Adherence, Shared Decision-Making and Patient Autonomy

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This is a “post-print” version of this article. The final version, which should be used for citations, is published in *Medicine, Health Care and Philosophy*, 2011, vol. 14: http://www.springerlink.com/content/p420410823746627/

Abstract

In recent years the formerly quite strong interest in patient compliance has been questioned for being too paternalistic and oriented towards overly narrow

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biomedical goals as the basis for treatment recommendations. In line with this there has been a shift towards using the notion of adherence to signal an increased weight for patients' preferences and autonomy in decision making around treatments. This 'adherence-paradigm' thus encompasses shared decision-making as an ideal and patient perspective and autonomy as guiding goals of care. What this implies in terms of the importance that we have reason to attach to (non-)adherence and how has, however, not been explained. In this article, we explore the relationship between different forms of shared decision-making, patient autonomy and adherence. Distinguishing between dynamically and statically framed adherence we show how the version of shared decision-making advocated will have consequences for whether one should be interested in a dynamically or statically framed adherence and in what way patient adherence should be assessed. In contrast to the former compliance paradigm (where non-compliance was necessarily seen as a problem), using observations about (non-)adherence to assess the success of health care decision making and professional-patient interaction turns out to be a much less straightforward matter.

Key words: Adherence, Compliance, Patient Autonomy, Patient Best Interest, Shared Decision-Making

INTRODUCTION

The continuing discrepancy between prescribed medical treatment and patient *compliance* with prescribed treatment has given rise to a large body of research on both how well a person follows ‘rules,’ and why these rules were not followed. ‘Compliance’ has been defined as “the extent to which a person’s behaviour [...] coincides with medical or health advice” (Haynes et al. 1979, p.2). As such, the concept in itself does not imply any specific view concerning how this medical or health advice is arrived at. However, traditionally the concept of compliance have been used to describe a situation where the health professional arrive at specific medical or health advice by consulting biomedical research for what is statistically in the best interest of the patient group to which the patient belongs, based on a professional view of what this ‘best interest’ consists in. From this traditional perspective, patients who are poorly compliant are not acting in their own best interests and the problem of non-compliance is mainly seen as a problem in and of the patient (Vermeire et al. 2001, Russell et al. 2003). We can call this the compliance paradigm and henceforth we refer to this paradigm when talking in terms of compliance.

However, the compliance paradigm has been questioned on the grounds that it comes from a biomedical health perspective, is paternalistic, and does not take the perspective of the patient into account (Conrad 1985, Trostle 1988, Donovan & Blake 1992). Critics from social science have suggested that ‘compliance’ literature fails to give credence to the patient’s own preferences and personal resources, such as social supports and non-traditional coping strategies. Alternative views of compliance have therefore been advanced that attempt to incorporate patients’ perspectives and resources (Russell et al. 2003, Broyle et al. 2005, Lutfey & Wishner 1999, Playle & Keeley 1998, Marland 1998). The most important shift has been the shift to what we will refer to as an *adherence* paradigm, supported by reference to the value of patient autonomy and shared decision-making (Russell et al. 2003, Lutfey & Wishner 1999, Playle & Keeley 1998, Marland 1998, Timms & Lowes 1999).

In both the compliance and adherence paradigms, interest is taken in whether and to what extent the patient follows a treatment plan. However, we interpret the change in wording as signalling a change as to why there is reason to take an interest in the patient not following (or following) the treatment plan. To some extent, the change in wording could be supported by looking at the etymology and common usage of the words 'compliance' and 'adherence'. ‘Compliance’ is usually defined in terms of a subservient conforming to, yielding to or following of someone else's ideas, whilst ‘adherence’ is defined in terms of willingly following someone else's ideas in allegiance or with devoted support (thereby an active decision of the adherent party) (se for example Merriam-Webster 2011). However, the interpretation in terms of two separate 'paradigms' is foremost supported by differences in how the importance of non-compliance/adherence is *motivated*. In the compliance focused literature, this motivation is in terms of an alleged best interest of the patient that has been predefined by health care. Supporters of adherence, in contrast, describe its importance in terms of how non-adherence represents a lack of fit with what patients find important themselves. This difference between the paradigms implies radically different stances as to how health care should and may respond to non-compliance/adherence. We will develop the nature of this paradigm shift further below.

In this article we will take this shift seriously and explore more in detail how and why we should take an interest in patient adherence[e] on the basis of the very rationale of the adherence paradigm. We will thus assume, for the sake of discussion, the idea of patient autonomy and shared decision-making having value and being something that should be given weight in the practice of health care, and discuss what this may imply for the importance of adherence. The need to explore this relationship arises from the fact that a shift towards shared decision-making is not a uniform shift into a well-defined decisional practice with clear implications for patient autonomy (Sandman & Munthe 2009). Depending on what form of shared decision-making that should be pursued, especially concerning factors like the extent to which the professional view on patient best interest can be taken into account and what view on patient autonomy is implied, different implications for why and how we should take an interest in patient adherence will follow.

To illustrate this, patients often make decisions not to adhere to a treatment plan at times, or many times throughout a chronic illness. For example, in heart failure, a patient may choose not to take diuretic medicines prior to a long day of travel, or he or she may choose not to limit dietary sodium on the occasion of a celebratory meal, despite having agreed to the treatment plan and knowing the likely result of the choice – symptom exacerbation and possible hospital admission. Similar examples can be found in many other cases, such as diabetes, vascular problems, etc. Is this lack of adherence problematic?

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[e] In taking this shift seriously we will also henceforth use the notion of adherence in the rest of the article, unless we are specifically referring to the traditional compliance paradigm.

If patient autonomy would be the only value to take into consideration, lack of adherence would not necessarily be problematic since, as shown in the examples above, new or unconsidered facts and circumstances can make it rational for patients to change their minds about the treatment plan. Lack of adherence could then be a way to exercise autonomy if the patient feels that the treatment strategies available are limiting, or too inflexible, thereby reducing the autonomy if applied according to the original agreement with the professional. Lack of adherence would be problematic from this point of view only if, either of two factors hold. First, the digression from the original treatment plan may be made non-autonomously – for example, due to external pressure, lack of internal resources to support the decision, or faulty information about the situation. If so, the focus of professional care and research should move toward empowering patients to make autonomous yet well informed decisions on when or whether to follow the treatment plan, and on removing obstacles to informed patient choice. Second, an autonomous decision not to adhere may damage the future autonomy of the patient or his life. In this case, the appropriate response would, once again, seem to be support to prevent or ameliorate such effects.

However, since the move towards adherence primarily is a move towards *shared* decision-making, this suggests that patient autonomy is not the only value to take into consideration, but that there is some room also for the professional perspective on patient best interest in the situation. At the same time, what (non-)adherence implies from this perspective is not clear– this depends, among other things, on what form of shared decision making is applied and what weight is given to patient autonomy. Hence, in this article we intend to provide a more balanced and multi-faceted view on patient adherence related to different forms of shared decision-making and what this implies in terms of patient autonomy.

Specifically, we will focus on if and how care professionals should take an interest in patient adherence from the perspective of the concerned patient. Whereas the compliance paradigm has been criticized for being overly paternalistic, the adherence paradigm may be biased in favour of the patient's autonomy, thereby failing to consider the possible harm caused by patient non-adherence to valid interests of other parties. Concerns about public health and the waste of health care resources are examples of such harms. However, to explore these issues, we first need a more detailed picture of if and how we should take an interest in patient adherence for the patient's own sake. In the concluding section, we will sketch what the implications may be at an overarching societal level and point to how this may serve to open up solutions to the various problems noted earlier.

We will begin by describing the conceptual shift from compliance to adherence, norms regarding patient autonomy and different forms of shared decision-making in more detail – thereby substantiating the general points alluded to above. The rest of the article will be devoted to exploring the relationships between these features, and discuss what reason may be mustered for solving conflicts that may arise.

THE PARADIGMATIC SHIFT FROM COMPLIANCE TO ADHERENCE

As was indicated in the introductory section, the compliance paradigm is traditionally derived from the biomedical view of health related decision-making, whereby the professional decides on care and treatment for the patient in line with what is, by scientific evidence and prevailing professional practice, considered to be in the best interest of the patient (Russell et al. 2003, Broyle et al. 2005, Playle & Keeley 1998, Marland 1998, Chatterjee 2006). In this paradigm, non-compliance is deemed problematic not only for patients themselves, but also for others since it can put the public health at risk or result in increased or inappropriately allotted healthcare costs (Russell et al. 2003, Broyle et al. 2005, Marland 1998). ’Compliance’ in this traditional sense is restrictive for patients by virtue of its emphasis on biomedical goals and its lack of emphasis on the short and longer-term life-goals of the patient (Russell et al. 2003, Broyle et al. 2005, Lutfey & Wishner 1999, Playle & Keeley 1998, Marland 1998). The shift towards using the concept of ‘adherence’ is supposed to emphasise the patient’s active role in decision-making around management of his treatment (Pitkala 2007, WHO 2003, Marland 1998)

Lutfey & Wishner (1999, p. 635) note that ‘adherence’ is used to label a paradigm that ‘characteriz[e] patients as independent, intelligent, and autonomous people who take more active and voluntary roles in defining and pursuing goals for their medical treatment’. In contrast to the compliance-paradigm, in which the patient is viewed as the problem, advocates of the adherence paradigm see the problem as largely related to the patient’s lack of involvement in decision-making around treatment and hence the solution being increased involvement, participation and patient autonomy (Pitkala 2007, Marland 1998). Also, part of the adherence paradigm is to widen the focus from the biomedical perspective and not concentrate solely on the individual patient’s behaviour (Lutfey & Wishner 1999). Basically, then, while the compliance paradigm relates itself to externally issued rules, instructions or norms, the adherence paradigm focuses on people's decisions and/or agreements.

This idea implies an increased role for patient autonomy, since the patient is allowed to affect the treatment plan and maybe also the goals and values underlying the choice of this plan. The patient is thereby supposedly encouraged to take an active part in effectuating the treatment plan decided upon. This also implies that the patient can alter the goals along the way as his situation, values or preferences change. This makes the compliance paradigm inapplicable in two ways: First, there is no preset standard in relation to which compliance may be assessed. Adherence is about assessment of patient behaviour relative to the decision made or the goals/values underlying this decision. Second, the compliance paradigm does not allow that the basis relative to which compliance is assessed varies over time independently of existing biomedical standards. This, however, is allowed by the adherence paradigm, since when people change their minds or discover flaws in earlier reasoning, this creates a new "index" for assessing adherence.

Encouraging the patient to define and pursue goals of treatment (or, at least, to take part in and deliberate about goals) is expected to result in improved clinical outcomes (Russell et al. 2003, Lutfey & Wishner 1999, Marland 1998). However, these outcomes are typically measured from the biomedical perspective and not from the perspective of patients. The underlying assumption therefore seems to be that if persons are allowed to decide, the decision will be in accordance with their own views on what is in their best interest, which in turn will enhance motivation to abide by the long-term decision to adhere to some regimen (Marland 1998). Due to the differences between the paradigms of compliance and adherence, however, this does not imply better clinical outcomes – unless these are redefined in adherence terms as well. Advocates of replacing the compliance paradigm with that of adherence still basically agree that there is a problem with non-adherence – i.e., failure to follow the treatment plan decided upon – and adherence is hence assumed to be in the patient's best interests (Pitkala 2007, Playle & Keeley 1998, Holm 1993). As observed, however, this is not necessarily the case and, furthermore, the rationale behind the adherence paradigm does not necessarily that the point of of adherence is to promote patient best interest. Rather, the reason for taking an interest for non-adherence within the adherence paradigm is that if a patient is allowed to influence the treatment plan in accordance with his/her perspective, his/her autonomy is thereby being promoted. At best, digressions from treatment plans may be argued to imply a digression from the patient's *own view* on what is in his/her best interest. However, the digression may just as well signal that the patient has revised this view.

More advanced models of shared decision making that give patients the authority and health care professionals the license to transform basic ideas about the objective of care in the individual case (Sandman & Munthe 2010), further distancing it from traditional conceptions of patient best interest, makes the situation more complicated. There is a qualitative difference between the adherence paradigm with shared decision making in the context of a health care system that in other respects remains traditional and the same paradigm placed in a context where it is allowed to influence the basic frames and premises of health care decision making. Shared decision making and focus on adherence in a system where authority over what procedures and regimens are recommended is reserved for standardised clinical and biomedical judgement[f] will be locked into certain predefined norms about the frames and objectives of care where the room for individual adaptation by patients is restricted. Given such a context, the room for applying an adherence paradigm is obviously limited even if some sharing of decision-making could take place and minor adjustments to adapt to the patient's perspective are possible.

We will call this form of adherence *statically framed*. Since the room for the patient's influence on decision-making is here rather limited, statically framed adherence is just the old compliance paradigm amended with the adherence label to signal that care is supposed to involve some sensitivity to the fact that patients may find good reasons not to comply and that this may be a reason for

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[f] Achieved through, e.g. professional consensus conferences or decisions by central quality assurance authorities.

professionals to apply a more personal approach in order to prevent such non-compliance.

However, shared decision making can be taken further, e.g., if clinicians are allowed to digress from standards of acceptable or best treatment as an answer to displayed unwillingness of patients to adhere to standard regimens or to explicit differences on what is the goal of care (Sandman & Munthe 2010). Such room for flexibility can vary in extent, but the model implies that non-adherence need not imply a problem seen from the point of view of a traditional health care standpoint. For example, the patient may be non-adherent by behaving more closely to what would have been recommended on the basis of a best treatment standard than what has been agreed, or non-adherence may be in the interest of the patient since what has been agreed upon is based on non-self interested patient preferences. We will call this form of adherence *dynamically framed*.

PATIENT AUTONOMY

In order to discuss the relationship between shared decision-making, patient autonomy and adherence, we need to briefly present the concept of autonomy and the different values and normative implications of autonomy used in this article (see Sandman & Muthe 2009 and Juth 2005 for a more detailed discussion about autonomy).

The concept of autonomy

The concept of personal (in this context, patient) autonomy consists of four components: will or preference (henceforth termed preference), decision, action, and the intermediate relation of ‘because’. Basically, in order for a person to be *self*-determined, the preferences need to be the person’s own, and the person needs to make a decision to realise or satisfy these preferences and then act on this decision. If the preferences are the person’s own, the more he decides and acts in line with these preferences, the more autonomous he is. The fourth component -- the ‘because’ component -- signals that the degree to which the person decides and acts on his own preferences and has them satisfied is controlled by this person. That is, all of the first three components have to be explanatory connected to each other. If they are not, for example, because the decision or action is a result of external manipulation such as hypnosis, autonomy is reduced.

The preferences, decisions and actions can be related to the features of authenticity, decision competence, and efficiency respectively – all possible to have in different degrees. Authenticity is concerned with whether the preference at the basis of autonomy is really one’s own. Decision competence is the ability to make decisions based on one’s own preferences and beliefs. To be decisions competent, the person needs to have some idea about what he or she wants, some ability to contemplate options and what they would result in, and an ability to judge the value of these results. Furthermore, the person needs to be able to connect beliefs to preferences in order to form a decision that, if acted on, would be efficient in satisfying the preferences. The decisions of people depend on the conditions under which they are made, and there are predictable biases influencing their decision-making. Thus, decision competence involves handling this in a rational way. However, external factors, threats, or other sorts of manipulation from outside parties may also influence decision-making, even when a person has a high degree of decision competence. Efficiency, finally, is the ability to implement a decision through action and thus (given a good decision) realise the person's preferences. Having the ability to control one's actions is of course crucial for this. However, efficiency, like decision competence, is also dependent on external factors, like being provided with enough relevant and accurate information (about *when* it is proper to act, for instance), having an opportunity to act, as well as the external resources required.

There are two different perspectives on autonomy that may be described using the outlined components. One focuses on the characteristics, capacities and surrounding conditions and hence the *ability* of a person to be autonomous. That is, practical decision making procedures or institutional arrangements that are in place for decision-making may affect a person's ability to make an autonomous decision. The same is true for the characteristics of the person, in that a person may be *unable* to make an autonomous decision; and of course these two may interact.

Another perspective of autonomy looks at the actual exercise of making decisions and acting upon these decisions, and not only on the ability to decide and act. This focus looks at the extent to which the person actually directs his or her own life on the basis of and through decision-making and (authentic) preferences.

The Value of Autonomy

It has been argued that autonomy can have value in five different ways, where three of these are candidates for final value: (1) self-realisation, (2) preference satisfaction, and (3) self-direction. (4) Binary autonomous ability (i.e. personal capacities and circumstances necessary for (1) and (3)) will take part in the value of (1) to (3). On top of these (5) gradual autonomous ability will have instrumental value, i.e. the more we have of the relevant capacities and circumstances, the better we will be able to achieve (1) to (3) (Sandman & Munthe 2009).[g]

Let us explore the aspects having final value somewhat more in detail before moving on to consider different versions of shared decision-making. If I have a heart condition and still wants to lead a normal life, not being hindered by my condition, this more general preference for a normal life might result in a specific preference for reducing the amount of diuretic medicine at times to avoid constant visits to the toilet. My preference for a normal life is strong enough to accept an increased risk for adverse effects when not taking my diuretic medicine according to prescription. In being able to live a normal life I achieve *preference-satisfaction*. If I do this through my own decisions and efforts, for example by deciding not to follow the treatment plan at times, I am also *self-realizing*. From an autonomy perspective, the value of my life will then consist not only of the value of preference-satisfaction, but is further

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[g] Here it should be noted that 1-3 is about successfully exercising autonomy and 4-5 is about having certain abilities related to autonomy, hence they are expressed in terms of nouns and adjectives respectively and ontologically different.

enhanced by the value of self-realization[h]. Even if I had not been successful in actually arranging a normal life for myself through my decisions and efforts, these decisions and efforts would still have made me *self-directing*, adding value to my life.

Since some of my preferences around my life may incorporate the doings of other people, I may autonomously choose to delegate decisions and actions affecting my life to other people to whom I want to grant some freedom or whom I trust to deliver preference satisfaction better than myself.[i] I might for example decide to trust my doctor to know what treatment plan would best satisfy my preferences. In doing so, I will still be directing my life to some extent, and if such a choice results in the satisfaction of my preferences, I can also be said to have achieved self-realisation. This implies that the value of self-realisation has to be balanced against the value of preference satisfaction, when the satisfaction of my preferences may involve the decisions and actions of other people. Even if having trusted the doctor in the decisional situation I might later arrive at a different balancing between self-direction and preference-satisfaction and autonomously decide not to adhere to the treatment plan.

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[h] The value of preference-satisfaction is a part of the value of self-realization since preference-satisfaction is a necessary condition for self-realization as used in this context.

[i] I may, of course, also abstain from complete delegation of authority, but nevertheless choose to involve other people as advisors and discussion partners from whom I welcome also critical views on my own lines of reasoning.

Having the ability to be autonomous is a necessary condition for exercising self-direction and self-realisation. Furthermore, we have to conceive of this ability of a person as a *gradual* property. Once autonomous to the minimal extent needed for decision competence, a person may further strengthen his capacities, and his circumstances may become more favourable. The more autonomous one is in this sense, the greater the one's chances of actually directing one's own life and satisfy one's preferences – i.e. achieve self-realization.

On a consequentialist approach, assuming autonomy to be of high value (which we find reason to do in our Western context), we have a general reason to promote the autonomy of a person, i.e. as a means to maximising the final value(s) of autonomy. This implies that we temporarily could have reason to restrict a person’s autonomy to promote even greater autonomy in the future. Here we can have one reason for why non-adherence is problematic – even if it is a result of an autonomous decision, it could restrict the patient’s autonomy in the future. But we might also have moral reasons to limit the autonomy of persons if the exercise of autonomy would be detrimental to other people’s autonomy or well-being or to the person’s well-being (if, as seems plausible to assume, there are other values (such as well-being) against which the value of autonomy needs to be balanced). If non-adherence has a negative impact on public health in the sense of putting other people at risk or result in increased health-care spending, even with an adherence paradigm we could find reasons for viewing non-adherence as morally problematic.

An alternative, more deontological stance towards autonomy, common in health care ethics, is to stress the importance of respecting (rather than promoting) autonomy. That is, the focus is not on increasing the occurrence of something (autonomy) that is of value, but rather on allowing people to exercise a certain degree of autonomy within a specific field. With such a view, if the person has authentic preferences and is decision competent and efficient enough, we simply accept any decision made by the person, regardless of how it affects her autonomy in the future. This type of idea can, however, be more or less pure – allowing to different extents effects on other people or the common good to motivate autonomy restrictions.[j]

SHARED DECISION-MAKING

Since the adherence paradigm implies shared decision-making between the patient and the health-care professional, we need a clearer picture of what shared decision-making can amount to, in order to assess the relationship between shared decision-making and adherence. In Sandman and Munthe (2009, 2010) a taxonomy of nine different versions of shared decision-making is presented and related to the above concept and ideals of autonomy. This taxonomy assumes the obvious fact that the professional is (almost) always superior in power to the patient and will to a large extent set the agenda for the decision-making process – thereby influencing the extent to which the patient can exercise his or her autonomy. Hence, from an autonomy-perspective it will

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[j] Variations in this respect will describe the "field" within which others have a moral reason to respect a person's autonomy (in the sense of abstaining from interfering with her decision making or execution of made decisions).

be important which of the described versions of shared decision-making the professional will apply. However, even so, there is a real chance that the patient in the end decides to trust the professional's perspective on how his preference set is best satisfied and accept a certain treatment plan more or less at face value. If so, the patient could find himself having made a decision that he later regrets. To the extent a version of shared decision-making is implemented as the ideal decision-making form, this is something one will have to be observant upon.

1. Patient Adapted Paternalism – where the professional decides in accordance with the individual situation of the patient, taking into account how the patient is different from the typical patient by allowing the patient to share information about his situation. This can result in preference-satisfaction, but the patient does not exercise autonomy since s/he does not make the final decision.
2. Patient Preference-Satisfaction Paternalism – where the professional decides in accordance with the preference set of the patient by letting the patient share not only facts about his situation but his actual preferences relative to the situation. This is probably better in achieving preference-satisfaction than 1 but still does not allow the patient to exercise autonomy.
3. Shared Rational Deliberative Paternalism – where the professional and patient engage in a shared rational deliberation, but in the end the professional decides. As to autonomy, this is more or less on par with 2, with the possible difference of allowing for more well-thought-through set of preferences and therefore also better preference-satisfaction.

4. Informed Patient Choice – where the professional shares the information she has with the patient, who then makes the decision. Here the patient is self-directing, but does not necessarily achieve preference-satisfaction and therefore neither self-realization due to interpreting the information wrongly.
5. Interpretative Patient Choice – where, in addition to what is mentioned in 4, the professional also aids the patient in working out his preference set, but the patient then decides. As to autonomy, on a par with 4 but with chances of better preference-satisfaction.
6. Advised Patient Choice – where the professional informs and helps the patient to work out his preference set and then also advises the patient on what the professional would find to be the best decision. In the end the patient decides. As to autonomy, on par with 5 but with the risk of manipulating the patient into accepting what the professional says for non-rational reasons.
7. Shared Rational Deliberative Patient Choice – the same as in 3 but the patient decides in the end. This will be best suited to achieve self-realization, i.e. achieve both preference-satisfaction and self-direction, since the preference set of the patient will be well worked through.
8. Shared Rational Deliberative Joint Decision – where the patient and professional engage in a rational deliberation that is brought to consensus and results in a joint decision. As to autonomy, on par with 7 with the difference that 7 is the alternative when the patient and professional is unable to reach a joint decision.
9. Professionally Driven Best Interest Compromise – where the professional, after having engaged in a rational deliberation with the patient and there is a

resulting conflict, strategically tries to influence the patient to accept the best possible decision (from the perspective of the professional). In this strategy, taking into account patient compliance and patient autonomy, the interaction should then result in and consensual agreement on a compromise[k]. Here the patient will still be self-directing, but it implies that the patient will have to give up on some of his preferences and accept the professional view on the patient's best interest. Hence the patient will have to accept less of preference-satisfaction and therefore also self-realization.

All of these variants will imply some extent of sharing in decision-making and are therefore to a greater or lesser degree in line with the adherence paradigm rather than the compliance paradigm. However, if, as we have assumed, the shift from the latter to the former paradigm is driven primarily by concern for the value of autonomy, we can narrow the list down to alternatives 4 to 9. If the patient is supposed to exercise autonomy in decision-making, s/he will have to share in the making of the final decision about the treatment plan. Hence, even if there is some sharing in 1-3, the final decision rests with the health-care professional and hence these alternatives are more suitable to the compliance

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[k] In addition to these nine variants, sharing may also take the form of a therapeutic measure in its own right, where the exchange and interaction between the patient and the professional in any of the versions 1-9 may serve the management of immediate psychosocial needs, such as reducing anxiety and feelings of uncertainty. [4]

paradigm. Next we will relate versions 4 to 9 of shared decision-making to patient adherence.

SHARED DECISION-MAKING AND ADHERENCE

We have now paved the way for exploring the relationship between different ideas about shared decision-making, patient autonomy and patient adherence. In the rest of the article we will argue that, taking the adherence shift seriously and grant the involvement of the patient in shared decision-making, depending on the type of sharing thus assumed to take place, our reasons for taking an interest in patient adherence will vary and so will the aspects of adherence thereby coming out as interesting. Moreover, depending on what type of shared decision-making model is assumed, the relationship between patient autonomy and patient adherence will be differently constituted. Hence, if we would end up with having reasons to pursue, for example, the Professionally Driven Best Interest Compromise (which we will *not* argue for in this context), this would affect whether and how we should take an interest in patient adherence as well as how patient adherence will be related to patient autonomy.

The models 4-9 of shared decision making can be related to the earlier made distinction between statically and dynamically framed adherence. Models 4-6 represent the former category (i.e. the sharing does not imply any room for revision of basic health care standards as to, e.g., what treatments to offer, but gives the patient room for declining to meet these standards by being non-adherent). As will be explained, such non-adherence may go against patient best interest as perceived by health care, but not necessarily from the standpoint of the patient. At the same time, these models do not imply much room for the health-professionals' own view on the best interest of a specific patient. Hence (assuming the implied importance attached to autonomy), there will be a tension between advocating any of these models and at the same time suggesting that it is important whether or not the patient is adherent in relation to the standard treatment for the patient-group to which the patient belongs. Still, we could have other reasons for taking an interest in the adherence of the patient (see below). Models 7-9, in contrast, all involve some room for the professional to be influenced by the patient's views on or attitudes to such standards and revise them in light of that. This gives room for the patient to be adherent without conforming to any preset health care standard, but also to be non-adherent in relation to whatever is chosen or agreed upon. Both of these possibilities may or may not be in the patient's interest from his/her own perspective.

Informed Patient Choice

This model is in line with the deontological version of autonomy presented above, where the patient's autonomy is respected if the patient is allowed to make the decision around his treatment plan (given the relevant information). However, the professional does not take an interest in the patient's actual ability to make a good decision, given the patient's preferences – as long as the patient is assessed as possessing enough of the abilities needed for autonomous decision making and action. This version of shared decision-making signals that the only thing we should be interested in when providing health-care is to respect the patient's autonomy.

If the patient later is found not to adhere to the treatment plan he decided on, this decision should be respected, if it is indeed a decision and hence autonomously made. As professionals we would have reason to explore whether the patient made an autonomous decision not to adhere, and it would be autonomous if the patient were autonomous when making it and had access to and understood the relevant information. There could be several good reasons for not adhering to the original decision: that the original decision wasn't very well thought through or that new facts and circumstances, unobserved in the original decision, has arisen. Mykhalovskiy (2008) noted how patients suffering from HIV/AIDS re-evaluated their adherence to the treatment plan when they realised what the side effects amounted to, or what the difficulties were in adhering given their social situation. He presented a spectrum of reasons for why a person might not adhere to the treatment plan, including an autonomous decision to steer the course of one's life based on social circumstances, making it impossible to uphold a consistent treatment adherence. It could, of course, also be a mere whim of the patient not to adhere, since, on this notion of autonomy, also whims could be accepted as autonomous decisions commanding respect.

On the other hand, there could be circumstances that would have made the non-adherence problematic also from this perspective. For example, it is problematic if the patient is forced or manipulated or if the patient is lacking in efficiency when it comes to implementing his decisions into actions. However, given this view on shared decision-making and the perspective on autonomy it implies, as long as the patient is efficient enough we would have to accept his non-adherence as an autonomous decision and action. This, since it is not implied by this view on shared decision-making and autonomy any importance of supporting or empowering the patient to become more autonomous. Moreover, removing obstacles to autonomy will not necessarily result in increased adherence; the patient might still use his capacity for autonomous decision making and action to opt for non-adherence (Broyle et al 2005).

Interpretative Patient Choice

The model of interpretative patient choice necessitates that the professional takes greater responsibility for helping the patient to make a decision that is in line with his preference set. In distinction to the minimalist notion of the moral importance of autonomy above, behind this version of shared decision-making lies a more developed such notion, where not only self-determination but also preference-satisfaction and self-realization are important. It is still only the patient's own perspective on his interest that is taken into account, and the professional is only acting as a facilitator in helping the patient work out what lies in his best interest (according to the patient's own preference set).

From an adherence perspective, the professional would here have reason to explore whether the patient's non-adherence is the result of an autonomous decision and whether it is actually in line with his preference-set. The professional would have reason to support the patient in being able to continue to adhere to the original decision and act accordingly (unless relevant new facts and circumstances have arisen). However, even if this implies a more developed notion of the moral importance of autonomy, still the patient's basic preferences, values or goals are not open for questioning..

Advised Patient Choice

With an advised patient choice model, a possibility is affirmed for the professional to express her opinion on what *she* finds to be in the patient’s best interest. Hence, besides patient autonomy, also the professional’s perspective on patient best interest is seen as a relevant value to be given some room. Still, patient autonomy is given primary weight, and the professional’s perspective only enters in the form of an advice for the patient to consider in whatever way he prefers. Given the (general) unequal power relation between patient and professional, the possible influence of such advice on the patient should, however, not be underestimated.

The patient could have reason not to adhere to an original decision made in this way, not only to the extent that new facts and circumstances arise, but also since he retrospectively finds the decision not to be the one he now wishes that he had made. Non-adherence without such factors being present would thus appear as problematic. However, from this perspective, we would also have cause to ask for what reasons patients *adhere*. How patient autonomy and the professional perspective on best interest is balanced in advised patient choice could become problematic if the patient adheres simply due to blind trust in the professional. Hence, the patient may adhere whilst at the same time having second thoughts about whether this is actually in his best interest, but being afraid of questioning the professional’s authority. From a professional perspective, taking patient autonomy seriously, if it is found that this is one of the reasons why the patient adheres, the professional would have reason to reconsider how advice was given in the decisional situation and maybe also how she relates to the patient in other respects.

Shared Rational Deliberative Joint Decision or Patient Choice

In a shared rational deliberative process of decision-making, the patient and professional enters with their respective knowledge bulks as well as views on what lies in the patient's best interest. The patient enters with an idea about his own individual preferences, efficiency, situation, and experiences, and the professional enters with her knowledge about the general medical facts and experiences about how patients generally are benefited in this type of situations. In entering a rational deliberative process, the patient and professional are ideally supposed to reach a common ground, where the patient's preference-set is scrutinised and well-thought through and matched against the medical facts of the situation, having together explored different facets of the situation not to miss out on any aspect or argument. Being an ideal, this might be difficult to achieve in practice. Truly 'tailoring' the directives of the biomedical model to the specifics of individual patients has proven difficult (Bosworth et al. 2008, Black et al. 2001, Bosworth et al. 2005, Ekman et al 2007). Still, if this version of shared decision-making is appealing, we should not stop trying.

If the patient and professional are able to reach a joint decision which they find to be supported by rational argument, this would imply a harmonious relation (in this particular case) between patient autonomy and a professional view on the patient's best interest. If this process is successful, the patient here faces the best possible chances of actually achieving self-realization through the decision, i.e., of making a decision that is also implemented in action and thereby capable of realising the preferences of the patient.

If autonomy is given precedence over the professional view on patient best interest and there is a remaining conflict as to what decision to make after having gone through this process, we should resort to shared rational deliberative patient choice, i.e., allowing the patient to have the final word.

Unless new facts and circumstances have arisen, non-adherence would here be problematic since it implies that the patient digresses from what, in his own perspective (and also from the professional), is in his best interest. Once again, it will be important to know whether the patient finds himself unable to adhere to the decision and, if so, whether professional support could empower the patient to thus adhere. On the other hand, the patient could of course decide autonomously to act against his own best interest – for example, since he decides to act in accordance with a preference for his short-term well-being or enjoyment, disregarding the long term consequences. Here we could enter into a new rational deliberative process with him (if he is up for it), to make sure he is aware of what he is doing and that he does not do it heteronomously.

The autonomy notion behind these versions of shared decision-making is the notion where the final value of self-realization is the most central. If we find that the patient's non-adherence would actually result in less self-realization (however self-determined the patient is) than if adhering to the original treatment plan, we would have reason to go temporarily against his autonomy to have him adhere. However, this action should obviously be taken with caution. First, we need good reason to believe that we will thereby succeed in helping the patient to achieve self-realization in the long run and that this strategy then is worth its price. Second, since there is a price related to this strategy, we should be careful not to intervene more into the autonomy of the patient than what is absolutely necessary.

Professionally Driven Best Interest Compromise

In the professionally driven best interest compromise model, the professional's perspective on the patient's best interest is given a more substantial role. The professional is not assumed to be only the servant of the autonomy of the patient, but given room to enforce some standards for what type of treatment plans could be accepted and/or are ideal from a professional perspective. If, after having shared in a rational deliberative process, there remains a conflict as to what to do, in distinction to the shared rational deliberative patient choice, the professional will *not* accept any choice by the patient. Instead, the professional will, by using open strategic action, try to have the patient change his mind about the evaluation of the treatment options, so that he accepts one within a set menu of options which is closest to the gold standard of treatment from the professional perspective. If the patient's preferences lie wholly outside of the initial menu, the resulting decision must be a compromise from the perspective of the patient, if any decision at all is to be reached. However, even if the situation is not that extreme, the professional may, in the end, have to compromise with her professional view on what treatment plan would be the best one.

If the patient, by being non-adherent, digresses from this compromise in a way that brings him further away from the professional standards, there will be a reason to take an interest in this, not related to patient autonomy. That is, apart from the reasons discussed above related to non-adherence being problematic from an autonomy perspective, non-adherence will here also be problematic from the professional perspective on patient best interest. Since this version of shared decision-making implies (in cases of conflict or disagreement) a continuing tension between patient autonomy and the professional perspective on patient best interest, the patient will always have a reason to digress from the original treatment plan. This digression might in some cases enable the patient to realise his preference-set better than the original compromise if it is up to the patient's own choosing to adapt treatment in a way that better fits this set. In such cases, taking an interest in non-adherence and finding strategies to get the patient to become more adherent is reminiscent of the old compliance paradigm, i.e. restricting the autonomy of the patient to safe-guard the interest of the patient as judged from a professional perspective.

However, in many cases, the non-adherence of patients will, as a matter of fact, not be very conducive to their lives becoming more in accordance with their wants and plans, but rather the other way around. What the patient often does is, as it were, to sacrifice the long-term autonomy of his life for short-term (and in comparison minor) gains. From an autonomy promoting point of view, this may motivate steps that momentarily disregard respect for autonomy in order to enable better self-realization (and then also outcomes better in line with professional best interest) in the long run.

Does Non-adherence Disrespect Health Care Professionals?

In the decision-making situations above, the professional will often take a personal interest in the patient and in what care the patient should receive. This interest is likely to have a number of different sources: having a genuine caring interest in the patient and also an understanding of the patient's perspective on his own life, being a representative of a health-care organisation with institutional norms for how patients should be treated, wanting to be successful as a competent professional in treating the patient's condition, having personal ideas on how one should relate to the condition in question and what type of life it is valuable to live etc. Here it is important to note that these different sources for taking an interest in the patient and how the patient is treated might not always harmonise.

In relation to this interest, both dynamically and statically framed non-adherence imply that the care professionals may be said to be disrespected in a rather classic sense: the patient fails to honour a promise made to the professional. However, when assessing the moral problem of not honouring a promise to adhere to a certain decision an essential aspects is to what extent the decision itself was morally legitimate. Unless we have a very strict deontological perspective, failing to honour a promise to partake in a bank robbery would not seem morally problematic at all. In that case, the decision lacks moral legitimacy simply because it is a decision to act morally wrong. However, in the case of shared decision making, the decision that the patient agrees to adhere to may lack moral force for other reasons. Suppose, for instance, that the professional's decision was influenced mainly by her personal interests. The lack of moral legitimacy of these interests in the health care context influences the legitimacy of this decision and thus affects whether honouring a promise in relation to this decision is morally problematic or not. If, for example, the main professional interest in the decision is how it will reflect on her status as a doctor or medical researcher, it seems to be very little of disrespect involved in breaking a promise to adhere to the decision. If, in contrast, the professional's interest is founded in a genuine caring for the fate of the patient or in the importance of upholding central health-care norms (taking into account justice, patient security and trust etc.) there seems to be more of disrespect involved in breaking such a promise.

In consequence, even if care professionals sometimes will take it personally when patients fail to adhere, this by itself implies no ethically important disrespect. To determine whether any such disrespect is involved, we need to probe the extent to which the interests behind the promise to adhere are legitimate. If they are, this may constitute a reason for why it could be problematic for the patient to break a promise to adhere. However, this question is not independent from the question of which form of decision making that should be applied in health care (be it a traditionally paternalistic one or any of the versions of shared decision making described earlier).

For example, if *Informed patient choice* was to be the valid norm of decision-making, there would not be any room at all for the professional to have a legitimate interest in what the patient decides since the only rationale behind such a decision-making model is respect for patient autonomy. On the other hand, if we advocate the *Professionally driven best interest compromise* model, there is room for such a professional interest. At the same time, making room for the professional to have a legitimate interest in what is in the patient's best interest, we need to assess on what grounds such a legitimate interest could be based. Here we merely state, having to some extent argued for this elsewhere, that we do not find the professional's own idiosyncratic views on this to be a sound basis for such a legitimate interest. Rather, a legitimate interest needs to be based primarily on the established view of the professional community to which the professional belongs, or the health care organisation that she serves. Thus, the agreement made with the patient should not be based on the private interests of the professional (cf. Sandman [2009]) and Sandman & Munthe [2010]), but on institutional values that the professional is supposed to represent.

At the same time, when agreeing to the treatment plan, the patient is not making a promise to an organisation or body of professionals. Rather, the agreement is directed at a specific individual professional to whom s/he has a care relationship. Thus, what we argue here is simply that when not honouring that promise to this professional, it is only under certain circumstances, i.e. depending on how much and on what grounds the professional has a legitimate interest in the patient, that this would amount to a morally important form of disrespect. From an autonomy and best interest perspective, such reasoning could very well be part of the arsenal of arguments wielded by the professional in the cases where the patient is tempted to follow short term preferences et cetera to the detriment of long-term health and autonomy. On the other hand, to press the binding nature of such a promise could also work as an obstacle in cases when the patient indeed has good reasons not to adhere. Consider the following statement: ‘I cannot see any real reasons for sticking to this decision, but alas, I have promised the doctor and I hate to break a promise...’ Hence, the analysis of adherence in terms of promise breaking, while sometimes having some credence, should be used with some caution (if at all) in the dialogue with patients[1].

SOME WORRIES LEAVING THE INDIVIDUAL PERSPECTIVE

There is a tight conceptual connection between those models of shared decision-making that represent the most ambitious take on the importance of patient autonomy (models 7-9) and the applicability of dynamically (rather than statically) framed adherence. At the same time, we live in a society where

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[1] A further aspect of this is to what extent the patient also gives a promise to him- or herself in arriving at a certain decision (or in accepting a certain decision). If giving a promise to oneself could provide extra reason for sticking to the decision and not abandon it lightly to satisfy short term preferences, such a promise could turn out beneficial (as far as it goes).

the idea that society should go to some lengths to promote and respect the autonomy of people enjoy notable popularity. At least, this holds for well-developed societies where the general health of the population is in good shape and where ideas about shared decision making have in effect been making headway.

This may raise worries as to the systemic effects on the very institution of health care and the ability of society to have this institution deliver the goods to the population that it is supposed to deliver. The mentioned shared decision-making models, when applied systematically by many people, may both stimulate a health care system driven by consumer demand rather than set standards of health care quality and accept care and treatment (and adherence to such care and treatment) that in the long run negatively affect the health status of the population.

One way of responding to such worries may be to look at what happens with autonomy as a value when placed on an overarching societal level and connected to the ethical assessment of public health and health policy. It has been argued that such a transition is possible, but that it implies that the importance of respecting and promoting individual autonomy needs to be constrained further than in the context of mainstream clinical health care ethics (Munthe 2008). For instance, a right of people to have their health related autonomy promoted needs to be constrained by the equal right of everybody else. Thus, if the systematic application of a version of shared decision making, connected to dynamically framed adherence as a ground for assessing the performance of health care, leads to a situation where, e.g., the economic basis of health care institutions is undercut through a strong tendency towards a consumer demand driven system and a gradually worsened health status resulting in even greater health care spending, this would be a reason to moderate the weight given to patient autonomy also on the individual level. This in turn would influence what version of shared decision-making we should advocate and thereby, accepting our analysis, also how we should take an interest in patient adherence.

A possible solution to how that is to be achieved without abandoning the ideas of autonomy as an important value in health care or shared decision making (of types 7-9) as an important instrument in this respect would be to keep some sort of institutionally preset quality standard that still allows patients to influence also the frames and goals of care. For example, the model of a best treatment standard (from which patients and professionals may digress in the process of shared decision making) may be complemented by a *minimally reasonable* treatment standard that sets an absolute lower limit in terms of, e.g. cost and prognosis, to what health care may offer. Patients are not allowed to influence this standard and professionals are not licensed to go below it.[m] With

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[m] Ideas in this direction is developed in a forthcoming paper by Christian Munthe, Lars Sandman and Daniela Cutas, that surveys the ethical implications of central ideas in shared decision making and person centered care.

this outlook, if the patient digresses from even such a minimally reasonable treatment standard, the traditional compliance paradigm may look as a defensible basis for deciding on how to respond. Minding patient autonomy is then not a main focus, which opens up for a different set of strategies for having the patient keep to this standard (i.e., comply). However, having given the patient status as trusted decision-maker concerning his own life, traditional paternalistic strategies (such as the more or less patronising issuing of orders) can be expected to be even less effective than they currently are. Rather, such patients will to an increasing extent have to be *rationally convinced* to stay within these boundaries, This may involve some actions that appear problematic from a pure autonomy perspective, such as emotional or moral pressures to have the patient's motivation better match the rationale behind the minimally reasonable treatment standard, but just as much inventiveness on the part of the professional to adapt the implementation of the treatment to the various surrounding preferences of the patient. Alternatively, the patient will be facing the autonomous choice between accepting the treatments that can be offered within the boundaries of minimally reasonable treatment standard, or receiving no treatment at all.

CONCLUDING REMARKS

Following the shift from a compliance to an adherence paradigm – the latter advocated with references to autonomy and shared decision-making – we have explored the relationship between different forms of shared decision-making, the implied view on autonomy and the extent to which and why (non-)adherence should be ascribed importance. Depending on what is implied by shared decision-making and the different roles for patient and professional involvement in the decision-making process and resulting decisions, we have reason to take an interest in adherence and specifically non-adherence in rather different ways. The logic of this interest does not necessarily follow the simple template of 'adherence is good while non-adherence is bad' – even if we restrict the outlook to the perspective of the patient. Adherence may be a problem for the patient by not expressing correctly her basic life-plans, or by not being sensitive to changes of these plans or revealed flaws in earlier decision making. Moreover, patients may be retrospectively dissatisfied with or simply harmed by the outcome of earlier decisions. Non-adherence, similarly, may be a *good* thing for the patient in all these respects. These reasons for (dis)valuing (non-)adherence encompass autonomy-aspects, experiential well-being and biological function and, of course, all of these factors may also provide reasons for adherence and against non-adherence. The point is that it is not facts about *whether or not the patient is adherent or not* that settles this, but rather surrounding factors such as the features of the patient, the surrounding situation and the ensuing effects of a clinical decision. Such aspects, in turn, need to be related to more specified norms as to the relative importance of respecting and promoting autonomy, promoting experiential well-being, biological functionality and length of life, and so on. Further analysis is then needed to balance the weight of these values as regards the patient with other legitimate interests.

ACKNOWLEDGEMENTS

This work was supported by the University of Gothenburg Center for Person-Centered Care (GPCC), Sweden. GPCC is funded by the Swedish Government's grant for Strategic Research Areas, Care Sciences [Application to Swedish Research Council no 2009:1088] and co-funded by the University of Gothenburg, Sweden.

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