SHARED DECISION-MAKING AND MORAL RESPONSIBILITY
-for Treatment and Health

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Abstract

How responsible are patients for adhering to treatment plans designed to optimize the treatment of their health-problem? This thesis analyses and explores a variety of ways in which this question can be understood, and how it links to the way in which health care decision-making is organized today. The analysis thus touches not only on issues of moral responsibility in health care ethics and health policy, but just as much on what reasons there are for patients to prefer certain organizational forms over others in the light of how these may impact their moral responsibility for the planning, execution and outcome of care. These issues also relate to health care professional ethics, as any responsibility ascribed to patients may still be more or less shared with health professionals. The content of this essay will be of interest for anyone who has ever reflected upon the sharing and division of responsibility within health care practice.
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1. Introduction

1.1 Background and Context

Lisa, an 82 years old woman who was diagnosed in her 70s with chronic heart failure, arrives at the clinic for a treatment follow-up. Her diagnosis basically means that the left chamber of her heart has diminished power to pump out the oxygen-filled blood that it has received from her lungs. Fluid from the blood that fails to be pushed through from the left chamber of the heart and out into the arteries to oxygenate her body is instead pressed backwards, from the veins of the lungs into the lung tissue, causing oedema of the lungs. This with the further result that the whole circulation of blood is hindered. The oxygen deprived blood of the veins is prevented from reaching the right chamber, wherefrom it should circle into the lungs to regain oxygen. This, in turn, is causing oedema in the extremities, most visible on Lisa’s ankles. Part of the treatment to keep her heart condition under control and to avoid oedema involves taking diuretic pills, causing Lisa to have to go to the toilet often, sometimes more than once an hour.

Lisa is an active person. She enjoys to dance, and does so two evenings every week. She also likes to travel with her pensioners' association. This makes the treatment difficult for her, considering her active lifestyle. Not only is it awkward for her to leave her partner in the middle of a dance to visit the toilet, or having to ask the bus driver to stop for toilet visits during trips to and from dance events, but the lack of sleep due to several toilet visits every night also brings about fatigue. Lisa never feels wholly alert.

If Lisa chooses not to take the diuretic pills, she risks pneumonia due to the oedema in her lungs attracting bacteria. And, as it turns out, Lisa has actually been forced to seek acute medical care because of pneumonia several times the last few years, with weeks of recovering at nursing homes as a consequence. Could a treatment plan that better suits Lisa's lifestyle and preferences be developed to decrease the conflict between her health needs and her preferred lifestyle, and thus help her adhere better to treatment, avoiding complications? What reasons would she have to choose, or not to choose, to join in a collaboration with health care professionals to design a customized treatment regimen? And how responsible would she be for the regimen and to follow it, once she has agreed to it? This is the main topic of this thesis.

During recent decades, health care practice has responded to a need of this sort to adjust treatment and decision-making to better suit patient preferences and to actively collaborate
with patients to achieve it. So called Person Centered Care (PCC) is an answer to this, taking a general form, corresponding to the imagined adaption of Lisa’s case above. The previous, more paternalist approach of medicine and health care, where the physician basically presented a pre-decided menu of possible alternative treatments for the patient to choose from, is today considered outdated and ineffective. Patients tend to take advice from authorities less serious, and are more likely to question treatment and care. They are also more informed, and we nowadays value the notion of people running their own lives as they please more than some decades back. As more and more health care is carried out in patients’ homes, increased demand for treatment necessitating adaption to patient preferences and lifestyle also follows. If a patient feels that the treatment regimen proposed by her physician is too demanding and intruding on the way she lives her life, as does Lisa above, she is more likely to diverge from it. A decrease in adherence to treatment is thus not only sub-optimal from an autonomy perspective, it is also costly, for the patient’s health and for health care budgets of society. Shared Decision Making (SDM), will be the organizational aspect of PCC I intend to use for exploring my topic in this masters’ thesis. The reason is that this is the step in which a patient is being given increased power to influence the design of the care (Sandman & Munthe, 2010). The thought is that patients, by joining in decisions about their own treatment and health, should be strengthened in their decision-making and performance abilities and gain more power over health care decisions. Decision-makers of society also carry the hope that health care organizational forms like SDM will help increase patient adherence, and thus help save scarce health care resources. Both goals, patient empowerment and resource saving, will need some balancing of interests between patients, professionals and decision-makers to be achieved (Cf. Munthe et al., 2012; Sandman et al., 2016). Ideas such as these seem to go beyond traditional notions of the value of patient autonomy in health care. This increased role, in turn, fit well to factors traditionally thought to ground responsibility (Sandman et al., 2016).

What I wish to explore in this essay is if, and if so, how the sharing of responsibility between health care professionals and patients changes when heading towards more patient influenced treatment plans, and, in the light of these eventual changes in responsibility, what reasons patients and health care professionals have to choose (or not to choose) SDM over other health care organizational forms?
Traditionally, the physician has had the power over and taken responsibility for selecting what treatments to recommend, and the patient has then had the possibility of either choosing a recommended treatment, or reject treatment altogether, thereby accepting responsibility for the health consequences of that. Hence, the moral responsibility for developing and carrying out a treatment plan, has been the physician’s, and patients have been responsible for what occurs only to the extent that they accept or reject what is offered, i.e. to choose to, or not to, engage in a care relationship with the physician. Even in cases when the treatment involves self-care, the traditional notion has been that the physician is responsible for how the treatment proceeds, and the outcome for the patient. This, since the physician has a duty to safeguard that the patient has the means needed for meeting treatment requirements involving self-care. With more SDM, however, patients’ contribution to the design of the proposed menu of treatment options has gradually increased, which means that they are increasingly participating in activities that for physicians are thought to produce moral responsibilities for the design, administration and outcome of treatments (Cf. Munthe et al., 2012; Tauber, 2005). Does this change also imply a shift towards an increased moral responsibility of patients for the design, performance and outcome of treatment? If not, why? If so, how, if at all, should this presumed responsibility be reflected in health care practices and health care ethical analyses?

A more general way of arriving at these questions proceed in terms of how SDM connects to general concepts of autonomy and freedom. Policy-makers carry the hope that health care proposals emanating from SDM will help save resources within the sector of health care. This by (i) presuming that patients who engage in decisions concerning their own treatment, and who get the opportunity to adjust treatment to better suit their lifestyle and preferences, will adhere better to treatment regimens, and (ii) hoping that patients who engage in organizational proposals like SDM will gradually take more responsibility for their own treatment. At the same time, should this succeed, patients are being given both more power over health care decisions and thereby more freedom to have health care measures designed and carried out according to their own preferences. In terms of standard conceptions of autonomy within health care ethics, they are given more control over what happens to them within the health care context, going beyond the traditional idea of a patient’s right to refuse treatment following from the notion of voluntary, informed consent (Beauchamp & Childress 2001; Sandman & Munthe 2009).
In most other areas and practices, we tend to think that being given increased individual freedom in this way implies increased moral responsibility (prospective and retrospective) for what one decides to do, using this freedom. One might expect, then, that this would also be the case for health care practice and patients. This since the emancipation in question (if successful) amounts to empowering the patient to have more control of the decisions made. In the case of SDM, the idea is further that the patient and the professional, through a collaborative deliberation based on the patient’s narrative (containing information about her life, preferences, interests and plans for the future) ideally reach a somehow joint informed decision on a treatment regimen (Sandman & Munthe, 2010). This, in turn, raises questions about how a possibly increased moral responsibility of patients relates to the responsibility of health professionals. We namely also tend to think that, in a given relationship, increased responsibility on one person implies decreased responsibility on another person. Finally, as mentioned, in many cases the decision reached will involve adjustments to the patient’s personal situation that are thought to empower the patient’s ability to perform the self-care involved, which means that the patient’s control over the actual outcome of the decision on the regimen increases. At the same time, there are, of course, many factors that contribute to the final result in terms of the health of the patient, and thereby it is less clear to what extent this particular dimension of the increased control leads to increased responsibility and, if so, how it is shared with the professional.

1.2 Issues About the Moral Responsibility of Patients

The extent of questions that may be asked about the moral responsibility of patients is vast. A basic distinction is between questions about to what extent the agent of an action or a decision should be regarded as responsible for it and/or its outcome, and to what extent this agent should be held responsible for any of these things, and – if so – how? (Cf. Persson de Fine Licht 2014). Based on the general characterization of what occurs when SDM is successfully applied given above, at least the following issues regarding patients’ and health professionals’ responsibility may arise:
1.) How responsible are patients for the making of decisions about treatment? (normative responsibility)

2.) How responsible are patients for carrying out such treatment decisions? (normative responsibility)

3.) How responsible are patients for the outcomes of such treatment plans decided upon? (retrospective moral responsibility)

and:

4.) To what extent are patients’ responsibilities 1-3 shared with professionals? (both normative and retrospective moral responsibility)

5.) What other possible responsibilities follow for professionals from 1-3? (both normative and retrospective moral responsibility)

6.) What reasons do professionals have to hold patients responsible for making decisions about treatment? (both normative and retrospective responsibility)

7.) What reasons do professionals have to hold patients responsible for carrying out the decisions made? (both normative and retrospective moral responsibility)

8.) What reasons do professionals have to hold patients responsible for the outcome of the decisions carried out? (retrospective moral responsibility)

9.) What forms of holding responsible can be motivated in 6-8? (retrospective moral responsibility)

Björnsson and Brülde distinguish between causal responsibility, normative responsibility and retrospective moral responsibility. Causal responsibility simply explains what or who caused something. Causal responsibility needs the addition of a moral value in order to explain moral responsibility of the normative or retrospective kind. Normative responsibility will explain the responsibilities a person has to see to it that something will happen. For example, a ward nurse will have a role-bound normative responsibility to see to it that her patients receive their prescribed medication. A parent will have the normative responsibility to see to it that her child is fed properly, or to see to it that someone else will provide her child with proper food. The retrospective moral responsibility will tell how well a person succeeded with her past normative responsibilities. Hence, it will provide the ground for attributing blame or desert for decisions, actions and outcomes. Since this thesis is about patients’ moral responsibilities for treatment and health, I will mainly focus on normative responsibility and retrospective
moral responsibility. However, causal responsibility will often affect how we judge moral responsibility. Furthermore, I will talk about patients’ capacity responsibilities, i.e. what lays in the patient’s capacity to decide upon and hence take responsibility for. I will thus argue that the patient must have some general conditions satisfied in order to be subject of holding responsible. Björnsson and Brülde separate capacity responsibility from virtue responsibility (having a responsible character) and manner responsibility (acting in a responsible manner, a manner appropriate to the risks involved) (Björnsson and Brülde, forthcoming).

From the 9 queries listed above, I will focus on 1-3, since the answer to these will have direct relevance for how to answer 6-8 (and thus indirectly also for 9). This since standard arguments for holding people responsible for their health – in terms of desert (Cf. Smart, 1994; Walker, 2010) or for egalitarian reasons (Cf. Arnesson, 1989) – all assume a basis of people being responsible for their health (to some extent). It thus seems that what comes out of 1-3 will form necessary conditions for how to answer 6-8 (and indirectly for 9). If the answer for 1-3 is that people are not to be considered more responsible after having successfully applied SDM, we may conclude that SDM does not provide more reason to hold them responsible on this ground. All claims of holding patients responsible for health care decisions would thus be undermined. On the other hand, if it should turn out that people are to be considered more responsible after having successfully applied SDM, it still remains an open question whether or not this new responsibility could/should also be a basis of holding patients responsible to a higher degree, i.e. how to answer 6-8 (and 9). If not, one will have to answer why, and if so, then why and how? Thus, if the basic assumption of such arguments that patients become more responsible for their health care-related decisions through successful SDM turns out to lack foundation, this also undermines standard attempts to argue that patients should be held responsible for such decisions, their implementations, or outcomes. Then again, if the assumption turns out to be well founded, this hurdle for the idea of holding patients responsible for health care decisions has been avoided. This last claim is the conclusion of a recent analysis on whether or not SDM may strengthen the reason for having patient’s health care decisions being reflected in priority setting in line with a luck egalitarian formula (Sandman et al., 2016). Still, and as we shall see, there may be other concerns in the patient-professional relationship that will complicate the initial soundness of this claim. Rounding up this essay, I will present an argumentation for how the answers for 1-3 may have an impact on 6-9. Based on this argumentation, I will also discuss why some
forms of holding responsible may be justified, and for why others may not. The queries 4-5 will be intertwined throughout the discussion, since the sharing of responsibility between professionals and patients will affect 1-3 as well as 6-9.

If we return to Lisa, her perspective on the value of keeping healthy differs from the general, societal perspective of this value. But the situation is also different from other cases often described in discussions of responsibility and health (Cf. Persson de Fine Licht, 2014). Lisa is namely already inside the health care system, receiving care. The question is thus not about whether Lisa should receive care or not, she already is. In the clinical health care context, issues about responsibility for health play out rather differently than in the general health policy discussion, typically revolving around the issue whether or not a person who has mismanaged her own health should receive care at all, or, alternatively receive lower priority. Even if such ideas are rebutted, we may view people as responsible for their decisions within a context where they are receiving care. According to Persson (2012), health care practice indeed has reasons to perceive patients as responsible for their health in a way that the rest of society does not. This, due to them having separate explanatory perspectives of responsibility. Society has reasons for keeping an excusing view on people’s responsibility for their own health, while health care practice has reasons not to, due to specific features of how health professionals need to view patients in other respects. This topic will be further developed in section 2 of this thesis. Also, it is not a given that, in the health care context, if patient responsibilities increase, the responsibilities of health professionals decrease proportionally; rather they may be shared. This is a stark difference to the basic assumptions to be found in discussions around responsibility for health with regard to policy and priority setting in general and may difficult discussions on holding responsible, for instance. I will elaborate on this in section 4. Moreover, as patients may just as much welcome and enjoy as they may resent or dislike being put into a position where they have to accept expanded responsibilities, new responsibilities may also occur for health care professionals in the context of SDM. This is how the issues 4-5 enter the discussion. The more precise aim of this essay is, then, to explore:

- Whether and if so to what extent SDM may constitute reasons for viewing patients as (more) morally responsible for design, implementation and outcome of health care plans
• In that case, to what extent this may affect the sharing of responsibility between health care professionals and patients
• In the light of this, what reasons patients and health care professionals have to choose (or not to choose) SDM over other, more traditional, health care organizational forms

1.3 Outline of the Thesis

In the introduction, I have construed a question based on a fictive patient narrative, influenced from a number of patients I have met during my own professional experience as a nurse. I intend to use the story of Lisa and her initiated engagement in SDM to illustrate my case and answer the posed questions. I will start, in section 2, by considering some relevant fundamental issues of responsibility theory, and place the ensuing discussion more firmly in that context, especially regarding what general background assumptions and concepts are employed later on, in particular those of rational agency (connected to capacity responsibility) and moral responsibility (normative responsibility and retrospective moral responsibility). Having sorted out what characterizes a rational agent, and how moral responsibility is to be understood, I continue explaining in more detail what SDM amounts to, in relation to the responsibility concepts mentioned, in section 3, where the case of Lisa will be further elaborated. Section 4 contains the substantial analysis of the main questions of this thesis about how the sharing of responsibility between patient and professional might change when introducing SDM, and how these possible changes might affect responsibilities for designing and deciding upon treatment plans, following them through, and also for evaluating their outcome. The results of this analysis is summed up in section 5, where there is also some discussion about the future implications of the conclusion, as well as some additional thoughts.

The main results of the analysis are that SDM, in some versions including the factor of a “high level dynamics” in the deliberation, will increase patient responsibility for the making of a treatment plan, its implementation, and the outcome of the resulting treatment. But while patient responsibility increases, it will not simultaneously be the case that professional responsibility decreases. Professional responsibility will arguably rather alter its shape, e.g., it would seem that professionals are responsible for informing patients about their new responsibilities due to SDM. Thus, there will be no transfer of responsibility in the way we
usually think about how responsibility is shared between two or more parties. This will make any discussions about holding responsible more interesting and also more difficult. Moreover, my conclusion supports the idea that SDM should not be routine, but an option that patients may choose to opt out of. There are strong reasons for patients to prefer SDM as decision-making procedure over more traditional forms of health care decision-making, such as the opportunity of keeping much of one’s old lifestyle, while still being able to make progress in treatment, maintaining a close collaboration with professionals. Nevertheless, there are also reasons for patients wanting to opt out of decision-making forms such as SDM that connect to my conclusion. Some patients might not want to be burdened with the responsibilities for decisions, but prefer professionals to decide for them. Some, therefore, might choose to opt out of SDM because of the increased moral responsibility that it brings. Both the choice to opt in and to opt out should be an informed and voluntary choice by the patient.
2. Moral Responsibility

2.1 Causal and Moral Responsibility

In order to explain why it is meaningful to assign people certain forms of responsibility in some cases, and other forms in other cases, and sometimes no responsibility of any sort, some theoretical grounding is needed. My outlook in this thesis depends on, primarily, a view on *moral* responsibility that requires more than mere *causal* responsibility. A person may be the cause or partial cause of an action or an outcome, just as a storm may be the cause of a tree falling down, and this may be described in terms of responsibility. However, such a relation does not necessarily mean the presence of a *moral* responsibility-relation. A responsibility of this latter kind may require causal responsibility as a *necessary* condition, but needs the addition of something more. For instance, one sense of a person being morally responsible for an event (say, the utterance of a false accusation against someone) is that not only the event, but also its *moral value* can be consistently attributed to the person in question. This plausibly implies that this person (partly) caused the utterance of the false accusation (or uttered it), but also that she was doing this by performing a *voluntary action* over which she was thereby exercising *adequate control* (she could have acted otherwise if she had wanted to) and that she was *motivated by morally relevant reasons* (she had at least some knowledge of the moral impact of the action and its outcome). If that holds, we may plausibly say not only that a morally bad thing occurred, but that *this person* should not have done this bad thing, and was acting impermissibly by doing it.

Historically, many philosophers have thought of having a *free will* as a necessary condition for being morally responsible in addition to merely causally responsible. The historical free will debate is primarily a *metaphysical* one, and the scope of views on free will emerging within it ranges from the view of human beings as completely free moral agents to totally determined non-moral agents. Descartes, for example, assumed the world to be completely deterministic, and held this to be incompatible with free will and responsibility, a position later termed incompatibilism (Cf. Van Inwagen, 1983). But what he did to nevertheless provide human beings with free will and moral agency was to place the will in the human soul, which he in turn localized wholly outside of space and time where causal links hold. Hence, Descartes provided for the will to be totally free of the bounds of causal
necessity, in line with human mind and rationality, which are also located in the thus free soul. Accordingly, Descartes provided a compatibilist metaphysical solution where the body is material and belongs to the physical world determined by causal chains, and the soul, containing our thoughts and ideas is non-material, free and indetermined (Descartes, 2015; Hatfield, 2014). Many philosophers, in line with Descartes, have attempted to explain how free will and moral responsibility may be compatible with determinism. Some have assumed, similar to Descartes, that moral responsibility necessitates an indetermined will, claiming agent causality, i.e. that people may be *causa sui*, the uncaused causes of their own actions (Cf. Kant, 2006; Sartre, 1956). Other philosophers have taken another route, seeking to explain how we can assign moral responsibility to individuals, regardless of how the metaphysics appear (Hume, 2003; Hume 1999; Frankfurt, 1999; Fisher, 2010; Strawson, 1974), they hold it possible to judge and hold people morally responsible even if metaphysical determinism turns out true. This view only requires that the person had at least one alternative action (at least the choice to act, or not to act) at the point of choosing, or that she could change or affect different states of nature by voluntary action, for being at least to some degree, responsible for her action. This view, although compatibilist in the sense that moral responsibility is compatible with metaphysical determinism, does not crave dualism in the Cartesian sense. Yet other philosophers claim that there can be neither free will, nor moral responsibility. This view though, however interesting it may be theoretically, does not resemble the way we act and react in our daily life, and most philosophers agree that we have reasons for regarding each other as morally responsible individuals.

Jeppsson (2012) argues for what she calls *compatibilism from a practical perspective*, (CPP). She assumes that regardless of the metaphysical status of the world, we have reason to regard people as morally responsible agents. Accordingly, Jeppsson’s reasoning connects to the thoughts of Hume (2003; 1999) and Strawson (1974), amongst others on moral responsibility; it is a practical matter. Based on this reading of moral responsibility as a practical matter – as involving practices such as assignation of agency, blame, praise and worthiness of these - the frames of responsibility seem to be of a predominantly *normative* nature; to be morally responsible is to be fit for certain reactive attitudes of others.

I will return to the thought of the conditions of moral responsibility as normatively determined. Before that, however, I will address briefly the role that causal responsibility may play in such normative conditions applied to the area of health, specifically.
2.2 Causal Responsibility for Health is Always Partial

Even if we are ultimately the causes of our own status of health in the sense that ‘if I had not existed, this status of health would not have existed’, our actions and decisions are almost never wholly or even largely causally responsible for our health state, due to the obvious determinants of genetic composition, individual abilities constraining what we can do, and social and environmental factors outside our sphere of influence. At the same time, we do seem to have some (varying) degree of causal control over how we fare health wise, and the presence of such control would seem to be a necessary condition for us to be morally responsible for our own health.

The question of what type of causal control is required for such moral responsibility partly takes us back to the basic philosophical debates on free will, discussed in 2.1. As concluded there, what moral responsibility seems to require is that an agent’s actions are explained by her practical reason in the right way, an issue that will be returned to shortly. However, such control would at least seem to require some sort of abilities enabling one to carry out what one has decided in a way that realizes what one’s decisions are aiming for, e.g. various results pertaining to one’s health. This may mean, amongst other things, having an ability to identify what food to consume in order to eat healthy, making decent trade-offs between work, rest and physical exercise, identify and avoid risky activities and substances, and carrying out a health care regimen set up by one’s physician, should such need arise. Now, both you and I, considering the above mentioned examples, probably see before us people in our lives who will be able to live up to this better or worse. If I say that this depends to a large extent on causal background circumstances in terms of external and internal determinants, you would probably agree. Marmot (2005) describes how social and economic inequalities work as determinants for health. He talks about social determinants being “the causes of the causes”. A person’s present status of health is in much dependent on how her life has been formed until now, in part by unchosen determinants, in part by own choices. Intuitively though, even considering the presence of such unchosen determinants, most people would probably nevertheless find it reasonable to assign people responsibility for their health on at least some level, implying certain internal abilities to decide what to do, and execute such decisions. Or else it would for example seem totally useless with both preventive and
motivational campaigns for health, health interventions that I guess most people find rational. Björnsson and Brülde (forthcoming) talk about capacity responsibility, i.e. what lays in a person’s capacity to decide upon and hence take responsibility for. It seems reasonable to assume that for being regarded and/or held responsible for the outcomes of one’s actions, one must have some general conditions satisfied. Capacity responsibility would suit well for health care discussions on responsibility, since it includes the knowledge and control criterions on moral responsibility (your ability to acquire (seek and take in) relevant knowledge, and your control over your doings make up your capacity for responsibility) and that it can gradually grow or decrease with changes in a person’s health status. The degree of decision competency, knowledge and control a person has, will thus make up the what she is capable of being responsible for.

2.3 Control and the Normative Frames of Moral Responsibility

To what degree and by what measures a person can be held responsible is yet to find out, and is a normative question that may be relative between levels and practices of society, depending on what norms and values rule these levels and practices. By immediate intuition, we may regard a person performing a certain action responsible for its outcome regardless of any mitigating factors preceding the action. However, when taking a step back, we may change our immediate intuition and consider possible responsibility mitigating circumstances. This, of course, goes for attributions of both blame and praise, and we often refer to such factors as factors of moral luck (Cf. Nagel, 1979).

Strawson’s theory makes room for both guilt and blame-/praiseworthiness, for attributing moral responsibility as part of a justifiable practice. He distinguishes between reactive and objective attitudes. The reactive attitudes of blame you would experience when someone, for example, pushes you over, may prove more or less correct when taking a step back, taking an objective stance. The objective stance provides the additional information, e.g. factors of moral luck, needed to correctly judge moral responsibility (Cf. Strawson, 1974). Jeppsson’s compatibilism from a practical perspective (CPP), together with the reasoning of Hume (2003; 1999) and Strawson (1974) thus seems acceptable as an explanation of how we can uphold practices of judging people morally responsible regardless of the actual metaphysics
of the universe. Björnsson and Persson (2012), in line with Hume (2003;1999), claim that all practices of attributing people moral responsibility assume or require some sort of control to be present in order for them to be defensible. Jeppsson (2012), also in line with Hume (2003;1999), puts forward convincing arguments for the existence of such control by appealing to our everyday practice of making judgments and decisions. Strawson’s perspective seems to imply that such control can be in place although there is a causal explanation for an action or a decision, but he also denotes that the causal explanation may sometimes undermine control, thus simultaneously undermine moral responsibility.

When looking more closely on specific cases, we can distinguish at least two perspectives of responsibility for actions and outcomes (Cf. Hume, 2003; Jeppsson, 2012; Kant 2006; Strawson, 1974). The first perspective treats what we assume that a person can control by her own means, the perspective bringing about attitudes that Strawson would call reactive, and for which I will attribute what I call personal responsibility (PR). This is an assignment of responsibility for outcomes of actions that may, when taking a step back and looking at all the features of the action objectively, alter. I propose that this type of responsibility for outcomes should be grounded in the control that exists from the point of deliberation through the realization of an action. Optimally then, it should cohere with capacity responsibility (Cf. Björnsson & Brülde, forthcoming). If it does not, this may mean either that we have underestimated or overestimated a person’s capacities, and both may harm the person affected. The second perspective includes all the paths and circumstances that brought the person to making the specific decision that she then personally carried out, i.e. the perspective that a spectator would assign attitudes that Strawson would call objective, and for which I will attribute what I call circumstantial responsibility (CR). Various determinants connected to CR, such as moral luck, for example, may undermine PR to various degrees (Cf. Nagel, 1979). When judging in terms of responsibility, we often get two seemingly contrary judgments of responsibility for one and the same action, PR and CR, and this may in turn explain why we sometimes find reason to view a person morally responsible for the outcome of a certain action on some level, but not to the degree that it seems reasonable to hold her responsible by any means. Regarding health, then, such reasons for ascribing moral responsibility to patients may occur on what Persson de Fine Licht (2014) has called the shop floor, that is in the interaction between clinicians and patients, but not on, what I call in a similar vein, the top floor (i.e. the level of health or health care policy). To demonstrate how
complex combinations of moral responsibility relations may be motivated is also one of the main points of Björnsson’s and Persson’s "Explanatory Model" (2012), where the authors acknowledge that which explanations undermine and which confirm moral responsibility-relations may vary and have to be determined based on more specific normative considerations linked to a particular practice, such as criminal law or health care. The justification of viewing people as responsible for something, which in turn may sometimes justify practices of holding responsible, must always be based on a backward-looking perspective, they say. The justification for PR would thus stretch back from the outcome of an action to the point of initiated deliberation, the point from where it can be safe to say that we have control in the practical sense that follows CPP. In health care discussions of responsibility, it will ultimately be up to the professional to judge the limits of both her own and the patient’s capacity responsibility to make sure that she does not over or underestimate what they can respectively be responsible for by means of PR. CR will contain PR in an extended perspective that also adds the factors that preceded the deliberation, be they mitigating or strengthening. We can thus distinguish two separate frames of responsibility, and see why the two might be differently and/or separately judged. This leads to what Persson (2012) calls "The Right Perspective", according to which the norms and values of a certain practice that seem evident for us at the shop floor/the frame of PR, might not be obviously proper for the top floor/the frame of CR, since other norms and values may take precedence there. We are now closing in on practice specific considerations, and my aim is to discuss moral responsibility from a patient/professional perspective in health care practice in 4.1. To ground that analysis, I will end the present chapter by discussing and mapping out the different general areas and forms of responsibility in health care.

2.4 Sharing and Division of Moral Responsibility in Health Care

Norms of morality may shift from practice to practice. The norms of medicine clearly differ from the norms of sports, which in turn differ from the norms of school, to name a few examples. Norms may also differ for different levels and professional positions within the same practice; e.g. in health care and medicine, norms differ between the political level and the clinical level. They also differ between physicians and nurses even though both operate on
the same level. In order to justify what each do, professionally, it will be of help to sort these norms and values out. Also, as patients become more aware of their rights, and make appeals to use them, it becomes more important for health care as organization, and for health care professionals in their work, to specify ethical guidelines, to know what normative framework their profession builds from, where profession-related moral responsibilities (being role-bound and prospective) start and where they may end. Individual reflection and collegial discussion are possible tools for sorting such ethical issues out. When I talk about health professionals, I refer to physicians and nurses together. When talking specifically about one of the two professions, I will spell this out clearly.

Due to separate explanatory perspectives, we can distinguish at least two different frames of responsibility, above referred to as PR and CR for health care. As Persson (2012) explains it, the top floor and the shop floor have reasons, depending on their different explanatory perspectives, to perceive people in need of care differently. Health care professionals should take on an everyday perspective of responsibility towards individual patients, applying the CPP view and using PR as responsibility framework, while politicians and decision-makers who rule over resources and budgets, should take on a broader perspective of responsibility in terms of groups and institutions rather than individuals, using CR as framework for assessing responsibility. Professionals thus have reason to regard patients’ behavior as significant explanations to their own ill health, which is equal to the perspective of PR, as this is included in the view of them as capable to participate in various health care measures. PR also includes, in contrast to CR, variables that may constrain this capacity, but that the patient and the professional can actually do something about, such as lack of information or emotional instability. Decision-makers of society have more reason to defer to the determinants that are likely to have contributed to the ill health of different patient groups, determinants that individual patients as a rule can do very little to affect, as they are usually found on a structural socio-economic level (Cf. Marmot, 2005). Hence, professionals have reason to perceive patients as responsible for their situation, while decision-makers of society do not. The reason for why decision-makers do not have the same reason as health care professionals to perceive patients as responsible is foremost due to a normative view on what society and its institutions should be doing (Cf. Persson, 2012). Decision-makers of society can namely either choose to compensate for moral luck, or not to do so. Different normative views on who should pay for what and why can explain why Sweden and the US, for example, have
such different health care institutional frames and policies. The US in contrast to Sweden has much less universal health care coverage, people are expected to pay for their imprudence to a much larger extent. This primarily depends on a view of individual moral responsibility that covers not only what I call PR but also parts of what I call CR (i.e. factors that most people would probably agree override a person’s capacity responsibility). People are to a large extent seen as responsible not only for the outcomes of their present actions, but also for the paths that led them there, thus disregarding the variable impact of resultant and circumstantial moral luck on specific individuals. Keeping a more excusing institutional policy on moral responsibility and health, as in the case of Sweden, leaves the question of individual responsibility less relevant, and policy makers can instead address structural factors affecting the population’s health to a larger extent. Persson uses this line of thought to argue against the step from viewing people as responsible to the step of holding them responsible for their ill-health, i.e. prioritizing on grounds of individual moral responsibility at the top floor (Persson 2012). Returning to the reasoning of Strawson (1974) and his reactive *viz-à-viz* objective attitudes, health care professionals may have reason to view patients as fellow human beings and rational agents, taking a so called participant stance, while decision-makers of society may have more reason to view patients as objects, asking themselves how structural changes can best help these objects to exhibit good health.

Leaving health policy as it is in the present context, this leads over to Persson's idea that, still, in the clinical context, the standard stance of a professional is to view the patient as responsible for her health on shop floor, but not to hold her responsible by top floor measures (e.g. by sanctions or prioritization). The patient is to be seen as capable of participating in a process of diagnosis and treatment, and take responsibility for carrying out ingredients in the treatment requiring self-care, or lifestyle adjustment (say keeping regular measures of blood glucose and being observant on what foods to consume, for a diabetes patient). To the extent that patients suffer inabilities or weaknesses in this respect, the standard stance should be to take actions to empower the patient to become more capable, or – in the last instance – commit the patient to a clinical ward, where professionals can do all the work.
2.5 Mapping out Patient and Professional Responsibility in Health Care

Traditionally, patients have been assumed to trust their physician to give them advice and treatment that they would then follow to the dot (or to the best of their abilities). Putting their whole trust in the skills of the physician, patients could feel free to lay aside any private concerns about diagnosis and treatment. The situation is different today, and, as mentioned, SDM is part of this change. Even if the physician has the last word in the sense that the patient cannot pick and choose to the extreme what type of care she receives, the patient has much more influence over and insight into her own care now than she did some decades ago.

When turning from more paternalist health care to more of SDM, the patient will contribute more actively to the menu of treatment plans, a relation that she was earlier a simple recipient of. What for the patient used to be a situation where she could either choose from a pre-set menu of treatment options, or choose to opt out of treatment entirely (and thus be responsible for that), will arguably by the influence of the patient turn into a responsibility-relation also regarding the design of the treatment plan. Accordingly, within the PR perspective of clinical practice, it seems at least prima facie reasonable to think that the patient might also take on more personal responsibility for how the treatment goes by engaging in SDM. Furthermore, and as we saw earlier in this section, health professionals have reason to view their patients as morally responsible or capable of taking responsibility for their health in the context of treatment. What may this imply for the extent to which such responsibilities may still be shared by professionals, and might SDM incur new duties for professionals?

With the right support from health care professionals, a patient’s ability to participate in the design and performance of his or her treatment may increase. In other areas of life, we tend to think that increased exercise of autonomy leads to increased responsibility for one’s actions. To take an obvious example: in the case of children growing up, we tend to assume that increased responsibility follows increased decisions capacities with an almost linear correlation. It seems reasonable to think that this assumption may also hold concerning patients and treatment, although with a less linear correlation due to occasional ups and downs in their respective illnesses. Nevertheless, old paternalist values of helping and tending to the sick, without expecting them to contribute very much on their own besides complying to instructions, still shines through in today’s health care. At the same time, it is also the case (as with children’s responsibility-relations to their parents, to revisit the earlier example), that
not until the patient is fully cured (or the child is a fully functioning adult) seizes the physician’s (or the parent’s) responsibility emanating from a duty of care. This is, of course, a stage that may never be fully reached concerning long-term and/or chronic illnesses. Accordingly, the physician will not let go of professional responsibility for as long as treatment is in process, even if the patient takes on a great deal of individual responsibility for her treatment. It may even be the case that the physician’s professional responsibility for treatment is left completely unchanged in degree, that it just takes on a different shape as the patient’s responsibility grows. This, since it will probably still be just as important (if not more) with careful documentation and follow-ups as the patient takes on more responsibility for the design and the implementation of the treatment, but the physician (or the nurse) might be relieved from some, or much, of what was earlier thought of as her clinical duties. Professionals will have to be very sensitive for where the patient is at in her process, in order not to underestimate her abilities, or to overload her with unreasonable responsibilities. Both extremes could namely harm the patient and undermine her control, and thus her responsibility (Cf. Munthe et al., 2012).

In order to balance the values and avoid causing unnecessary harm, it may be of help for the professional to take on the perspective of responsibility proposed in 2.3 and 2.4; to regard the (at least minimally decision competent) patient as responsible for her doings. The professional will in addition have reason to reflect on her own responsibility, how far it stretches. Carefully judged then, this will make up what Brülde and Björnsson (forthcoming) refer to as their respective capacity responsibilities.

Factors of moral luck can of course be relevant to consider also in health care practice, as such factors will be the ones where a patient and/or a professional has deliberated and decided upon something that then is impeded by factors beyond their control. Some such cases will be possible to address by further empowering actions on the shop floor that change the factor (e.g. corrects a misunderstanding or introduces a simpler practical routine) (Cf. Mele, 2006). In other instances, however, the factors may instead be more properly addressed on the top floor, as they regard structural factors, and in yet other instances, none of these levels will offer any hope of change.
3. Shared Decision Making

3.1 The Idea of Shared Decision Making

Having established that theoretical arguments and models regarding moral responsibility in general and related to health and health care in particular provide at least some room for the general intuition that SDM would increase patients’ prospective moral responsibilities for care, this section takes a closer look at the SDM-factor in this idea. The general notion of SDM, as well as its different variants, are described and related to underlying ethical aspects, especially factors of relevance for the responsibilities of patients and health professionals.

Traditionally, the good patient, or the model patient if you wish, would be one following the health care regimen proposed by her physician to the letter. This would be a case of good patient compliance, striving for the professional’s biomedical goal of patient’s best interest, usually in terms of physical recovery relative to diagnosis criteria or amelioration of measurable symptoms. The biomedical goal does not provide us with any information about what the patient’s own interests and priorities are, however. Accordingly, patients often fail to live up to traditional treatment plans, because of simply having conflicting personal preferences and values, that will on occasions take precedence over the biomedically motivated health care regimen. Hence, it would probably not be farfetched to assume that an adjusted regimen that takes patient preferences into account, adjusting goals according to the wants and needs of the specific patient, might receive better individual patient adherence (a term that has replaced patient compliance in recent years to signal such a shift of focus) (Cf. Sandman et al 2012). The notion of SDM connects to both these aspects: increased consideration of patients’ points of view and preferences, and (a hope of) improved alignment between health care treatment plans and actual treatment outcomes.

Normally, a person receiving information about having an incurable disease or chronic illness has her whole world turned upside-down. Suddenly she will have to defer to a whole new set of factors, some maybe depriving her of her earlier capacities, leading to lost control and frustration. However, beside the newly received diagnosis and the loss of control, the patient is still the same person as before, with the same interests and preferences. It thus

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1 The question of if SDM may also bring retrospective moral responsibility for the outcomes of treatment will be discussed in section 4.
seems reasonable to assume that a treatment regimen made up to suit her lifestyle and preferences could help her to regain control over her life faster than the sort of old fashioned paternalist prescriptions described earlier.

SDM as a tool of decision-making in health care organizations has emerged from this insight, and is increasingly applied in clinical practice (Cf. Sandman et al., 2016), not least for chronically ill and/or conditions necessitating long term rehabilitation, like diabetes, hypertonia, chronic heart failure, depression and bipolar disorders, and Parkinson’s and similar neuromuscular diseases. Properly adjusted to the individual patient, SDM may be used in most long-term illnesses, both somatic and mental. In the acute phase of seeking care, with a call for quick decisions, SDM is of less use. But once faced with the fact that a patient will be in need of long-term care and/or rehabilitation, we have reason to assume that both the individual patient, her fellow group of patients, and the scarce budget of health care will benefit from introducing a suitable version of SDM. Presuming that SDM is introduced and followed through as intended, the patient herself will be empowered in her influence over how care proceeds, her own decision-making abilities as well as in her abilities concerning the performance of treatment, and thus enjoy increased freedom compared to the standard way of making health care decisions. This emancipating aspect is also one of the main arguments in favor of SDM (Cf. Sandman & Munthe, 2010; Sandman & Munthe, 2009; Tauber, 2005). Above this, decision-makers also carry the hope that society will benefit from having patients thus empowered. This as less of health care’s earmarked resources will be wasted in the effort to achieve the desired effect, thereby saving resources for the not yet so capable patients, who may need more support to achieve effective care (Cf. Gustavsson et al. 2015; Sandman, et al., 2016). So far, we can thus distinguish at least three positive expectations of introducing SDM:

(i) Autonomy/emancipation: patients will be empowered in their decision-making and performance-abilities, becoming more in control over their own care as well as their own health and life in general.

(ii) Adherence: due to (i), SDM will thus help the patient to adhere better to the treatment plan.

(iii) Efficiency and justice: SDM, successfully carried out, might help free health care resources for those in greater need of help.
When explaining the criteria for rational agency and moral responsibility in section 2, I argued that a person must be decision competent to count as a rational agent. To fully join in SDM and successfully carry out the decisions made, this type of rational agency will be crucial. Minimally, the patient should be receptive of information and capable of processing, deliberating upon, and together with the professional come to an agreement on decided treatment proposals. All patients that are not decision incompetent due to some inescapable internal impediment can thus be considered possible candidates for SDM (Cf. Munthe et al., 2012, p. 238). The capacity for control over decisions and actions that is necessary for such rational agency and thus moral responsibility can, and is by SDM presumed to, gradually develop and grow. With this in mind, there may be reasons for the organizational procedure of SDM to be introduced in a supporting manner also in cases where the patient is less decision competent. The professional’s role is then to empower and prepare the patient towards becoming more decision competent, thus more capable of making and following through autonomous decisions, and once this is achieved the patient is prepared to collaborate in the decision-making related to the design of treatment plan and its implementation, as sketched earlier (Sandman et al., 2016).²

Central concepts connected to SDM as a health care organizational tool are patient narrative, collaboration and continuity (Munthe et al., 2012). The patient narrative is the information the professional will receive from the patient concerning her background and lifestyle as well as future plans, interests and preferences. What type of, and how much information, the patient will be willing to share with the professional will be vary from case to case and depend to a large extent on the experienced trust in the patient-professional relation. This holistic view of collecting information about the patient and her situation, and taking this into consideration in decisions concerning treatment, is not new, but has gradually evolved as PCC-related ideas have taken hold. Although, the amount of information needed to customize treatment to suit individual patients (thus, ultimately, achieving better adherence) will be proportionally much larger for SDM than simple deference to lifestyle and preferences in an otherwise paternalist decision-making. Confidentiality and patient integrity is always an

²This creates a need to interpret the presumably sparse information coming from the patient herself before empowerment has taken hold, and the need to supplement this information with additional information, e.g., from relatives and friends, as well as interact in a way that is likely to stimulate rather than undermine competence development, which creates a risk for misinterpretations and unintentional harm (Cf. Entwistle & Watt, 2013; Munthe et al., 2012; Herlitz et al., 2016).
important aspect of professional responsibility in medical and health care, but the two concepts will be all the more actualized as an ethical challenge when handling more, and perhaps more sensitive information. Also, the professional must be careful not to misuse the patient narrative in a manipulating manner. By the information gathered, the professional might, if not reflecting carefully, drag the patient towards her own biomedical goal by manipulation, thus failing to recognize patient autonomy (Cf. Beauchamp & Childress, 2001; Munthe et al., 2012).

SDM also demands close collaboration. Important for the professional here is to neither over- nor underestimate the patient’s capacities. This, to avoid causing harm, but also to let the patient exercise her autonomy within the limits of what she can personally control. If she feels overwhelmed with responsibility, she might end up refusing to participate. If she instead feels pampered with, and underestimated in terms of capacity to take responsibility, she might lose her sense of dignity and give up for that reason too. In both cases, lost adherence will most likely follow as a result. Hence, when applying SDM, professionals have reason to seek to provide patients with adequate tools to balance preferences, probabilities, costs and risks according to their subjective capacity. Professionals must thus continuously ask themselves what stage the patient is at, what she is able to control and decide upon at the moment. This process of gradually developing control and decision competence is not a steadily up-going curve, but might go up and down, back and forth. The process of recovery, and hence also of SDM, must be sensitive to this variable pattern. This links to the last crucial concept of continuity. Close follow-ups on treatment is crucial to uphold the collaboration needed for safeguarding non-maleficence, for continued autonomy promotion, and for patient adherence. Failing to see the importance of the mentioned three concepts will undermine the aims of SDM and might bring immediate harm to the patient (Cf. Munthe et al., 2012).

In light of the above mentioned emancipation, resulting in the patient gaining increased control over her own situation, that successful SDM will bring, the basic intuition that successful SDM will also increase the patient’s moral responsibilities (to the extent that they cohere with her capacity responsibility) for her own care may seem sound and obvious. However, a closer analysis of what SDM may involve reveals that the sort and magnitude of capacity empowerment and increase of control over decision-making involved may vary considerably. Sandman and Munthe (2010) have distinguished nine different variants of SDM
described in the literature, each relating rather differently to the traditional paternalist idea of health care decision-making and the idea of promoting patient autonomy and power:

1.) Patient Adapted Paternalism: The professional chooses a health care regimen suiting some aspect of the patient’s narrative that has been perceived as important.

2.) Patient-Preference-Satisfaction Paternalism: The professional chooses a health care regimen according to what has been perceived, through patient narrative and patient-professional dialogue, as suiting the wishes of the patient.

3.) Shared Rational Deliberative Paternalism: The professional chooses a health care regimen suitable with what she perceives to be beneficent for the patient from the patient narrative, expressed wishes, patient-professional dialogue and deliberation.

4.) Informed Patient Choice: Taking into account the patient narrative, the professional proposes and informs the patient about the options available regarding diagnosis and treatment. The patient is left to choose one of the proposed health care regimens.

5.) Interpretative Patient Choice: In addition to what is proposed in version 4, the professional assists the patient in interpreting what the options might imply in the patient's own life. The patient then chooses one of the proposed options.

6.) Advised Patient Choice: As an extra addition to version 5, the professional here gives explicit advice as to what option would be preferable. The patient then chooses one of the proposed options.

7.) Shared Rational Deliberative Patient Choice: On the base of the patient narrative and the professional’s information about diagnosis and available options of treatment, the patient and the professional gather in a dialogue, deliberating about what should be the goal of the health care regimen, and hence the base on which to evaluate the continuing work and decide how to proceed. Mutual consent is not reached, but the patient chooses a treatment plan of own interests.

8.) Shared Rational Deliberative Joint Decision: In this version, as opposed to version 7, the patient and the professional reach consensus through a dynamic deliberation upon the goal of, and plan for, the health care regimen.

9.) Professionally Driven Best Interest Compromise: In cases where 8 is not achievable, and 7 turns out professionally unacceptable, the professional may adjust her biomedical health care goals to better suit the patient’s preferences, and hence also accommodate the base for
evaluating the continuing work, in order to reach a compromise that better suits the patients' views and wishes. Should this attempt fail, the patient will fall back to version 7.

Which one of these will be applied will in turn depend on how the mentioned objectives (i-iii above) for SDM are traded off against each other. The variants 1-3, for instance, clearly play down the autonomy/emancipation objective. The variants 4-6 less so, but to the extent that they mean an increase of patient power and control over what decisions are made, it still seems marginal compared to the standard situation described at the outset of this thesis. Therefore, none of these variants seem to lend obvious support for the intuition that successful SDM increases patients’ moral responsibility for the care and its outcome. This since the envisioned far-reaching empowerment and increase of control supporting this intuition is not clearly a part of SDM in these cases. In fact, 1-3 could even be used to disempower patients in order to manipulate them to achieve better compliance to preset biomedical goals (Munthe, et al., 2012). In this respect, 4-6 are different, as they include various actions of professionals to apply measures, tailor-made to the patient's situation, to empower the patient’s decision-making related to a pre-decided menu of options presented by the professional. But all of these fail to engage with the issue of whether this menu should be amended, or to include critical discussion of the goals of the care that may inform such amendments, or to address measures to improve the patient's abilities to participate in self-care measures. This, in contrast, is exactly what is involved in the variants 7-9, which all in this way include such "high level dynamics" (Sandman & Munthe, 2010), that may transform the conditions of the design and implementation of the care plan taken for granted in 1-6 based on patient criticism (Sandman et al., 2016).

This "high level dynamics" in the SDM may have different results, one of which is a full consensus, represented by variant 8. If full consensus is not reached, the professional can still try to make a strategic compromise, represented by variant 9, hoping to motivate the patient to move closer to a biomedically more ideal view over time, for instance by offering various empowering measures to handle the care. If the difference of opinion and perspective between the patient and the professional is too wide to accomplish this, the result is variant 7, which basically means that the patient abandons the caring relationship with the professional and that the professional accepts this. What any of these developments mean concretely will depend on the care situation, the health problem, the situation of the patient, and so on. But all
may have the outcome that the patient decides on a biomedically less efficient treatment plan, or a less efficient implementation of a pre-existing treatment plan, in order to make room for preferences and values related to other aspects of life than (biomedical) health. In all these instances, there seem to be some reason for the intuition that the patient is then more morally responsible for the decisions and its outcome than if a procedure of SDM 7-9 had not been applied. To further imagine the plausibility of such “high level dynamics” in the deliberation justifiably paving way for increased patient responsibility, it may help to think about other processes where we assume “high level dynamics” in the deliberation to make decisions more legitimate, e.g. when buying a house or a flat, we seek counselling from qualified professionals (e.g. legal, economic and building counselling) to avoid making costly mistakes. I find it reasonable to assume that we, after such counselling and following deliberation, have an increased moral responsibility for our choosing to sign the contract, or not to, and for the eventual consequences of that choice.

3.2 Prospected Outcomes of SDM (7-9)

If we go back to Lisa, 82 years old, with chronic heart failure; how could SDM 7-9 be introduced to help her gain more power over and adhering better to treatment? Suppose that Lisa has just arrived at the clinic for a follow-up on her treatment regimen. Until now, she has mostly been given medical advice and prescription of medicines from her physician as treatment. The physician has trusted Lisa to follow the proposed treatment regimen. As it turns out, though, Lisa has not been taking her diuretic pills according to the proposed scheme, which at least twice the last year has resulted in her acquiring oedema of the lungs, followed by pneumonia. This is not something that Lisa is proud of, and hence not something that she herself admits at first. Rather, the physician happens to look at her medical journal and finds two occasions of hospital visits, followed by recovery in nursing homes. When asked about this, Lisa admits not having taken her pills because they induce annoying complications to her lifestyle (as described in section 1.1).

The physician then asks Lisa if she is willing to have a discussion about adjusting the treatment and jointly seek to reach an agreement on a regimen that would suit Lisa’s lifestyle better, and still allow her to make progress in treatment. The goal need then not be set as high as before, accounting for the outcome of the failed plan, keeping Lisa out of hospital might be
sufficient, considering circumstances such as her age and willingness to cooperate. Lisa and her physician engage in a discussion, where both present their concerns. Lisa expresses her wishes, wants and worries, as explained earlier. The physician puts forward alternatives on treatment, but states that to avoid complications from her heart condition, Lisa should at least consider a small daily dose of diuretics. The alternatives will all involve daily attention by Lisa on her health status and its eventual changes. Compression treatment with compression stockings will help relieve oedema in the extremities and increase overall blood circulation. When sitting still (e.g. for long bus rides), Lisa may help her calf-muscle pump by moving her feet up and down. All bodily motion will be of help, which means that one of her biggest interests in life, dancing, could actually make up part of the treatment regimen. To self-monitor her health, the physician wishes for Lisa to keep a daily journal of measured values or parameters important for detecting over-hydration. Relevant measured values would for Lisa be bodyweight, circumference of the ankles, respiratory rate, blood pressure and pulse. By following such regimen, Lisa might keep her intake of diuretic pills at minimum, and make sure to recognize changes in health status in time. A worsened status of health might, of course, lead to a maybe temporary, maybe persistent change and/or increase in medical treatment, but that will be a task to tend to if/when this situation arises.

Having considered the physician’s proposal, Lisa admits that she might need some encouragement and support in between, in order to succeed with adherence. She acknowledges there to be a risk that she will forget to keep a journal continuously, and that she needs to be reminded once in a while. They both agree that, for a start, Lisa should bring a copy of her measures to the nurse at the clinic once every week, and that they should have closer follow-ups for a start, with meetings once a month. The physician is also eager that Lisa agrees on contacting the clinic before she decides to adjust anything in the treatment plan herself, so that they can mutually decide on how to react to any changes. If the plan goes well, and Lisa at least maintains her health status and avoids any major complications, in line with the minimal goal for treatment, meetings might be set with longer intervals in the future. Lisa’s new treatment plan is thus formed on a narrative-based and a mutually agreed upon balancing of personal preferences and biomedical standards, hopefully balancing the relevant values of health care practice in a result-optimizing way. According to the versions of SDM listed above, I would address the above described initiation of SDM equal to an 8 or 9. The
A different scenario would be if Lisa insisted on either not bothering with the extra support and control measures, although still wishing for reduction of the medication or, alternatively, if she insisted on carrying on with the failing regimen, and refused to address the lack of adherence. In both of these cases, the professional might have problems maintaining the care relationship, and thus not accepting Lisa’s decision, ending up in a variant 7 of SDM, where, in both cases, the professional continues the misfiring treatment plan (prescribing the original dosage) in lack of a better option, although not agreeing that it is an acceptable decision in light of the adherence problems of Lisa. Also here, Lisa has a strong influence on the outcome, the main difference being that the professional is not collaborating in the decision, although administrating the wish of the patient. An even clearer example of variant 7 would be if Lisa had insisted on that the doctor prescribe an unacceptably low dosage, or asked for an alternative medication incompatible with professional responsibility (due to, e.g., lack of effect or too high risks). In such a scenario, the care relationship would probably have been severed altogether, as the professional would most certainly have refused to administer the treatment plan decided by the patient by deference to biomedical standards. Variant 7 of SDM would thus be the physician’s giving up on trying to reach a mutual decision with the patient and just prescribing original treatment because it seems better than nothing. In case the patient demands biomedically (or ethically) unacceptable modifications of treatment, this will result in the physician’s refusal of administering treatment, a scenario where SDM is repealed.

3.3 Patients’ Reasons for Preferring SDM

One issue raised regarding SDM, has been to what extent patients should be given the opportunity to choose between a more orthodox model of decision-making around the treatment plan and some form of SDM (Munthe et al 2012). Similarly, it may be asked to what extent patients should be given a say on what variant of SDM that should be applied, if any. This, in turn, links to an underlying question of to what extent the use of SDM may be in the interest of patients.
Returning to Lisa above, her earlier bad adherence to treatment at least partly depended on her having personal interests in conflict with her interest of good health. Introducing SMD might help reduce, or even erase such conflicts. It may thus seem beneficial to be given the chance to customize treatment with the help and support of health care professionals, keeping much of one’s old lifestyle at the same time as upholding individually set goals of health. Being thus regarded as decision competent and autonomous rather than sick or incapacitated may furthermore empower and strengthen the healthy capacities in the patient (Cf. Brülde, 2011, pp. 241-247). The experience of contributing to, not just receiving, treatment may also help the patient to uphold self-respect. Through the close collaboration and continuity that should be present all the way, the patient may hereby, despite taking on more personal responsibility for decision-making, be made to feel more safe and secure in the close cooperation with professionals. Even though she may take on many new responsibilities, the patient is never alone, but always in a team, where the professional concurrently has taken on new prospective role-related responsibilities as coach, supporter and facilitator.

In the variants 8 or 9 versions of Lisa’s case, it seems quite obvious that she will profit, both in terms of health and personal interests, from engaging in SDM. But, as the variant 7 scenario illustrates, this must not be the case for all patients who could be considered candidates of SDM. Furthermore, former traditional (paternalist) norms and values still in much shines through in today’s medicine and health care. Some severely ill with little or no chance for recovery ought maybe not to be burdened by decisions and resulting responsibilities. Beauchamp and Childress (2013, pp. 108-109) address this issue, and note that by respect to autonomy, participating as well as refraining from participation in decision-making concerning one’s treatment must be optional. The patient should have the choice to opt out not only of specific treatments, but of particular decision-making procedures such as SDM as well. Forcing patients to decide may cause more harm than good, and it is not obvious that a patient always has a reason to prefer SDM. Furthermore, defaulting, forcing, or persuading patients to engage in SDM against their wishes would also weaken the claim that patient responsibility is enhanced by SDM. As I argued in section 2, voluntariness is a crucial factor for moral responsibility, and all such manners of implementing SDM undermines voluntariness, even in the cases of the variants of SDM (7-9) most strongly aimed to promote autonomy and empower patients.
Since it is deeply rooted as a social norm, almost socially required, to show compassion and care for the sick, many patients, and/or relatives, and often health care professionals as well, will find it reasonable to give the patient some (at least initial) room for grief and self-pity when stricken by disease. The phrase “regression in service of the ego”\(^3\) is a reminder of the need to, in times of hard challenges, alleviate oneself of the burden of everyday chores, to rest ones ego for regaining strength for future challenges. This may thus be a counter argument against introducing SDM very early in treatment, as it requires of the patient to immediately focus on rational decision-making and attendance to the problem at hand. The judgment of when the patient is done with the grieving phase and is receptive of the challenges of SDM will ultimately be up to the professional to decide, and will vary between individual cases.\(^4\) In the meantime, the professional may, of course, do her best to empower the patient to reach this stage, but the point is that this empowerment may plausibly partly consist in shielding the patient from responsibilities (Cf. Herlitz et al., 2016).

Moreover, it is not uncommon that, e.g., elderly people are of the opinion that health care professionals, especially physicians and nurses, are authorities, and should act as such. If not explaining fully the meaning and point of SDM to the patient, there is a risk of having the use of SDM causing the patient to find health care professionals indecisive and incompetent. One could thus argue that the emphasis on information when seeking to introduce SDM to possible candidates should lay in explaining thoroughly its aims, what the hopes are, and what research has found. It may also help to explain for the patient and her relatives why health care practice has reasons, that the rest of society may not have, to treat patients as competent decision-makers, i.e. that it may help in adherence and thus help reaching individual treatment goals. Introducing SDM in a professional manner may be crucial for how the patient will regard her own possible responsibilities towards adhering to the later mutually agreed upon treatment plan. If that is implemented, and the patient agrees on SDM of any of the variants 7-9, we are back to the initial conclusion that successful use of these may indeed ground the intuition that successful use of SDM will make patients more morally responsible for the design,

\(^3\) A phrase coined by Sigmund Freud (Cullberg, 2003).
\(^4\) In my own professional experience as a nurse, I have also noted that this phase of regression does not have to occur concurrently with diagnosis, but may come later, and often unexpected. It is thus possible that such a phase might interrupt already initiated SDM, which in turn adds extra weight to the importance of close collaboration and continuity between patient and professional, and for the latter to keep a close eye on how the patient narrative evolves during the care.
implementation and outcome of the treatment plan. Although, the increased moral responsibility that would follow successfully carried out SDM (7-9) could in itself be a reason for some patients to opt out of such forms of decision-making procedures. Some patients may not feel comfortable taking on increased responsibility for treatment, regardless of the possibility of upholding lifestyle and preferences, and regardless of whether it may bring increased adherence and better health.
4. SDM, Patient, and Professional Moral Responsibility

4.1 Introduction

In this section, I will bring together partial claims from earlier sections, and relate these to the main questions of this thesis to produce a unified and more developed analysis. In section 1.2, I described nine possible areas or questions of moral responsibility that might be affected or change when turning from more traditional health care decision-making towards more SDM. Of these I decided to focus on 1-3, regarding the extent to which patients and professionals are responsible for the design, implementation and outcome of the care, since the answer to these will form the base for how to answer the latter ones, about to what extent these parties to a greater or lesser extent should be held responsible in light of the presence of such moral responsibility.

All of the nine mentioned areas of responsibility are actualized on the shop floor of health care, that is, where I have assumed PR to guide what one is responsible for, in line with the practical perspective on moral responsibility (CPP) described in section 2. Hence, both for the patient and the professional, the frame of PR will be the limit of moral responsibility here and a patient’s capacity responsibility will set the degree to which she can be regarded responsible. Concerning the first three areas, about the patient’s responsibilities for making decisions about her own treatment and following them through, I pointed out that it is a tentatively plausible intuition that a transfer from more traditional and paternalist health care organization towards more patient centered forms of decision-making such as SDM may imply a shift in the way consideration of the patient’s autonomy empowers her to be more in control over what treatment plan is chosen, how it is implemented, and the outcome of that. In the traditional conception of patient autonomy in health care practice, grounding only a negative right to refuse suggested treatment, the control of the patient may at best ground that she is retrospectively morally responsible for such a refusal and its outcome. While a patient's acceptance of an offered treatment might be seen as an agreement that grounds some normative responsibility of patients for adhering to what has been agreed, since the designer of the plan is the professional, any such responsibility must be rather limited. This is due both to the patient’s lack of control over this design, and the very likely explanation of non-adherence as depending on personal or structural weaknesses of the patient undermining the
voluntariness of his or her actions, factors which have not been accounted for correctly by the professional when construing the treatment plan. If the mentioned responsibility-undermining factors are changed by SDM to instead empower patients and make them more in control of the design of the care and its implementation (for example by adjusting treatment to lifestyle), the tentative plausibility of the intuition about increased normative patient responsibility remains. This would mean that the patient is to be regarded as more normatively responsible for the development of a treatment plan, for administering treatment, and retrospectively morally responsible for the outcome of treatment. But the patient being more normatively and retrospectively morally responsible for treatment does not necessarily form a base for holding her responsible for treatment. One factor that will difficult any discussions on holding patients responsible for outcomes of treatment is the stark assumption that there is no transfer in moral responsibility from the professional to the patient through SDM, but that all responsibility will remain shared with the professional. Section 4.2-4.3 will explain the patient’s normative responsibilities, what she should be regarded responsible for in SDM (queries 1-3 from the list in section 1.2). Section 4.4 elaborates further on the sharing of responsibility between the professional and the patient (queries 4-5 in section 1.2). Section 4.5 will provide some final thoughts on SDM and holding responsible, that is, for the queries 6-9 from section 1.2.

4.2 Patients’ Responsibility for Adhering to Agreed Treatment Plan

In section 3, it was found that the image of what SDM may actually mean is rather heterogenous, especially with regard to what extent SDM will make increased patient responsibility more likely. Out of nine main variants of SDM presented in the literature, only three of these exhibit potential in this respect. The first three variants were concluded to just as likely decrease the patient’s power and control, while numbers 4-6 where not found to make a difference in comparison to the traditional way of organizing clinical health care decision-making. Through their inclusion of a "high level dynamics" in deliberation, however, variants 7-9 exhibited promise in this respect. At the same time, as it is far from obvious that it has to be in patients’ interest to enter into such active participation, it was also concluded, in section 3.3, that the extent to which these variants would be able to ground an increase of patients’ normative responsibility for the design and implementation of the treatment plan in line with the intuition, would also depend on the extent to which professionals provide them
with an opportunity to make an informed voluntary choice whether or not to venture into a more traditional or a "high level dynamics" SDM-procedure of decision-making.

Now, suppose that a patient voluntarily agrees to engage in SDM (7-9), as in the case of Lisa. What normative and/or retrospective moral responsibilities would follow? It seems that such engagement would include at least three elements, all adding to the thesis that the patient through joining in SDM may be on the whole more responsible for the decision-making, the carrying out of decisions made, and the outcome of decisions. These elements would be (a) the informed and voluntary engagement based on prudential reasons, (b) the use of one’s autonomy in a positive sense, contributing to the treatment plan, and (c) the intention and increased ability to follow the decided treatment plan. Furthermore, if Lisa is also informed about what each of the nine versions of SDM would demand of her, responsibility-wise, and then choose one version out of 7-9, aware of what it will imply, this in turn might add extra to justifying increased normative responsibility for 1-3 of the areas of responsibility described in section 1.2. So, SDM (7-9) will, provided it is voluntarily chosen, bring increased responsibility for making decisions about treatment together with the physician, a responsibility that has been absent in traditional paternalist health care. Plausibly, it also adds (through the three above mentioned elements, and to some varying degree depending on the extent of patient engagement) to the responsibility of the patient for carrying out the decisions made, and for the outcome (retrospective moral responsibility), the latter a responsibility that has traditionally been seen as very limited. The more a patient influences care in the substantially voluntary way assumed, the more patient responsibility results across all of the questions 1-3.

The patient’s normative responsibilities for adhering to the treatment plan will thus arguably increase the more influence she has had in designing her own treatment, and the more customized support that has been built into the SDM for her to carry out the plan. Different versions and degrees of patient/professional influence in SDM can be seen in the versions explained in 3.1. Variant 7 is the one, where the patient would decide exactly as she herself wants, while the professional is not endorsing the patient’s decision. Provided all the assumptions about voluntariness, empowerment, etc., made, this would seem to make for a very high degree of patient normative responsibility for both the design and the implementation of the treatment plan. Considering Lisa again, this would consider (the unlikely but possible) scenario that she opts out of medication altogether, demands a
prescription that the professional finds unacceptable to provide, or refuses the various empowering measures suggested to help her adhere better to an adjusted treatment. The other two scenarios regarded outcomes à la SDM variants 8 or 9. In both these versions, patient-professional collaboration remains, and while the degree of patient responsibility will increase (by the elements of a, b, and c above), the degree of professional responsibility will presumably remain unchanged. Variant 9 is primarily to be seen as the professional’s last strategy for avoiding that the caring-relationship is undermined by variant 7.

One might intuitively think that the professional’s responsibility will decrease as the patient’s responsibility increases. I hesitate to draw any such conclusions, however, mainly because the patient empowerment that may result from SDM does not seem to imply a disempowerment of the professional. Rather, the strength of professional responsibility remains unchanged, and it is only what the professional is required to do to meet this responsibility that changes. Thus, professional responsibility will alter in shape, not in degree. The question of what other responsibilities follow for professionals when introducing SDM depends strongly on the change of shape of responsibility that SDM will bring for the professional, and will be further elaborated on in section 4.4.

4.3 Patient Responsibility for Suboptimal Treatment Outcomes

The conclusions in 4.2 may seem unproblematic to accept in the case where the outcome of the SDM is the optimal combination of enhanced patient autonomy, improved adherence and a better result in terms of health. To the extent that the patient has had control over this outcome, she is also normatively and retrospectively morally responsible for it. But what if this is not the case, what if the outcome is instead worse health, albeit voluntarily effected by an empowered and more autonomous patient?

Take the case of Lisa again, and suppose that either she opts for the SDM variant 7 solution to the design of the treatment plan (i.e. the one with too bad health prospects for the professional to agree on this course), or she fails to adhere to a modified treatment plan (for which she clearly has capacities to follow, had she wanted to), à la SDM variants 8 or 9, that is acceptable to the professional. She will plausibly be retrospectively morally responsible for

5 Meaning, for instance, that acting in a way that would not have had such a good outcome may have been morally wrong.
her worsened health status, but what further responsibilities may follow? When initiating SDM, the professional must take into consideration how much time could be spent on Lisa’s treatment in relation to other patients. Should the outcome be that Lisa’s health deteriorates seriously (either by a suboptimal treatment plan, or by failure to adhere to a plan accepted by the professional), additional resources will typically be required from the professional to get Lisa back on track, resources that were earlier earmarked for other patients. Provided the assumptions made earlier, it might then be argued that Lisa is here retrospectively morally responsible for the consequences that such a development has for other patients and health professionals. This would, in turn, mean that the patient has, when agreeing to SDM (7-9) and through the decision-making she engages in there, acquired (and implicitly approved of) some responsibility for not wasting scarce health care resources, i.e. she has acquired some responsibility for upholding shop floor justice. That is, due to her increased responsibility, the patient has at least some moral obligation to take such aspects into due consideration both when deciding on the design of the treatment plan, and when making decisions in her life affecting her adherence to the treatment plan. This conclusion may sound controversial, but when discussed in its essence in 4.5, its implications in PR will presumably be regarded plausible. The mere fact that she is to be regarded responsible does not necessarily mean that there are grounds for holding her responsible.

4.4 The Sharing of Responsibility Between Patients and Professionals

In 2.5, I pointed out that, just as the parent’s normative responsibilities for her child does not end until the child is a fully functioning adult, that it simply alters to its form, so does health care professionals’ normative responsibilities for their patients. The professional normative responsibility does not seize until the patient is fully recovered (which might of course for patients with chronic and semi-chronic diseases never happen), or leave the care relationship for other reasons. And, as explained in 4.2, whilst patient responsibility (normative and retrospective moral responsibility) will plausibly increase by introducing SDM (7-9), professional responsibility (normative and retrospective moral responsibility) will presumably not decrease. The only change in professional responsibility will be its shape. I will here recapitulate a few important such changes.
First of all, given the assumed scenario that the professional offers the patient the option of "high level dynamics" SDM, the professional is, of course, fully responsible for the consequences of making this offer, and of the way in which she makes it. A crucial part of this is to have the patient comprehend the aspect that SDM may increase the patient's normative and retrospective moral responsibility in various ways. Apart from increased responsibilities for designing and implementing treatment plans, and for the outcomes of these, it would plausibly include also the possibility that the patient may be made at least partly responsible also for the just allocation of health care resources, which would make up primarily a normative responsibility, acknowledging fellow patients. The increased normative and retrospective moral responsibilities acquired through engagement in SDM, as noted in section 3.3 and 4.2, may be reasons for the patient both for and against SDM.

The mentioned responsibility of the professional to clarify the aims and implications of SDM when it is offered, including clarifying that normative and, to some extent, retrospective moral responsibilities will increase (for versions of SM including high level dynamics) does not seem to be shared with the patient at all. In line with the earlier reasoning, however, the responsibility for the design, implementation and outcome of the treatment plan will by SDM (7-9) be shared between the patient and the professional. Professional responsibility will thus not decrease, but, once again, the shape of the professional’s responsibility changes due to (voluntary chosen) SDM (7-9). First of all, the professional responsibility in the traditional organization of health care decision-making to uphold a defensible standard of decided treatment remains, which may then lead to either of the results of variants 7-9. In one of these cases, variant 8, the shape of the responsibility remains much as before, it is just that a consensus with the patient can be reached. In variant 9, the shape is different, as the professional here accepts a treatment plan that she would ideally not have accepted, but yet does for long-term pragmatic reasons related to the patient’s health. This may be in line with a responsible professional position given that the alternative to 9 is not 8 but 7, i.e. that the patient by herself decides on a plan that is even worse from a medical standpoint. That is, the shape of the professional responsibility will be partly dependent on the context of what the patient wants, and the "high level dynamics" of SDM 7-9 means that this context may be transformed and revisited repeatedly in the collaborative process during the SDM.

Besides this, we have seen how SDM in several ways actualizes responsibilities of professionals to address and consider particular aspects. One of these is the mentioned duty to
clarify how SDM may increase the normative responsibility of patients. But we have also seen how, once SDM has been initiated, the professional may be obliged to communicate with the patient about her responsibilities, to herself, her close ones, other patients and perhaps by extension even to society (although for the reason that it is not within the limits of PR, not further discussed here). Such responsibilities of the professional become actualized on the assumption that the SDM proceeds in a way that empowers the patient to handle such considerations and discussions, that is, to a degree that coheres with her capacity for responsibility.

At the same time, the balancing of how much professional responsibility for treatment that can reasonably be acquired by the patient is up for careful judgment by the professional(s). The primary appeal with SDM, and with such acquired responsibility, for the patient is that she may carry out much of her treatment in her private sphere, still feeling supported and safe within the close collaboration with professionals. The acquired responsibility may not only affect the patient, but also her close ones, family and friends. As more care is carried out in patients’ homes, by patients themselves and by their relatives, new factors relevant for patient and professional responsibility will arise. Possible support and help from relatives will become an additional measure to balance when assessing the patient’s individual prerequisites and capacities. A severely ill patient may thus have greater prospects of succeeding with following her treatment plan than a less ill patient, simply because of having a greater support in her network of friends and family. The possible network of friends and family should not be taken for granted as a source of support, though. Nevertheless, when it exists, and offers its support, it might be regarded as an extension of the patient’s own capacity for responsibility. An extension that patients who lack supportive networks of friends and families miss out on.

Likewise, the professional will not escape normative responsibility for keeping watch on lapses of the patient’s capacities, e.g. to perform self-care well, and come up with means to empower the patient in these respects. This is actualized as soon as the patient departs from an agreed treatment plan, but it should also be a vital ingredient from the start of any "high level dynamics" SDM process. As entering such a process actualizes new, or strengthened, value aspects about the promotion of patient autonomy and related ideas of empowering patient capacities, besides aiming for better health, this is a change of the shape of professional responsibilities. What the professional is not responsible for, though, is decisions by the
patient that are not joint, and the outcomes of these, unless they spring from faulty clinical support.

The optimal distribution of responsibilities will be individual and can only be worked out in a mutual collaboration between the patient and the professional, according to their respective frames of PR. This level will furthermore not be static, but will change dynamically with patient progress.

4.5 SDM and Holding Responsible: Distinctions and Limits.

Having concluded that versions of SDM including high level dynamics in deliberation theoretically does increase patient responsibility in the sense of being responsible for treatment-plans, for administration of treatment, and for the outcome of treatment, the question of if this increased responsibility could reflect, somehow, in health care practice arises. These are the queries 6-9 mentioned in the introduction and not yet directly addressed. I will elaborate briefly on these queries in this last section of the essay. To conclude, as we have, that the patient through engaging in some version of SDM including high level dynamics becomes more normatively and retrospectively morally responsible for treatment, is not in itself controversial by any means. Not taking it further, it is simply a theoretical conclusion. Any discussions on holding patients responsible for outcomes of treatment, though, will be somewhat controversial.

As stated, the mere conclusion that SDM in some cases will make the patient more responsible for the outcome of treatment does not necessarily form a base of holding the patient responsible, since there may be other relevant arguments speaking against this; e.g. practice-related concerns about role-bound responsibility and the stark assumption that there will be no transfer of normative responsibility from the professional to the patient in the way we usually tend to think that normative responsibility is transferred between parties. The responsibility for making decisions about treatment will be shared. The responsibility for implementing the treatment-plan will be shared. Thus, the responsibility for outcomes will be shared. Shared decision-making thus seems to imply shared responsibility. Nevertheless, there may be other normative reasons, also based on practice-related concerns, for discussing some mild forms of holding responsible. Both professionals and patients namely have no choice but
to defer to the scarce health care resources on shop floor. As hinted in 4.3, it may be the case that, when sharing to an increased extent normative and retrospective responsibilities with the professional for treatment, as in versions of SDM including high level dynamics, the patient will also share with the professional responsibilities for just distribution of health care resources on shop floor, within the frame of PR. This is a presumption that may in effect form one good reason for health care professionals to hold patients responsible for outcomes of treatment, should they affect distribution of care to other patients negatively.

If we then were to imagine versions of SDM including high level dynamics as forming a base for holding patients responsible on shop floor (where we imagine PR to rule, through the patient and the professional’s respective capacity responsibilities) based on normative concerns for just distribution of health care, there are some crucial distinctions and limits needing to be sorted out. First, there is the distinction between being and being held responsible. We may have both forward-looking and backward-looking reasons for assigning responsibility (being responsible). We may think that the mere acquiring of personal responsibility (being responsible) for treatment and health will bring about better consequences in the future (in terms of achieving better adherence to treatment and thus better reach individual biomedical goals, which in turn would help free health care resources on shop floor, facilitating just distributions) and/or we may use it as part of a base for holding patients responsible.

The just mentioned consequences that are thought to succeed being given increased responsibility for treatment also make up the answers to queries 6-8; what reasons professionals have to hold patients responsible for making decisions about treatment, what reasons professionals have to hold patients responsible for carrying out the decisions made, and what reasons professionals have to hold patients responsible for the outcome of the decisions carried out. That is, for their own time-managing (patients are adhering better and recovering faster) and for the justice of other patients (more resources freed to the yet not so able patients). Holding patients responsible will always be based on a backward-looking perspective, asking how the patient succeeded with her past normative responsibilities, and may be informal or formal. Grounded in a strive for just distributions, though, the reasons for holding patients responsible would be forward-looking, hoping for better consequences in the future. This normative view will thus bring premises for by what means we can reasonably hold someone responsible. For example, practices of shaming or blaming patients for bad
outcomes would probably lead to even worse outcomes (imagine for example the result of shaming a kid who peed in bed, compared to just cleaning up and moving on), and would thus be out-ruled. To informally hold a patient like Lisa responsible for treatment outcomes would be to just confirm present status; “I see that you managed to keep your daily measures”, or “I see that you wear your compression stockings according to agreement”. And hope for continuance. Alternatively, if she did not adhere; “I hear that you are not exercising regularly as we agreed”, and hope for a change. The line between informally and formally holding responsible is somewhat blurred, but to formally hold the patient responsible will always include some form of reaction or intervention by the professional. Presuming Lisa succeeded well with following her part of the joint treatment decisions (having established retrospective moral responsibility), holding her responsible for that may mean to discuss with her if she is willing to take an even more active part in her own treatment, an intervention that could give her a sense of increased freedom, and also free professional resources that may be distributed to other patients in greater need. The joint decisions will be revised and renewed.

Should Lisa instead have diverged from the treatment-plan (having established retrospective moral responsibility), formally holding her responsible for subsequent outcomes may be to, after having confirmed what went wrong and why, discuss if she is in need of more professional support, or perhaps introducing to her again the option of higher doses of diuretics. The joint decisions will be revised and renewed. Any forms of holding responsible for reasons of justice on shop floor must not only be limited to patient and professional capacity responsibility, what they can respectively derive from PR, they must also cohere with the norms and values of health care practice. Hence, they must cohere with promoting patient autonomy, upholding biomedical standards, and avoid doing harm. This means that holding responsible in health care practice can never involve sanctions or other forms of punishment (practices like these would also be paternalist, and thus decrease patient responsibility), but will instead focus on patient support and empowerment (encouraging the patient to become more responsible in the future). Transparency and thorough information, i.e. to explain, discuss with the patient and make sure that she understands, not only how SDM is thought to ground patient responsibility, but also what this increased responsibility might amount to, including the patient in every step of the decision-making (which in this case will include not only biomedical discussions on treatment and treatment-outcomes, but also discussions on the scarcity of resources and shop floor justice) will be crucial, both for (i)
legislating increased normative responsibility for treatment, and for (ii) justifiably holding the patient retrospectively morally responsible. If the professional fails in this respect, then the whole base for holding responsible will fail as well.
5. Concluding Remarks

The aim of this essay was to explore whether, and if so, to what extent successful SDM may increase the reasons for viewing patients as (more) morally responsible for design, implementation and outcome of health care treatment plans. And, in that case, to what extent this may affect the sharing of responsibility between health care professionals and patients. Related to this, I also wanted to sort out what reasons patients and health care professionals might have to choose (or not to choose) SDM over other, more traditional, health care organizational forms. Unavoidable became to address the topic of if the presumed increase in normative and retrospective moral responsibilities that might follow SDM could somehow reflect in health care practice, and this thus became the topic of the last chapter.

Beginning the thesis, I provided an outlook on moral responsibility for health care practice, based on a practical perspective on moral responsibility, from which it seems reasonable to view patients as morally responsible. To this outlook, I related SDM. The analysis brought forward conclusions such as that SDM, in versions containing “high level dynamics” in the patient-professional deliberation, will increase the patient’s responsibility for contributing to the design of the treatment plan, for the performance of care, and for its outcome. The more influence the patient has had over the shape of the treatment plan, i.e. the more modified treatment according to patient preferences and life-style, the higher degree of patient responsibility. At the same time, professional responsibility will not decrease in degree (for as long as the care relationship lasts), it will only take another shape, co-related to the patient’s new and increased responsibilities. This conclusion would prove to complicate all discussions on holding responsible. Nevertheless, the assumption that by joining in SDM, the patient will share with the professional at least some responsibility for upholding shop floor justice, may form reasons for mild forms of holding responsible for consequentialist forward-looking reasons.

While there are some obvious benefits for patients engaging in SDM, such as being able to make progress in treatment, while at the same time keeping much of one’s old lifestyle and interests, the increased responsibility that follows engaging in SDM might also be a reason for some patients to want to opt out of such decisions-making procedures. For professionals (as well as for health care budgets of society), the main reason for having patients engage in SDM is increased adherence, providing increased deference to biomedical standards as well
as freeing resources for other patients. Time-managing is a central aspect of justice for professionals, seeking to provide all patients their fair share of adequate care.

Rounding up this essay, I conclude that all forms of holding patients responsible for treatment outcomes and/or ill health must be limited to the shop floor, and what one can there derive from PR. Since the pattern of treatment-adherence and the process of recovery is unpredictable and may go up and down, back and forth, the concepts of patient narrative, collaboration, and continuity will help guide professionals to continuously understand and respond to transforming circumstances around the individual patient that policymakers on the top floor will never be able to access. This, together with the assumption that society will not profit from holding patients responsible for their ill-health on the top floor, partly due to lack of pragmatic reasons available to a professional interacting with an individual patient, partly because on the top floor, health patterns depend mostly on socio-economic and other factors or determinants that the individual herself can do very little or nothing to change, will make conclusions about holding patients responsible on the shop floor mostly inapplicable to health policy on the top floor.
Reference list


Björnsson, Gunnar., Brülde, Bengt, Forthcoming.


Hatfield, Gary. 2014. *The Routledge Guidebook to Descartes’ Meditations*.


