to have gained experiential knowledge, and having experiential knowledge does not necessarily make a patient an experiential expert. We speak of experiential knowledge when that knowledge is articulated or made explicit by assigning someone an epistemological position: that person possesses practical wisdom or '*phronesis*'. In his work *Ethica Nicomachea*, Aristotle wrote "it [*phronesis*] is thought to be the mark of a prudent man to be able to deliberate rightly about what is good and advantageous for himself; not in particular respects, e.g. what is good for health or physical strength, but what is conducive to the good life generally."⁴² Although sometimes experiential knowledge seems to be interchangeable with experience, and these two concepts sometimes seem to refer to the same phenomenon, the distinction between the two can be considered an attempt to make an epistemic position explicit: to indicate that someone has 'gained' some knowledge or wisdom. When someone possesses this kind of knowledge, this person is required to develop certain skills in order to become an experiential expert and be able to share their knowledge in a formal setting like policy-making. However, one could also say that the acquisition of experiential knowledge does not always lead to practical wisdom, since knowledge and wisdom are not necessarily the same thing.

The aim of defining patients' experiences and knowledge in this way aims to demonstrate how patients' experiences can be valuable and why it is important to take them into account. However, I argue that setting these criteria and thereby establishing a hierarchy does not have the desirable outcome for patient participation. I have found that, due to the way it is now shaped in the Netherlands, it can also have negative implications for patients like the provocation of epistemic injustice. In the next sections, I will explain why.

⁴² Aristotle, Thomson, J. A. K., Tredennick, H., & Barnes, J. (2004). *The Nicomachean Ethics*. Penguin Books, Book VI, chapter v, 1140a26-1140a29.

1.2 Epistemic injustice

British philosopher Miranda Fricker was the first person to use the term epistemic injustice. In her book *Epistemic Injustice - Power and the Ethics of Knowing*, she demonstrates that there is a distinctive form of injustice which is related to knowledge. The idea of epistemic injustice is about distributive unfairness regarding epistemic goods such as information or education.⁴³ Fricker defines epistemic injustice as a wrong done to someone in their capacity as a knower.⁴⁴ Any epistemic injustice wrongs someone in their capacity as a subject of knowledge, and in a capacity essential to human value. She makes a distinction between two types of epistemic injustice: testimonial injustice and hermeneutical injustice. In the following sections I will explain these concepts and how they can occur within the healthcare field, specifically within patient participation.

1.2.1 Testimonial injustice

Testimonial injustice occurs when a hearer wrongs a speaker in his capacity as a giver of knowledge or as an informant, for instance when prejudice or bias causes a hearer to give a deflated level of credibility to a speaker's word. Fricker defines prejudices (or stereotypes) as widely held associations between a given social group and one or more attributes.⁴⁵ A stereotype embodies an unreliable empirical generalisation about the social group in question.⁴⁶ Fricker argues that identity prejudice can distort a hearer's credibility judgement and the hearer's perception of the speaker.⁴⁷ When these prejudicial stereotypes interfere with credibility judgements, knowledge that could be passed on to a hearer is not received. This is both an epistemic disadvantage to the hearer and a moment of dysfunction in the overall epistemic practice or system, and an epistemic harm to the speaker.⁴⁸ Within patient participation, testimonial injustice can occur when a physician does not take a patient's testimony about their symptoms seriously, due to (unconscious) bias about the person they are. This bias can be about the patients not being well-educated or in a certain physical or mental state, which makes the physician assign less credibility to their word. For example, a recent study showed that patients with anorexia nervosa often feel like their eating disorder is

⁴³ Fricker, M. (2007). *Epistemic Injustice*. Oxford University Press, p. 1-2.

⁴⁴ Fricker, M. (2007). *Epistemic Injustice*, p. 1.

⁴⁵ Fricker, M. (2007). *Epistemic Injustice*, p. 30.

⁴⁶ Fricker, M. (2007). *Epistemic Injustice*, p. 32.

⁴⁷ Fricker, M. (2007). *Epistemic Injustice*, p. 36.

⁴⁸ Fricker, M. (2007). *Epistemic Injustice*, p. 43.

part of who they are.⁴⁹ Healthcare professionals, therefore, tell them their eating disorder is independent of their identity (the externalizing approach). By labelling certain thoughts and behaviour as stemming from the anorexia nervosa, healthcare professionals help patients to recognise which thoughts are linked to their eating disorder and which are not. The authors argue that the externalizing approach may cause epistemic injustice due to unconscious bias about anorexia nervosa. Patients who feel like their anorexia nervosa is part of their identity, therefore feel like they are not taken seriously when healthcare professionals tell them their thoughts “are not them”. As a result of testimonial injustice, subjects of testimonial injustice may lose confidence in their belief, or in their justification for it, so that they fail to satisfy the conditions for knowledge.⁵⁰ Under-confident subjects will tend to back down in the face of challenge, or even at the very prospect of it.⁵¹ This means that marginalised patients who are not considered credible will be discouraged to share their experiences again in the future. When this intellectual undermining is persistent, it can cause them to lose confidence in their beliefs or justification for them. Fricker states that such a prolonged erosion of epistemic confidence makes people continuously disadvantaged, repeatedly failing to gain the knowledge they would otherwise have been able to gain.⁵² In this way, when it occurs within the context of medicine, knowledge is lost by both the people that are part of the medical institutions and by the patients themselves.

1.2.2 Hermeneutical injustice

Hermeneutical injustice is defined by Fricker as the injustice of having some significant area of the subject's social experience obscured from collective understanding due to persistent and wide-ranging hermeneutical marginalisation.⁵³ Hermeneutical injustice occurs when a gap in collective resources of knowledge puts someone at an unfair disadvantage when it comes to making sense of their social experiences, which is caused by structural prejudice in the economy of collective hermeneutical resources. The nature of the primary harm caused by hermeneutical injustice is analysed as a matter of someone suffering from a situated hermeneutical inequality: their social situation is such that a collective hermeneutical gap

⁴⁹ Voswinkel, M. M., Rijkers, C., van Delden, J. J. M., & van Elburg, A. A. (2021). Externalizing your eating disorder: a qualitative interview study. *Journal of Eating Disorders*, 9(1).

<https://doi.org/10.1186/s40337-021-00486-6>, p. 2.

⁵⁰ Fricker, M. (2007). Epistemic Injustice, p. 47.

⁵¹ Fricker, M. (2007). Epistemic Injustice, p. 50.

⁵² Fricker, M. (2007). Epistemic Injustice, p. 49.

⁵³ Fricker, M. (2007). Epistemic Injustice, p. 158.

prevents them in particular from making sense of an experience which is strongly in their interests to render intelligible. In such a situation, the powerful have an inequitable advantage in structuring collective social understandings.⁵⁴ For example, within the context of patient participation in The Netherlands, untrained patients (as opposed to experiential experts who did receive training) might not possess the adequate language to make sense of their experiences. In other words, they lack the language to express their experiences and feelings to accurately match the discourse of, for example, biomedical researchers. When there is such an unequal hermeneutical participation with respect to some significant areas of social experience, members of the disadvantaged group are hermeneutically marginalised. Hermeneutical marginalisation is always a form of powerlessness, whether incidental or structural.⁵⁵ The subject's marginalisation can be either a result of material power or identity power. In the former case, the subject's socio-economic background has put the kinds of jobs that make for full hermeneutical participation largely out of their reach. In the latter case, subjects do not have certain jobs because there are prejudicial stereotypes in the social atmosphere that represent them as unsuitable, and which negatively influence the judgements of employers.⁵⁶ In the context of patient participation this would mean that certain patients will not be able to participate in formal settings like policy-making or biomedical research. However, it must be noted that hermeneutical injustice is purely a structural notion: no agent consciously or actively perpetrates hermeneutical injustice. The background condition for hermeneutical injustice is the subject's hermeneutical marginalisation.⁵⁷ In the next sections, I will argue that within patient participation awareness should be created about this phenomenon.

1.3 Epistemic injustice within patient participation

In the context of the healthcare field, epistemic injustice can occur more easily than in some other contexts, since patients are often considered more vulnerable because of their physical state, and because of the fact they are often reliant on another person to provide them the treatment or medication they need. Philosophers Ian James Kidd and Havi Carel have analysed the phenomenon of epistemic injustice within contemporary healthcare. They write

⁵⁴ Fricker, M. (2007). *Epistemic Injustice*, p. 147.

⁵⁵ Fricker, M. (2007). *Epistemic Injustice*, p. 153.

⁵⁶ Fricker, M. (2007). *Epistemic Injustice*, p. 154.

⁵⁷ Fricker, M. (2007). *Epistemic Injustice*, p. 159.

that being physically or mentally unwell puts patients in a position of vulnerability and dependence (e.g. for medical treatment) which erodes their social and epistemic confidence and capacities.⁵⁸ According to the authors, two kinds of epistemic complaints are being made within contemporary healthcare: patient complaints and physician complaints. The former entail complaints made by patients who have prolonged experiences within the healthcare field and consist of reports about their medical condition being ignored or marginalised, or that physicians do not take their concerns seriously.⁵⁹ The latter form of complaints are put forward by medical professionals who state that patients often provide medically irrelevant information and fail to contribute epistemically to the collection of medical data.⁶⁰ Kidd and Carel argue that these epistemic complaints have two implications: they have the consequence of complicating the epistemic relationship between the patient and the physician, and they are systematic and longstanding characteristics of healthcare systems, rather than isolated incidents. The structures of healthcare institutions are underpinned by biomedical approaches that focus upon the biological rather than existential aspects of illness, and therefore lower the level of attention paid to the subjective experience of being ill.⁶¹

Moreover, within the specific context of patient participation programmes in The Netherlands, I believe there is a risk of provoking epistemic injustice being done to patients. Therefore, I argue that it is *a fortiori* important that awareness should be created of this tendency within the medical practice. The risk is due to the categorisation of the knowledge of patients in the threefold way described in section 1.1, and the way different epistemic positions are assigned to patients. Put differently, I argue that if epistemic legitimacy is solely ascribed to patients who meet the requirements to be experiential experts, this has some negative implications that can result in epistemic injustice in the following six ways:

1. *Hermeneutical marginalisation*: The hermeneutical marginalisation of certain groups of patients may cause their knowledge to be considered less important, which can result in both the hearer losing important information and patients being epistemically under-confident.
2. *Hierarchy of credibility*: When patients do not meet the requirements to be an experiential expert, they can per definition not contribute to enhancing healthcare like

⁵⁸ Kidd, I. J., & Carel, H. (2016). Epistemic Injustice and Illness, p. 174.

⁵⁹ Kidd, I. J., & Carel, H. (2016). Epistemic Injustice and Illness, p. 172.

⁶⁰ Kidd, I. J., & Carel, H. (2016). Epistemic Injustice and Illness, p. 173.

⁶¹ Kidd, I. J., & Carel, H. (2016). Epistemic Injustice and Illness, p. 176.

experiential experts can. This implies that only the experiences of the people who actually receive training will be taken into account, for instance within policy-making and medical decision-making. By imposing additional requirements, a hierarchy is created in the credibility of different patients and the value and usefulness of their knowledge. As a result, certain groups, and thus the knowledge they possess (i.e. valuable information for the doctor), are excluded. In addition, not every patient is able or willing to develop the specific skills needed to become an experiential expert. Socially marginalised groups of patients are less likely to develop themselves in this way. Experiential experts are often people with the same characteristics (e.g. white, highly educated, communicatively skilled).⁶² The vision of experiential experts is therefore only representative of a certain group of patients, and in that way important information about certain groups of people is lost. For instance, groups of patients that do not perfectly master a certain language cannot become experiential experts when a requirement is to have great language and communicative skills. This gives the patients that are able to become experiential experts the unfair advantage over other patients to make sense of their experiences. However, the knowledge of the groups of patients that are left out can be important and also be expressed in other contexts. Thus, unreflected knowledge is rejected and untrained patients are not heard.

3. *Hierarchy of expertise:* The more patients are privileged, language-skilled and well-educated, the more other expertise within different fields they can use to participate with. This is not morally bad in itself, but I argue that is not how patient participation should be shaped because there is a risk that certain groups of patients are considered more credible because of their expertise in other fields. This can undermine patient participation in general as aiming for patients to participate, solely in their role as a patient. In other words, patients should participate within the healthcare field so that their knowledge and experiences can be taken into account, specifically from a patient perspective, instead of from the perspective of their personal profession or education.
4. *Social framing:* Within biomedical research, creating experiential expertise is a way to adapt the patient's knowledge to the discourse in which it becomes credible and useful for a researcher. The experiential knowledge that is supposed to be contributed does

⁶² Ten Haaft, G. (2020, maart). *Ervaringsdeskundigheid een stap verder*, p. 4.

not always fit within existing settings and systems. Therefore, the authentic experiences of the patients can easily be undermined because they have to be adapted to the language of the researcher. Put differently, the training for experiential experts is aimed at using certain words and articulating experiences in a certain way. This adaptation can be harmful because there is a risk that what patients really have to say is not heard and therefore no justice is done to their authentic experiences. At the moment, there is merely a focus on certain knowledge that fits into the system: experiential expertise is therefore to a certain extent a social adaptation. The use of authentic experiences and experiential knowledge in this way is restrictive: experiences, if they are in line with the views of other actors, are used to legitimise decisions, but if they conflict with the existing discourse or when they are not useful for specific ends, they easily get lost. So first, some people who, for some reason, cannot or do not want to become experiential experts are left out, and second, the things experiential experts contribute are socially framed.

5. *Division of labour:* Commonly, experiential knowledge is assigned to lay people or aims to describe the contribution they make in certain professional contexts. Traditionally, in health care on an individual level the patient is expected to contribute experiential knowledge, and the physician to contribute professional knowledge (medical or scientific knowledge). The potential harm of this so-called “division of labour”, is that it could undermine the concepts of shared decision making (henceforth SDM) and person-centred care. Some of the relevant literature shows how experiential knowledge is often only ascribed to patients, while professionals also have experiential knowledge (or: clinical expertise), from their experience as a doctor throughout the years or even their own experience as a patient, that could be valuable to put into practice. Here, I am not advocating for healthcare professionals to participate from their role as a patient, but to avoid a division of labour.
6. *Contempt of experiential knowledge:* It can also be vice versa: in some cases patients may know more about (certain parts of) their disease than the healthcare professional. However, experiential knowledge is often described as “complementary”, “subsidiary” or even “subordinate” to professional knowledge. When experiential knowledge is seen as subordinate to professional knowledge (e.g. because it would be unscientific), patients can be hermeneutically marginalised. This can lead to a patient's

experiences and knowledge being considered less credible or valuable from the outset. Even when a patient is ‘officially’ considered an experiential expert, this can lead to epistemic injustice (both hermeneutical and testimonial) being done to them. In other words, even though experiential knowledge is acknowledged as a form of knowledge, it has to be taken as seriously as professional knowledge in order for the use of it to really do justice to patients. Acknowledging this, and the fact that patients might also possess medical knowledge, can stimulate SDM and avoid epistemic injustice.

In short, there are two main causes for both testimonial and hermeneutical injustice to occur within patient participation: first, due to (unconscious) stigmatisation, disease is sometimes considered an epistemic failure, and second, due to (unconscious) bias, marginalised groups are given less epistemic credibility. However, there are pragmatic reasons for using the threefold division in practice, and in certain contexts it can be valuable to make those extra demands on patients for gaining experiential knowledge. Offering courses and training can undermine the authentic experience of the patient by teaching them the same language as healthcare professionals, while at the same time it is true that it can increase the acceptance of patients and their experiences. For example, ascribing an epistemic position to patients can grant them a status of credibility and give value to what they contribute to the healthcare field. On the other hand, such hierarchies in knowledge can discredit what patients without such an epistemic position could contribute. I believe that the aim should not be for every patient to be able to contribute the same content in the exact same manner. Authentic experiences, for instance, can sometimes be just as epistemically valuable as experiences that are translated into experiential knowledge or expertise.

1.4 Patient knowledge as a way of avoiding epistemic injustice

In this chapter I will explain how I believe the knowledge and experiences patients can contribute to the healthcare field should be understood and used.

1.4.1 How the concepts should be understood and used

I argue that three changes should be made in how the concepts of experience, experiential knowledge and experiential expertise are understood. First, the role of the concepts should be understood as a mere social one. This means that the concepts simply have a practical

function in the sense that they articulate how and why patient experiences can be valuable. Experiential expertise is a term that distinguishes one patient from another because one has continued learning (e.g. learned the language of researchers) and the other patient has not. This can be useful strategically, but it should not make their experiences more valuable epistemically. Thus, although the distinction between experience, experiential knowledge and experiential expertise is considered to have social meaning, I believe it should not have epistemological meaning. Second, we should stop viewing the distinction as a hierarchy of knowledge and valuing one epistemic position more than another. We could distinguish the concepts to have a clearer view of what sets them apart, but we should not connect any value judgments to them anymore. This also includes stopping structurally valuing professional knowledge over experiential knowledge (ascribed to both patients and healthcare professionals). Both professional knowledge and experiential knowledge are necessary because SDM cannot be practised without either one of them. At the same time it is true that in some situations medical knowledge is more urgent than the knowledge patients bring in (e.g. in the emergency room). In short, we should quit assigning higher or lower epistemic positions to patients and professionals by the knowledge they possess when we are trying to enhance patient participation. Third, instead of using the term experiential knowledge when addressing the knowledge or experiences patients can contribute, the term ‘patient knowledge’ should be adopted. In the next section I will explain the meaning of this term and in the following chapters I will examine how this concept can be best utilised in practice.

1.4.2 Patient knowledge

In her paper “Knowing patients: turning patient knowledge into science”, Jeanette Pols (2013) examines how to articulate the particular knowledge that patients use and develop in their daily practices in order to live with their chronic disease, and how this knowledge relates to forms of medical knowledge. She aims to show that this knowledge can be identified as a particular *epistème* or form of knowledge: patient knowledge. According to Pols, patient knowledge is “a practical knowing in action”, from which different techniques for living with disease may be derived.⁶³ This definition corresponds to the original use of the term experiential knowledge by Borkman. Patients use and develop this practical knowledge to

⁶³ Pols, J. (2013a). Knowing Patients. *Science, Technology, & Human Values*, 39(1), 73–97. <https://doi.org/10.1177/0162243913504306>, p. 75.

translate knowledge from different sources into usable techniques, and coordinate this with the different aims they have in life, in a context that is always changing.⁶⁴ In short, according to Pols, patient knowledge consists of transportable knowledge that is translated into something useful for the patients themselves but also for other patients with the same (chronic) disease. I agree with Pols that patient knowledge is a more appropriate term than experiential knowledge, since patient knowledge can consist of more than mere experiences. However, I believe that the way Pols defines this term is partially flawed and that understanding the concept in this way can constitute the same negative effects as the use of the term experiential knowledge. Therefore, I argue that patient knowledge should be defined in a different way. I will define these flaws and propose an alternative definition and use of the term patient knowledge.

First of all, Pols states that patients use and develop patient knowledge in order to relate to medical knowledge and live their daily lives with disease.⁶⁵ I argue that patient knowledge entails more than practical knowledge about chronic disease: it can also be raw experience or medical knowledge without that being translated into phronesis. For example, solely having stepped into a hospital without having reflected on that experience could be considered a raw experience. Thus, patient knowledge can be related to any sort of medical encounter, experience or disease and be useful in any context. Second, Pols understands patient knowledge in terms of its utility or use-value for other patients. I argue that when patient knowledge is measured by its utility hierarchies are created. Moreover, sharing patient knowledge can (and should) also take place between patients and physicians, not merely amongst patients themselves. Physicians can gain new information and insights by listening to patients share their knowledge. What is important here, is that they also — or maybe even particularly — listen to patients who are not patient experts. By listening to “regular” patients, physicians can gain valuable insights about how patients experience disease. In this way the physician can gain clinical knowledge. The healthcare providers can incorporate these insights into their practice, which consequently can be valuable for other patients. For this purpose, I argue that space should be created for an equal conversation between doctor and patient within the doctor’s office. In section 2.3 I will suggest ways of doing that.

⁶⁴ Pols, J. (2013a). Knowing Patients, p. 78.

⁶⁵ Pols, J. (2013b). The Patient 2. Many. *Science & Technology Studies*, 26(2), 80–97. <https://doi.org/10.23987/sts.55300>, p. 80.

However, there are also some limitations to this approach. First, the term patient knowledge might not (sufficiently) differentiate between experiential experts and untrained patients. For instance, the term patient knowledge is often abhorred in psychiatry because there has been quite a struggle to put experiential expertise on the map as a serious and official profession. By rejecting experiential expertise, there is a risk that the effort that is put into the education of ex-clients is being dismissed and continuing using the term patient knowledge thus undermines this effort. This also entails the risk that the whole territory of the patient's experiences becomes a “grey area”. By arguing for patient knowledge I acknowledge these risks, but it is not my intention to entirely dismiss experiential expertise: the situation I argue for is creating space for patients who have a lot of experience with their disease, but also for the patients who do not (yet). The crucial point here is that the latter group of patients do not have a subordinate (epistemic) position to the former group of patients. In short, both forms of patient knowledge should be taken seriously. Second, having to take all patient knowledge into account can be too ambitious, in the sense that it takes a lot of time at the expense of another aspect of health care. A consultation cannot take three times as long because of the elaborate exchange between patient and physician, as this can be at the expense of the care that can be provided. For example, in some situations deploying expert patients is simply more pragmatic or time efficient because they are easy interlocutors.

In short, in this section I have argued that knowledge and expertise should not be defined in such a specific way, because this turns out to be restrictive and to sometimes actually constitute the opposite effect of what they aimed to do. So then how should patient knowledge be defined and why? I suggest that patient knowledge should simply be understood as any kind of knowledge patients have and can express to any person in any context, without any requirement or required setting. It is morally undesirable to say that one patient has experiential knowledge, while the other has not. Neither does it make sense to measure patient knowledge by its utility: this is purely subjective and can be very restrictive. Even though healthcare policy in many countries encourage patients to be empowered or become experiential experts can be considered good in itself, it is not realistic to think every patient is capable or willing to become one. Physicians should therefore make an extra effort to comprehend this group of patients in order to avoid the epistemic injustice being done to them. In order to do this, formats or programmes should be created on both an institutional and an individual level that enable patients to put to use their personal strengths and

capabilities. In the next chapters I will examine if a capabilities approach can be a way to make an equitable design of patient participation.

Chapter 2 A capabilities approach within patient participation

2.1 The conceptual framework of a capabilities approach

The term capability approach or capabilities approach was first posited in the work of philosopher and economist Amartya Sen. Capabilities are what individuals are able to do and to be (or: ‘functionings’), which Sen defines as ‘substantive freedoms’.⁶⁶ Unlike other theories, within the theoretical framework of a capabilities approach, the capability to function is to be the main indicator for assessing people’s quality of life. For welfare egalitarians, for instance, equal welfare is a way of assessing equality, whereas for utilitarians equal weights for all utilities is important. On the assessment of public policy, Sen writes that the capability perspective has multiple advantages. He states that “individual functioning can lend themselves easier to interpersonal comparison than comparisons of utilities.”⁶⁷ The capabilities approach accepts the fact that not every person is equal in functioning, but asserts that everyone should at least have the same capabilities to function. Thus, based on a capabilities approach, the opportunity to exercise freedom is valuable in itself. There are multiple variants of capabilities approaches. For example, philosopher Martha Nussbaum (among others) substantively developed the theory in her work. According to philosopher Ingrid Robeyns, who has written an extensive work on the capabilities approach titled *Wellbeing, Freedom and Social Justice: The Capability Approach Re-examined*, the capabilities approach knows many different “modes”.⁶⁸ By saying this she means that scholars have been using the approach for different types of analyses with different aims. In order to demonstrate this, she made a table which shows the main modes of capability analysis.

⁶⁶ Sen, A. (1999). *Development as Freedom*. Oxford University Press, P. 18.

⁶⁷ Sen, A. (1999). *Development as Freedom*. Oxford University Press, P. 76.

⁶⁸ Robeyns, I. (2017). *Wellbeing, Freedom and Social Justice*. Macmillan Publishers, p. 31.

Table 2.1 The main modes of capability analysis

Epistemic goal	Methodology/discipline	Role of functionings and capabilities	Examples
Normative theories (of particular values), e.g. theories of justice, human rights, wellbeing, sustainability, efficiency, etc.	Philosophy, in particular ethics and normative political philosophy.	The metric/currency in the interpersonal comparisons of advantage that are entailed in the value that is being analysed.	Sen 1993b; Anand and Sen 1994; Crabtree 2012, 2013; Lessmann and Rauschmayer 2013; Robeyns 2016c; Nussbaum 1992, 1997; Nussbaum 2000; Nussbaum 2006b; Wolff and De-Shalit 2007.
Normative applied analysis, including policy design.	Applied ethics (e.g. medical ethics, bio-ethics, economic ethics, development ethics etc.) and normative strands in the social sciences.	A metric of individual advantage that is part of the applied normative analysis.	Alkire 2002; Robeyns 2003; Canoy, Lerais and Schokkaert 2010; Holland 2014; Ibrahim 2017.
Welfare/quality of life measurement.	Quantitative empirical strands within various social sciences.	Social indicators.	Kynch and Sen 1983; Sen 1985a; Kuklys 2005; Alkire and Foster 2011; Alkire et al. 2015; Chiappero-Martinetti 2000.
Thick description/descriptive analysis.	Qualitative empirical strands within various humanities and social sciences.	Elements of a narrative.	Unterhalter 2003b; Conradie 2013.
Understanding the nature of certain ideas, practices, notions (other than the values in the normative theories).	Conceptual analysis.	Used as part of the conceptualisation of the idea or notion.	Sen 1993b; Robeyns 2006c; Wigley and Akkoyunlu-Wigley 2006; van Hees 2013.
[Other goals?]	[Other methods?]	[Other roles?]	[Other studies may be available/ are needed.]

Figure 1: The main modes of capability analysis. Source: Robeyns, I. (2005a)

As we can see in the image above, Robeyns (2005a) distinguishes between disciplines, goals for the creation of knowledge and methods used within the capabilities approach. In the table it becomes clear that within philosophy, specifically within ethics and normative political philosophy, capability approaches are often used. They aim for interpersonal comparisons of advantage that are entailed in the value that is being analysed. Since I am aiming to show how patient participation in The Netherlands creates hierarchies, and consequently can provoke epistemic injustice being done to patients, I choose to use a theory about social justice and therefore I will focus on Nussbaum's work. In the next section I will further explain her version of the capabilities approach.

2.2 Nussbaum's essentialist approach

When philosophically writing about the healthcare field, Aristotle's humanitarian focus on human flourishing (*eudaimonia*) as an end of social activity has great appeal. Throughout this

thesis, I focus mainly on Nussbaum's 'essentialist' version of the capabilities approach, because it provides a clear framework which is particularly concerned with fighting entrenched social injustices. Moreover, providing a list of capabilities myself is beyond the scope of my thesis. Such an essentialist list has Aristotelian characteristics and could be desirable for shaping patient participation, because it can help to not only take into account an individual patient's point of view, but also put forward values that have a general validity. Policy makers, for example, want to work with experiential experts on an institutional level who are willing to do more than express their own opinion and who are able to contribute more generic things and consider the interests of everyone involved. It is precisely there that it is attractive to use an essentialist framework as it connects with the supra-individual. However, I also aim to take the individual level into account, where person-centred care and individual representation are important. At this point, I suspect that an essentialist approach is not as suitable on an individual level as it is on an institutional level. Later in this thesis I will delve deeper into that matter, but I will first explain what an essentialist theory entails.

Nussbaum defines her capabilities approach as a comparative quality-of-life assessment to analyse an individual's basic social justice.⁶⁹ This approach is focused on the set of opportunities each person possesses to choose and act. According to Nussbaum, just societies and policies should be promoting these substantial freedoms.⁷⁰ The central value of the capabilities approach seems to be freedom: each individual has the freedom to seize these opportunities, but the choice whether or not to do so remains theirs. In her work *Creating Capabilities: The Human Development Approach*, Nussbaum provides us with a list of ten central capabilities. In this thesis, I will refer to these central capabilities as the 'essentialist capabilities'. They are essentialist in the sense that they aim to provide a basic quality of life, from which individuals have the freedom to shape their lives the way they want. This idea of a basic quality of life goes back to Aristotle: he argued that the excellent legislator should see how a city, a family of human beings will share in the good life and in the happiness that is possible for them.⁷¹ This relates to the concept of capability in the sense that policy-making should enable people to live flourishing lives. The analogy between the Aristotelian notion of flourishing and the capabilities approach, is that capabilities provide a solid basis for every

⁶⁹ Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach* (Reprint ed.). Belknap Press: An Imprint of Harvard University Press, p. 18.

⁷⁰ Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 18.

⁷¹ Aristotle, & Rackham, H. (1944). *Politics* (Ser. Loeb classical library, 264). Harvard University Press, 1325a7-10.

person to flourish. According to Nussbaum, it is the government's task to enable individual people to pursue a dignified and minimally flourishing life, by securing to everyone at least a threshold level of these ten capabilities⁷²:

1. *Life*: Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. *Bodily health*: Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. *Bodily integrity*: Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. *Senses, imagination, and thought*: Being able to use the senses, to imagine, think, and reason—and to do these things in a “truly human” way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non beneficial pain.
5. *Emotions*: Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)
6. *Practical reason*: Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)
7. *Affiliation*: (A) Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be

⁷² Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 33-34.

able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.) (B) Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.

8. *Other species*: Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. *Play*: Being able to laugh, to play, to enjoy recreational activities.
10. *Control*: over one's environment. (A) Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association. (B) Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

Nussbaum states that these central capabilities support one another in many ways and that specifically two of them play a distinctive fundamental role, in the sense that the other capabilities are built on them. She calls these capabilities 'affiliation' and 'practical reason'.⁷³ She writes that:

Good policy in the area of each of the capabilities is policy that respects an individual's practical reason; this is just another way of alluding to the centrality of choice in the whole notion of capability as freedom. What is meant by saying that the capability of practical reason organizes all the others is more obvious: the opportunity to plan one's own life is an opportunity to choose and order the functionings corresponding to the various other capabilities. As for affiliation, the point is similar: it pervades the other capabilities in the sense that when they are made available in a way

⁷³ Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 39

that respects human dignity, affiliation is part of them—the person is respected as a social being.⁷⁴

‘Affiliation’, according to Nussbaum, is connected to the other capabilities for instance in the context of deliberation about public policy.⁷⁵ Here, several relationships, such as familial, friendly, group-based, political relationships, and thus also patient participation play a structuring role. Nussbaum argues that a capability to function, and not an actual functioning, should be the goal of legislation and public planning.⁷⁶

2.3 A capabilities approach within patient participation

What makes a capabilities approach generally suitable for policy-making, is that it takes into account the fact that individuals have different (degrees of) needs for resources to be able to pursue the same level of capability.⁷⁷ Multiple scholars have applied the capabilities framework to policy-making in several contexts. For example, Entwistle et al. (2012) have presented a conceptual map of patient experiences within health care, such as doctor-patient relationships and their implications for people’s valued capabilities. The capabilities mentioned are, for instance, to feel respected, to be enabled to contribute to their own care and to experience reciprocity.⁷⁸ In the following two sections I will examine if Nussbaum’s capabilities approach could be applied on both institutional and individual levels of patient participation, and therefore could be a plausible theory to reshape patient participation in The Netherlands, by examining three arguments in favour of it and three counter-arguments.

2.3.2 Capabilities Approach on an institutional level

Most of the capabilities on the list of essentialist capabilities Nussbaum suggested are applicable to enhance the quality of life of patients in general. More specifically, for patient participation on an institutional level, I argue that the focus should be on four particular capabilities of the list. These capabilities are important to enable patients to participate within

⁷⁴ Ibid.

⁷⁵ Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 40

⁷⁶ Nussbaum, M. C. (1992). Human Functioning and Social Justice: in Defense of Aristotelian Essentialism. *Political Theory*, 20(2), 202–246. <https://doi.org/10.1177/0090591792020002002>, p. 221.

⁷⁷ Ruger, J. P. (2010). *Health and Social Justice*. Oxford University Press, p. 58

⁷⁸ Entwistle, V., Firnigl, D., Ryan, M., Francis, J., & Kinghorn, P. (2012). Which Experiences of Health Care Delivery Matter to Service Users and Why? A Critical Interpretive Synthesis and Conceptual Map, p. 70

all contexts of the healthcare field, are ‘Control’ in the political sense and ‘Senses, imagination, and thought’. They are indispensable for shaping patient participation, as they are interconnected with— and related to— the two architectonic capabilities of affiliation and practical reason. On both levels, patients should be enabled to think about their own care, what they need in order to function in the best way possible despite their condition. On the capacity to think, Aristotle writes: “Now the life of animals is defined for the capacity of sensation, and that of man by the capacity for sensation or thinking. But this capacity is relative to its activity, and its realization depends upon the activity. Hence it appears that to live is primarily to perceive or to think.”⁷⁹ Therefore, a capabilities approach should enable patients to cultivate their capability to think and reason. This could mean, on an individual level for example, that the physician stimulates patients to think about what is important to them when it comes to health or quality of life. So, this means that a capabilities approach should consist of an essentialist framework which can help patients flourish on an institutional level, from where they can participate in their own care and be empowered on an individual level. Patient participation on an institutional level has essentialist characteristics and therefore a list with essentialist capabilities could be helpful to shape our institutions in such a way that as many patients as possible can function well within the institutions.

2.3.3 Capabilities Approach on an individual level

In the previous section, we have seen that an essentialist list of capabilities can provide a good framework to shape patient participation on a macro level. However, at first view an essentialist capabilities approach seems to provide little action-guidance on a micro level. For patient participation on an individual level it is more complicated to create such a list: every patient needs something else to function well within a doctor-patient relationship. So, there is quite a lot of room here for the doctor and the patient to fill in the framework themselves. This has advantages and disadvantages. On the one hand it gives patients a lot of freedom to participate in whatever way they want. On the other hand, we may wonder what the capabilities approach can actually add on a micro level? The essentialist list provides a number of starting points for the conversation (communication) between healthcare professional and patient, but the interpretation of the framework is left to them. How do we

⁷⁹ Aristotle, Thomson, J. A. K., Tredennick, H., & Barnes, J. (2004). *The Nicomachean Ethics*, book VIII, chapter ix, 1170a16-a19.

ensure that the space is used as efficiently as possible? In the context of using a capabilities approach, it is actually desirable to provide to the patient the freedom to decide how to function in such a setting. In this manner, they can decide for themselves if, and to what extent they participate. Here, it can be, for example, the professional's job to create the space for the conversation and be sensitive to the individual patient's needs. We can then ask ourselves whether it is desirable for a capabilities approach to also be action-guiding at an individual level? If this is considered important and more guidance on this level is needed, I suggest that, for example, the two of the following approaches can be used as tools for the conversation between a patient and a healthcare professional on the micro level.

First, the Dutch Institute for Positive Health (iPH), provides a method called "the spider web diagram". This method provides a broad interpretation of health, which has been elaborated in six dimensions: bodily functions, mental well-being, meaningfulness, quality of life and participation.

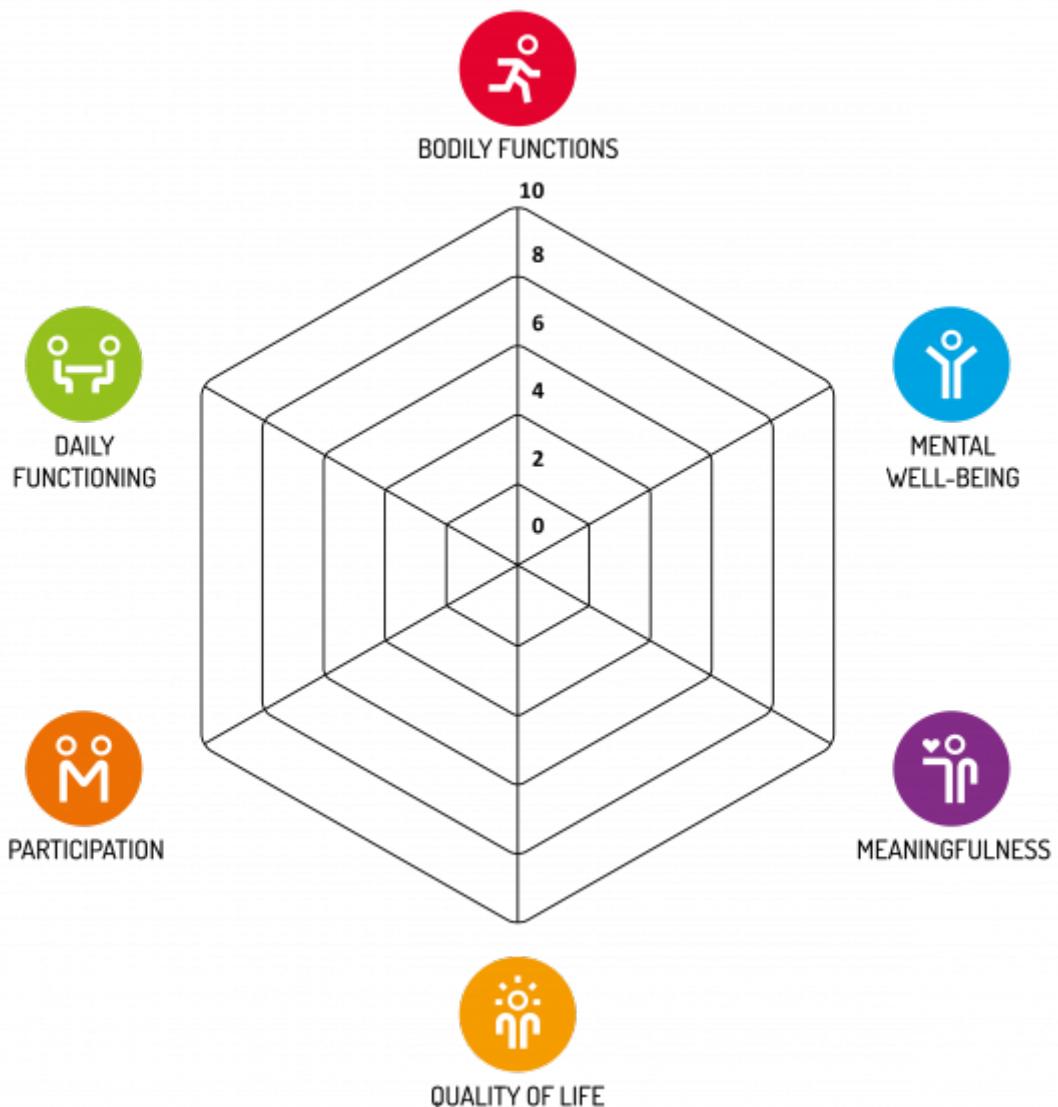


Figure 2: Spider web diagram Positive Health. Retrieved from “Institute for Positive Health”, December 8, 2020, (<https://www.iph.nl/positieve-gezondheid/wat-is-het/>).

The picture above (Institute for Positive Health, 2022) shows the spider web diagram with the six fundamental elements of health. These arose from research into how patients understand the concept of ‘health’. They include not only physical health, but also, for example, meaning, participation and quality of life. The diagram is an instrument for patients to measure their own health and can be used as a prelude to a discussion about health and well-being between healthcare professionals and patients.

Second, Aristotelian virtue ethics can be included into the picture, meaning that a doctor must possess certain virtues.⁸⁰ I have argued elsewhere that physician's should possess certain virtues in order to best fulfil their professional role, which should not only be moral virtues, but also epistemic virtues.⁸¹ It is important for a physician to possess moral virtues because they enhance the physical healing process and the well-being of both the patient and the physician. For example, there is a strong correlation between the way healthcare professionals communicate and how patients respond to that, both mentally and physically.⁸² In other words, when a patient is able to trust a healthcare professional this positively affects the patient's mind, and consequently the patient's body. The former attributes an instrumental function to the virtues. The latter attributes a fundamental function to the virtues, as we see in Aristotle. He does not make this clear distinction, but considers the virtues to be both the means to and the components of the end of human flourishing.⁸³ Epistemic virtues in medicine provide guidance for the physician to act in the best possible way. Epistemic virtues could be, for example, 'epistemic courage', 'epistemic responsibility', 'inclusiveness', 'open-mindedness', and to be 'well-informed' or 'truth-loving'. Aristotle defines several intellectual virtues, which can be considered similar to epistemic virtues, such as 'judgement' (*gnōmē*) and 'understanding' (*eusunesia*). In *The Nicomachean Ethics*, he writes: "What is called judgement, in virtue of which we say that people are considerate and have sympathetic judgement, is the faculty of judging correctly what is equitable."⁸⁴ The virtue of epistemic courage can function, for example, as a way of being open about the uncertainty of medical facts. This is the courage to discuss the uncertainty of the medical profession and entails the recognition of the relativity of the facts. In the context of patient participation, there is a risk that a division of labour is created: the healthcare professional provides the facts and the patient provides their opinions. It takes courage to recognise that as a doctor you are not always on "solid ground". By involving epistemic virtues I do not aim to make any claim

⁸⁰ Some scholars argue that it is also important for patients to acquire certain virtues, see e.g. Campbell & Swift (2013). Due to the scope of this thesis, however, I decided to limit myself to mentioning the acquisition of virtues for healthcare professionals.

⁸¹ Van Wijck, N. (2021). The Healing Factor of Virtue in Medicine: Why physicians should apply virtue ethics to best fulfil their professional role, p. 11.

⁸² Verheul, W., & Bensing, J. M. (2008). *Het placebo-effect in de huisartsenpraktijk: communicatie als medicijn*. Bijblijven, 24(2), 38-44, <https://doi.org/10.1007/bf03076330>, p. 42.

⁸³ Van Wijck, N. (2021). The Healing Factor of Virtue in Medicine: Why physicians should apply virtue ethics to best fulfil their professional role, p. 19.

⁸⁴ Aristotle, Thomson, J. A. K., Tredennick, H., & Barnes, J. (2004). *The Nicomachean Ethics*, Book VI, chapter xi, 1143a19-a21.

about the nature of knowledge or truth: my aim is to argue that the best (intellectual) character traits lead to best epistemic and moral practices. The epistemic virtue can function as a way for physicians to structure or shape patient participation on the micro level, making sure they meet the needs of individual patients and giving them epistemic credibility by acknowledging their capacity as a knower. Here, physicians gain epistemic responsibility: they have to be aware that epistemic actions have consequences, and thus can also be responsible for epistemic failures. In this sense, not only the patient can be held responsible for epistemic failures and is “burdened” with a certain extent of responsibility by participating in their own care: also the physician has to take responsibility over their epistemic actions (e.g. by the acquisition of epistemic virtues). In section 4.1 I will elaborate on the responsibility patients have within patient participation.

Chapter 3 A Capabilities Approach as a way of putting patient knowledge into practice

Through the way patient participation is currently shaped in The Netherlands with the threefold division of experience, experiential knowledge and experiential expertise, demands are made on patients to be able to participate, when in fact patients should be enabled to choose to participate if - and to what extent - they want to participate. In this chapter I will provide three arguments for why an essentialist capabilities approach is a good way of taking patient knowledge into account within the healthcare field. In section 3.1, I will argue that a capabilities approach provides a good framework to enable patients to cultivate their individual strengths and capabilities. In section 3.2, I argue that this consequently enhances diversity and inclusivity within the healthcare field. In section 3.3, I argue that applying a capabilities approach to patient participation on all levels is a way of avoiding- or at least minimising epistemic injustice within patient participation. I choose these three specific arguments, because they all represent aspects of a capabilities approach that can help reshape patient participation in a way which aims to avoid epistemic injustice.

3.1 Putting to use the strengths and capabilities of patients

Using a capabilities approach within the healthcare field is a fairly common step in a thinking defined by positive health and treating patients as people with possibilities rather than with defects caused by their condition. In this section I will argue that a capabilities approach is a way to take into account patients' knowledge, strengths and capabilities. When the tripartite division or step-by-step plan of experience, experiential knowledge and experiential expertise we currently see in patient participation in The Netherlands can be dropped, and switched to a capabilities approach, there is no longer a need for all patients to be (able to be) the same. By expecting patients to follow certain courses to learn skills that allow them to participate, everyone is expected to be able to do the same things. A capabilities approach, on the other hand, aims to provide everyone with the same basis, from which everyone has the freedom to express themselves and develop in their own personal way. At the institutional and individual level of patient participation, a capabilities approach must therefore take individual differences into account. Entwistle et al. (2012) make a similar argument by stating that "the

capabilities approach considers the genuine opportunities that people have to be and do what they value.” They continue that “it is particularly well suited to reflecting the importance of people’s experiences of being respected (or not) as individuals with an interest in their own particular identities and lives, and of being enabled (or not) to engage with their health care providers and in their health care in ways that they value, and have reason to value.”⁸⁵ The capabilities approach thus allows the patient to 1. have the freedom to choose if they want to participate and to what extent, and 2. if they participate, to use their individual strengths and capabilities. Even if patients do not want to, or cannot, participate, the system does not fail them because the essentialist list of capabilities applied on an institutional level should ensure their care is not substandard. So, the capabilities approach requires equality of capabilities, and not of functionings. Concretely, within patient participation this means that every patient is being enabled to participate from the same starting point, but at the same time it is not important that each patient does this in a different way. In other words, every patient’s essentialist capabilities should be promoted, so that they can cultivate their own personal functionings. The idea behind applying the capabilities approach in this context is thus not striving for every patient to be equal and for every patient to participate in the exact same way: it is about giving everyone the same opportunities. In this way, the marginalised groups can be prevented from falling behind or already being disadvantaged from the outset.⁸⁶ Consequently, all of this enhances diversity and inclusivity within the healthcare field. In the next section I will explain how.

We can still ask ourselves though, if a capability should be something that patients have and, based on their wishes, if medicine should be adjusted to them. Or should there also be some degree of education integrated in patient participation policies? I argue that using a capabilities approach to enhance patient participation does not imply that it is only important what the patient wants: the healthcare professional should also have a voice and help foster a patient’s autonomy. Fostering autonomy does therefore contain a certain guidance: the doctor can also expect the patient to have a certain extent of “reasonableness”. In the end, within patient participation there is an aim for SDM, which means a certain effort is expected from both parties. Like mentioned before, one could also argue that not only the healthcare

⁸⁵ Entwistle, V., Firmigl, D., Ryan, M., Francis, J., & Kinghorn, P. (2012). Which Experiences of Health Care Delivery Matter to Service Users and Why? A Critical Interpretive Synthesis and Conceptual Map, p. 73.

⁸⁶ This idea is similar to John Rawls’ difference principle, which requires systems to be organised so that the least advantaged members of society are better off than they would be in any alternative arrangements. See Rawls, J. (1971). *A Theory of Justice*. Harvard University Press.

professional should possess virtues but the patient needs to acquire them too. In other words, still some reflection of patients can be expected. In that sense, patient participation can be regarded as an emancipatory programme.

3.2 Enhancing diversity and inclusivity in the healthcare field

Inclusivity and diversity are widely used concepts that have recently also taken on a greater role in the context of Dutch healthcare systems.⁸⁷ These concepts are interrelated but should also be differentiated. Diversity advocate Verna Myers made the distinction clear by stating that “diversity is being invited to the party; inclusion is being asked to dance.”⁸⁸ In an article about diversity and inclusion within healthcare, Stanford et al. (2020) refer to diversity and inclusion of patients with different ethnicity, gender, sexual orientation, immigration status, physical disability status, and socioeconomic levels.⁸⁹ In this context, diversity and inclusivity go beyond these levels: it is also about diversity and inclusivity of epistemic and intellectual levels. Put differently, within patient participation it is important to take into account the knowledge and experiences of all patients who want to participate, and not solely the knowledge of more “intellectually developed” patients.

I believe, in order to guarantee good healthcare for all individual patients, no matter who they are or where they come from, enhancing diversity and inclusivity within the specific context of patient participation is important. Diversity and inclusivity are important here, because they enrich the body of knowledge and experiences which can be taken into account when, for example, making healthcare policy on an institutional level or providing personalised care on an individual level. Currently, however, by expecting all participating patients to have the same skills, little diversity is created, which consequently limits the ratio of patient knowledge and experiences that can be taken into account within the healthcare field. In this way, knowledge is getting lost. According to professor of Education and

⁸⁷ For an action plan for enhancing diversity and inclusivity in Dutch health care systems see, for example, Amsterdam UMC. (2021). *Diversiteit & Inclusie in Amsterdam UMC ‘Verschil maakt ons samen sterker’*. <https://www.vumc.nl/web/file?uuid=fad3a672-a00c-4a3e-99c1-3e5ec980d0b3&owner=5ec2d559-9d3f-4285-8c bd-140abc921b69&contentid=16951&disposition=inline>

⁸⁸ Sherbin, L., & Rashid, R. (2021, August 27). *Diversity Doesn’t Stick Without Inclusion*. Harvard Business Review. Retrieved 17 May 2022, from https://hbr.org/2017/02/diversity-doesnt-stick-without-inclusion?referral=00563&cm_mmc=email_-_newsletter _daily_alert_-_alert_date&utm_source=newletter_daily_alert&utm_medium=email&utm_campaign=alert_dat e&spMailingID=16466199&spUserID=MTk2NDkwMjE1NwS2&spJobID=960100237&spReportId=OTYwMTAwMjM3S0

⁸⁹ Stanford, F. C. (2020). The Importance of Diversity and Inclusion in the Healthcare Workforce. *Journal of the National Medical Association*, 112(3), 247–249. <https://doi.org/10.1016/j.jnma.2020.03.014>

Psychology Daryl Smith (2012), leaders in academic medicine should shape institutions that serve diverse populations of patients. In order to do that, she argues, they should increase their institutional capacity for diversity.⁹⁰ In line with my Aristotelian reasoning so far, she states that academic medicine should consider diversity as a core to excellence.

So how can a capabilities approach enhance diversity and inclusivity? In the context of patient participation, ensuring sufficient diversity would be about patients feeling invited to participate, regardless of their background. By enhancing inclusivity within patient participation, differences between patients should be considered a source of inspiration and strength. Therefore, patient participation should revolve around enabling patients to cultivate their strengths and capabilities in practice. I argue that a capabilities approach is a good theoretical framework to do this, because it creates freedom for patients to participate in the way they want, and thereby introduce the specific knowledge and experience they possess as an individual. By giving patients freedom and enabling them to participate, they are not expected to be the same: to participate in the exact same way and acquire the exact same skills as other patients. This will enrich the body of knowledge within the healthcare field in general, because it can eventually enhance the diversity of knowledge and experiences that can be taken into account when structuring our medical institutions. In addition, by not setting epistemic requirements within patient participation anymore, every patient is offered the chance to participate, which will naturally enhance diversity and inclusivity in the healthcare field as well because marginalised groups will no longer be excluded.

3.3 Avoiding epistemic injustice

The question still remains if –and how– a capabilities approach could actually entirely avoid epistemic injustice. In section 1.3, we have seen that within medicine, and specifically patient participation, there are two main causes of epistemic injustice: first, due to (unconscious) stigmatisation, disease is sometimes considered an epistemic failure, and second, due to (unconscious) bias, marginalised groups are given less epistemic credibility. About the former cause of epistemic injustice, sociologist Arthur Frank argues that “the power of stigma has fed on seeing the body’s condition as an expression of morality”.⁹¹ In other words, disease is sometimes considered a moral, social and epistemic failure. About the latter cause of

⁹⁰ Smith, D. G. (2012). Building Institutional Capacity for Diversity and Inclusion in Academic Medicine. *Academic Medicine*, 87(11), 1511–1515. <https://doi.org/10.1097/acm.0b013e31826d30d5>, p. 1511.

⁹¹ Frank, A. W. (2002). *At the Will of the Body: Reflections on Illness* (Reprint ed.). Harvest, p. 96.

epistemic injustice, we have already seen that the threefold division currently used in patient participation in The Netherlands plays a crucial role. However, when an essentialist capabilities approach is used to shape patient participation on an institutional level, there is still a risk that not every patient's needs are fully represented in the list. This could again provoke epistemic injustice being done to specific groups of patients. Nussbaum argues that the capabilities approach is concerned with structural social injustice and inequality, especially capability failures that are the result of discrimination or marginalization. This is because, according to her, the approach ascribes an urgent task to government and public policy—namely, to improve the quality of life for all people, as defined by their capabilities.⁹² The list of essentialist capabilities should make sure that biases and marginalisation have less of an effect on patients, by fostering every patient's capabilities to help cultivate their strengths and functionings. Within patient participation, this would imply that every patient has the same opportunities and freedoms to express themselves, regardless of their (e.g. socioeconomic, ethnic or intellectual) background. Currently, requirements are set for patients to participate, which excludes marginalised groups from participation and makes important knowledge get lost. Instead of setting these requirements, patients should be enabled to participate and take them seriously in their capacity as knowers. On general political participation Nussbaum writes:

[...] it [the CA] insists that the political goal for all human beings in a nation ought to be the same: all should get above a certain threshold level of combined capability, in the sense not of coerced functioning but of substantial freedom to choose and act. That is what it means to treat all people with equal respect. So the attitude toward people's basic capabilities is not a meritocratic one-more innately skilled people get better treatment-but, if anything, the opposite: those who need more help to get above the threshold get more help.⁹³

Put differently, a capabilities approach is aimed at enabling people to choose and act the way they want to. For patient participation, this means that all patients' capabilities are promoted to help them participate, without excluding certain groups or giving preference to the patients

⁹² Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 19.

⁹³ Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 24.

who are more skilled. In this manner, the hierarchical threefold division between experience, experiential knowledge and experiential expertise can be dismissed. About the aim of an essentialist approach in practice, Nussbaum writes that “government is not directed to push citizens into acting in certain valued ways; instead, it is directed to make sure that all human beings have the necessary resources and conditions for acting in those ways. It leaves the choice up to them.”⁹⁴

⁹⁴ Nussbaum, M. C. (1992). Human Functioning and Social Justice: in Defense of Aristotelian Essentialism, p. 225.

Chapter 4 Counter-arguments to a Capabilities

Approach within patient participation

In this chapter, I will set out three arguments against using a capabilities approach to take into account patient knowledge within patient participation and reply to these criticisms. Hence, this chapter is focused on investigating questions and debates that I believe could arise when theorising about a capabilities approach within patient participation. I will look into the following issues. In section 4.1, I explain how expecting patients to participate in their own care increases the responsibility placed on them and why this could be problematic. Then, I consider an argument of neglect of autonomy, by explaining how one could argue that by positing a list of essentialist capabilities, the patient's autonomy of deciding what they need is being undermined. In section 4.3, I discuss the issue of non-participation by arguing that it could again provoke epistemic injustice.

4.1 Responsibility

When making patient participation the norm within the healthcare field, a certain responsibility is assigned to patients by inviting them to participate. On an individual level, for instance, patients cannot rely on a quick fix: the physician will not make the decisions for them without having deliberated with them. However, I believe patient participation can only function well when you assign responsibility to a patient. This means that the responsibility should not be assigned to merely the patient, nor the physician, but there should be an aim for shared responsibility between patient and physician (SDM). Patients have some responsibility to participate, and physicians have the responsibility to cultivate their epistemic and moral virtues. Patient participation inevitably involves inviting individual patients to take some responsibility at the individual level of their own care to some extent, but at the same time the capabilities approach should be supporting them to carry that responsibility on both levels. So what should be done if patients do not want to —or cannot participate? And what should be expected of patients? The American Medical Association (AMA), for example, has set out ten patient responsibilities. On their website, they write that good healthcare is about cooperation between patients and healthcare professionals. They argue that patients take responsibility and contribute to the collaborative effort when they:

1. Are truthful and forthcoming with their physicians and strive to express their concerns clearly. Physicians likewise should encourage patients to raise questions or concerns.
2. Provide as complete a medical history as they can, including providing information about past illnesses, medications, hospitalizations, family history of illness, and other matters relating to present health.
3. Cooperate with agreed-on treatment plans. Since adhering to treatment is often essential to public and individual safety, patients should disclose whether they have or have not followed the agreed-on plan and indicate when they would like to reconsider the plan.
4. Accept care from medical students, residents, and other trainees under appropriate supervision. Participation in medical education is to the mutual benefit of patients and the health care system; nonetheless, patients' (or surrogates') refusal of care by a trainee should be respected in keeping with ethics guidance.
5. Meet their financial responsibilities with regard to medical care or discuss financial hardships with their physicians. Patients should be aware of costs associated with using a limited resource like health care and try to use medical resources judiciously.
6. Recognize that a healthy lifestyle can often prevent or mitigate illness and take responsibility to follow preventive measures and adopt health-enhancing behaviours.
7. Be aware of and refrain from behaviour that unreasonably places the health of others at risk. They should ask about what they can do to prevent transmission of infectious disease.
8. Refrain from being disruptive in the clinical setting.
9. Not knowingly initiate or participate in medical fraud.
10. Report illegal or unethical behaviour by physicians or other health care professionals to the appropriate medical societies, licensing boards, or law enforcement authorities.

So, patient responsibility comes back to contributing to the SDM between patient and healthcare professional. To achieve a good level of SDM, both the patient and the professional have a certain responsibility. In order to do this, for instance, a list like presented by AMA could be taken on. They continue that “their partnership requires both individuals to take an active role in the healing process. Autonomous, competent patients control the decisions that direct their health care. With that exercise of self-governance and choice comes

a number of responsibilities.”⁹⁵ I will elaborate on patient autonomy within patient participation in the next section.

4.2 Autonomy

‘Autonomy’ is a concept that is used in multiple contexts and therefore has been defined and interpreted in many different ways. According to philosopher Joel Feinberg, autonomy can be defined as a capacity to support oneself and to direct one’s own life.⁹⁶ Feinberg states that self-government de facto presupposes luck. If a person’s luck is bad, circumstances beyond his control can destroy his opportunities.⁹⁷ As the way patient participation is currently shaped in The Netherlands and the way it can provoke epistemic injustice, the risk that patients’ autonomy will be undermined is rather large. For example, marginalised groups are likely to, due to unconscious bias, be excluded from participation. Therefore, the aim of applying an essentialist capabilities framework, is to involve these groups of patients and consequently protect their autonomy within participation. This implies that they are enabled to choose whether or not they want to participate and to what extent, while otherwise they might not have been able to. However, a point of critique on using an essentialist framework for patient participation can be that it does not leave any room for choice in the following two ways. First, by making patient participation the norm, patients have to choose whether or not to participate. Second, an essentialist list of capabilities which is predetermined does not leave any choice to the patient about what they think are capabilities that could enable them to function well. In the rest of this section, I will try to demonstrate why these critiques do not hold.

Feinberg states that a distinction can be made between four kinds of meanings of autonomy: the capacity to govern oneself, the actual condition of self-government, a personal ideal, and a set of rights expressive of one’s sovereignty over oneself.⁹⁸ I use Feinberg’s definition of autonomy because he emphasises that autonomy is not solely about rights and capacities, but also about taking control, becoming who you are, reasonableness, self-determination. The two important values authenticity and reasonableness I implicitly

⁹⁵ American Medical Association. (2016, November 14). *Patient Responsibilities*. Retrieved 7 June 2022, from <https://www.ama-assn.org/delivering-care/ethics/patient-responsibilities>

⁹⁶ Feinberg, Joel, 1986. *Harm to Self. The Moral Limits of the Criminal Law* (Volume 3), Oxford: Oxford University Press. “Autonomy,” in Christman, (ed.), p. 28.

⁹⁷ Feinberg, Joel, 1986. *Harm to Self. The Moral Limits of the Criminal Law* (Volume 3), p. 31.

⁹⁸ Feinberg, Joel, 1986. *Harm to Self. The Moral Limits of the Criminal Law*, p. 28.

mentioned throughout this thesis are common threads in autonomy as ideal. Feinberg writes that we can “refine a conception of ideal autonomy according to which other things being equal, it is better to be autonomous than not. If we are successful, it will follow that insofar as a person is autonomous, he is to that extent admirable. Indeed “autonomy,” if we construct the ideal carefully, might even designate a necessary element in any full ideal of human character.”⁹⁹ Feinberg argues that not everyone is equally capable of reaching this ideal. The capabilities approach, however, should at least be able to enable every patient to have the same capabilities and therefore the freedom to cultivate their autonomy if they wish to. In this sense, the argument of neglect of autonomy does not hold, since Feinberg’s definition of autonomy as ideal can be considered very similar to what an essentialist capabilities approach aims to do: it is about giving patients an equal starting point, from where they can decide for themselves how they want to function. Nussbaum states that “this respect for choice is built deeply into the list itself in the architectonic role it gives to practical reasoning.”¹⁰⁰ A capabilities approach, thus does not require patients to participate if they do not wish to. The capabilities approach is actually designed to stimulate citizens’, and in this case patients’, freedoms. On this charge of limiting people’s autonomy, Nussbaum writes:

First the list is a list of capabilities, and not actual functions, precisely because the conception is designed to leave room for choice. Government is not directed to push citizens into acting in certain valued ways; instead, it is directed to make sure that all human beings have the necessary resources and conditions for acting in those ways. It leaves the choice up to them.

So, within the framework of an essentialist capabilities approach the four forms of autonomy are warranted (specifically autonomy as ideal), but outside of the framework one could say the approach is limiting patients’ autonomy in the sense that they still have to choose whether or not to participate, and if they do, the capabilities are already chosen for them.

⁹⁹ Feinberg, Joel, 1986. *Harm to Self. The Moral Limits of the Criminal Law* (Volume 3), p. 45.

¹⁰⁰ Nussbaum, M. C. (1992). Human Functioning and Social Justice: in Defense of Aristotelian Essentialism, p. 225.

4.3 Non-participation

In chapter 1, I have already mentioned why patient participation is important and what its positive effects are: that patient knowledge and experiences can improve the quality of life of patients and healthcare in general. Naturally, on the other hand, when patients do not participate this can have some negative implications for them. These effects have been defined by Eldh et al. (2004) as to “not understand”, “not be in control” and “not be accountable”. They refer to this phenomenon as ‘non-participation’.¹⁰¹ By assuming that patient participation is valuable and desirable, patients seem to be expected to be capable of—and willing to—participate within the healthcare field. However, some patients might actually be incapable of articulating their needs and desires. The risk of focusing on enhancing patient participation and to put to use patient knowledge is that the group of patients that do not participate for whatever reason tend to be forgotten. On this topic, Nussbaum writes:

Many people who are internally capable of participating in politics are not able to choose to do so in the sense of combined capability: they may be immigrants without legal rights, or they may be excluded from participation in some other manner. It is also possible for a person to live in a political and social environment in which she could realize an internal capability (for example, criticizing the government) but lack the developed ability to think critically or speak publicly.¹⁰²

This tendency could again provoke epistemic injustice being done to these groups. On the one hand, it should be made sure that either every patient participates to some extent, or that our institutions are at least shaped in such a way that non-participation does not harm patients. On the other hand, there must also be room for non-participation: patients should have the right not to respect their autonomy. Here I refer to Feinberg’s definition of autonomy as an ideal: you can never be forced to live up to an ideal. Building on Aristotle’s theory of human flourishing, Nussbaum states that the goal of political or social activity is defined in terms of “the capability to function well if one so chooses”.¹⁰³

¹⁰¹ Eldh, A. C., Ehnfors, M., & Ekman, I. (2004b). The Phenomena of Participation and Non-Participation in Health Care—Experiences of Patients Attending a Nurse-Led Clinic for Chronic Heart Failure.

¹⁰² Nussbaum, M. C. (2013). *Creating Capabilities: The Human Development Approach*, p. 22.

¹⁰³ Nussbaum, M. C. (1968). *Nature, Function, and Capability: Aristotle on Political Distribution*, p. 165.

Conclusion

In this thesis, I have painted a picture of how patient participation is currently shaped in The Netherlands: I have provided an epistemological and an ethical analysis of how patients' experiences and knowledge are taken into account and how this can affect them. I have argued that the way this is currently being done assigns different epistemic positions to patients, which creates a hierarchy between patients, and consequently could provoke epistemic injustice in six different ways. In the first chapter, I suggested that a useful response to the risk of causing epistemic injustice within the healthcare field is to develop new ways of discussing patients' experiences and knowledge. For this purpose, I argued that we should replace the term 'experiential knowledge' for 'patient knowledge'. In order to put patient knowledge into practice, I have examined if a capabilities approach framework could provide an equitable design for taking into account patient knowledge within patient participation on both an institutional and an individual level. For this purpose, I have sketched the theoretical framework of an essentialist capabilities approach set out by Martha Nussbaum. I have considered three arguments in favour of a capabilities approach and three counter-arguments. I conclude that patient participation at a macro level has essentialist characteristics and therefore a list of essentialist capabilities could be helpful to reshape patient participation. At a micro level, it provides a number of reference points for the conversation between physicians and patients. Here, it leaves the freedom to interpret the framework to both the patient and the physician (together). The task of the physicians is to create the space for good communication, by the acquisition of both moral and epistemic virtues. However, at a macro level it seems to remain difficult to construct a list of capabilities that represents as many patients as possible without excluding certain groups of patients.

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