The Principle of Respect for Autonomy in the Care of Nursing Home Residents

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Key words: autonomy; care; ethics; nursing homes

Respect for autonomy is well known as a core element of normative views on good care. Most often it is interpreted in a liberal way, with a focus on independence and self-determination. In this article we argue that this interpretation is too narrow in the context of care in nursing homes. With the aim of developing an alternative view on respect for autonomy in this setting we described four interpretations and investigated the moral intuitions (i.e. moral judgements) of caregivers regarding these approaches. We found that these caregivers seemed to value different notions relating to respect for autonomy under different circumstances. There was no significant difference in moral judgements between men and women or between doctors and nurses. We conclude that a multidimensional understanding of this principle would best fit this context. We end this article with a description of a modest theory of respect for autonomy in nursing homes.

Introduction

It is often said that ethics always comes after the change. When new technology is introduced, this is usually followed, not preceded by, ethical assessment. This, however, does not mean that ethical deliberation is fruitless. Health care ethics has, for instance, had major consequences for ideas about the (moral) characteristics of good care. More specifically, the moral principle of respect for autonomy has proved to be a very successful tool in the struggle for the emancipation of patients. Awareness among health care professionals that patients have a right to be treated as individuals and requirements such as informed consent are the result of emphasizing respect for patient autonomy. It is safe to say (at least in the Netherlands) that there has been formal implementation of this principle. In several recent laws concerning health care, as well as in policy documents, respect for autonomy is an essential element.

It is surprising, however, that most (policy) documents relating to the Dutch health care setting do not contain an explicit definition of respect for autonomy.

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In the ethics literature there are different opinions about its meaning:

> It is apparent that the term is used in very different ways by very different authors. . . . It is apparent that, while not used as a synonym for qualities that are usually approved of, the term is used in an exceedingly broad fashion. It is used sometimes as an equivalent of liberty . . . sometimes as equivalent to self-rule or sovereignty, sometimes as identical with freedom of the will. It is equated with dignity, integrity, individuality, independence, responsibility and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom of obligation, with absence of external causation, with knowledge of one's own interests. It is related to actions, beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts and to principles.[1]

In spite of this variety, a closer look at the functioning and interpretation of this principle in health care shows that the dominant understanding of it in this field is best characterized as liberal.[2–5] The focus is on independent individuals, who want to shape their own life by choosing freely. The professional role of caregivers is to provide the information and assistance needed by patients to make their own decisions and to pursue their self-chosen goals.

A liberal interpretation of the principle of respect for patient autonomy has probably contributed significantly to its success. Elements such as liberty and freedom from coercion are concrete and recognizable, because they are also part of the legal discourse. However, this success also has some downsides.

Interpreting respect for autonomy in a liberal way is not satisfactory in long-term care settings for several reasons. First, dependence on the care of others and vulnerability are important characteristics of most of these patients. The liberal image of the life of an autonomous person differs radically from the reality of life in, for example, a nursing home. This gap between the ideal and practice diminishes the positive effects of a strong emphasis on the principle of respect for autonomy. If the aim of care is always and only to maximize independence, this could be contrary to the patients' real needs.

Secondly, the emphasis on a liberal interpretation of autonomy makes those who do not have the capacity for autonomous decision making look as if they lack a vital capacity. This lack is normally overcome by substituting the actual autonomous decision of a patient with something else, for instance by nonactual decisions of the person (i.e. decisions made for the future, as in living wills) or by the actual decisions of others than the patient (as in substituted judgement). We think that both strategies are problematic. We cannot go into the details of these problems here, but point out just one of them: both living wills and substituted judgements can be contrary to the expressed (non-autonomous) wishes of a patient. Ignoring these problems is mainly justified by referring to the importance of the principle of patient autonomy. There are better ways, however, of dealing with problems than ignoring them.

Thirdly, comes the practical level. A study among nurses in nursing homes showed that the vast majority agreed on the importance of the principle of respect for autonomy. However, in day to day practice they had many problems in trying to meet the criteria designed to shape respect for autonomy by the Dutch Association for Nursing Home Care[3,5]; examples are using informed consent procedures and problems with offering an acceptable level of privacy.

Various authors have anticipated (some of) these problems and questioned

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whether the principle of respect for autonomy is a suitable starting point for nursing home care.[6–8] We believe that it is an important value in health care and one that cannot be dismissed if we want to protect patients against total loss of control over their bodies and circumstances. However, the conceptual and practical problems that are encountered by caregivers when trying to encourage respect for autonomy need serious attention. We therefore tried to construct an alternative understanding of this principle that fits the context of the nursing home.

Alternative interpretations of respect for autonomy

The dominantly liberal understanding of respect for autonomy is not the only one that theories of ethics have to offer. On the contrary, many different opinions on how we should interpret this principle can be found in the literature. Our goal was to come to an alternative understanding of respect for autonomy that really fits the field for which it was designed. We therefore needed the input of caregivers in nursing homes. Using an empirical study, we presented caregivers with different normative views on respect for autonomy. We identified a limited number of views that seemed to cover most of the thoughts on this topic. From a general overview of the relevant literature, we identified four approaches. For methodological reasons we chose one description from the literature for each approach. These are deliberately stated in general terms. We emphasized one or two concepts that are central to the views presented. In this way, caregivers were able easily to distinguish the different views from one another and it is likely that their preferences were related to these central notions.

The liberal view

At the heart of the liberal approach of respect for patient autonomy is the idea that it is important to be independent and free to make one's own choices.[9] This emphasis on so-called 'negative freedom' (or the right to be left alone) implies that caregivers should abstain from interference in the lives of the residents as much as possible. When applied to nursing home care, this approach would mean that caregivers take each resident's expressed wishes as the starting point of care. The limit to their right to autonomy consists in the freedom of others and the task of caregivers to prevent serious harm. In general, patients are considered to be autonomous until their incompetence becomes evident. Surrogate decision making is used to respect autonomy when a patient is no longer competent.

The Kantian ideal of moral autonomy

The Kantian view is based on the idea that autonomy does not only imply self-determination (as is the case in the liberal approach) but it also requires a choice to be rational.[10] In a nursing home setting, this view would mean that caregivers have to respect the autonomous choices of patients; however, they can question choices that they consider to be irrational. Respect for autonomy does not mean noninterference (as in the liberal view) but implies an attentive attitude of caregivers concerning the motivation behind patients' choices. When the need to make

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decisions for an incompetent patient occurs, caregivers must try to determine what a rational person would have done under the same circumstances.

A narrative approach

Using a narrative approach, respect for autonomy consists of respect for each individual's life plan within its own historical and cultural context. The focus is not on isolated choices, but caregivers concentrate (in dealing with competent as well as incompetent patients) on the norms and values that are important in a person's life story and in specific situations.[11] This life story continues in the nursing home. A decision should therefore be respected when it is understandable in the light of the life story of the patient.

Respect for autonomy in an ethic of care

Finally, in an ethic of care, the central value is not independent decision making but a caring attitude towards each other, because decisions are made as a result of communication with others.[12] The relationship between caregivers and nursing home residents is the most important instrument in respecting patients and in taking into account the vulnerability and the dependence on others that we all share. Caregivers have to build a caring relationship with patients and, in this relationship, answers to questions about right decisions or courses of action can be found in a process of mutual 'longing for goodness'.

Empirical study: moral judgements of caregivers in nursing homes

Objectives and research question

The objective of the empirical study was to gain insight into the moral intuitions (i.e. moral judgements) of caregivers regarding different concepts of the norm of respect for patient autonomy. We believe that practice contains a form of 'practical wisdom' that should be taken into account in normative reasoning.[13] In this study we tried to gain insight into this practical wisdom. We therefore focused on the moral judgements of nurses and physicians in nursing homes, using prereflective normative judgements about particular cases or situations within cases.[14]

We formulated the following research question: which of the four above approaches to respect for autonomy is the best example of moral judgement regarding patient autonomy by caregivers in nursing homes?

Sample

The study population consisted of nurses and physicians. We drew a random sample of 50 nursing homes from a list of all the 190 Dutch homes that care for both psychogeriatric and medical patients. With each head of nursing staff we went through the following procedure:

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- The psychogeriatric and medical wards chosen were those that came second in alphabetical or numerical order: In this way, we selected 100 wards.
- Selection of one nurse from each ward: Nurses had to have worked in a current position of 'teamleader' for at least six months. We chose to involve teamleaders because they are responsible for both patient care and co-ordinating that care; charge nurses are directly senior to teamleaders.

From the Dutch Association of Nursing Home Physicians (NVVA) we obtained a membership list containing 981 names, from which we drew a random sample of 50. In order to be included, they had to be registered as a nursing home physician.

To recruit 100 nurses we eventually had to approach 60 nursing homes because, in ten of the original 50, the head of nursing staff refused, mainly because of the workload on nurses. We sent out questionnaires to two nurses in each remaining home; 94/100 were returned. We had to identify 63 physicians in order to be able to send questionnaires to 50 of them. Ten physicians did not meet the selection criterion for inclusion and three refused. Of the 50 questionnaires sent out, 31 were returned. Thus, 94 nurses and 31 nursing home physicians participated in the study.

Data collection instruments

We presented the four approaches to respect for autonomy to the participants in two ways. First, we developed four views on patient autonomy in nursing homes. Each of these consisted of the same elements, namely: a concept of persons (containing a description of what is considered to be important in life according to a particular view); a characterization of good care; and a view on dealing with patients who are not (fully) competent. The respondents were asked: If you had to decide on one of these views to be implemented in your own nursing home, which would you choose? The answers to this question yielded information on the general views on autonomy held by caregivers.

Secondly, we wanted to know which approach these nurses and physicians would prefer if presented with (descriptions of) particular situations. Would the approach they preferred in general also be considered the best when they were given information about the relevant facts of a case? To answer these questions we designed ten vignettes, which were short case descriptions that make it possible to investigate moral judgements indirectly. The vignettes were in simple Dutch language and based on the following variables, which were systematically varied between the vignettes: the competence of the patient (competent/incompetent); the patient's request (yes/no); and whether the situation or request was beneficial to the patient (yes/no) and the workload (high/normal). With each vignette, we offered four options to choose from, based on the four interpretations of the principle of respect for autonomy. Each option consisted of a comment on the case and contained a suggestion for an approach to the issue at stake. The respondents were asked explicitly to choose the option that best reflected their normative ideas, not the one that most adequately described everyday practice. In this way, we obtained information about the moral judgements of caregivers, not about actual behaviour. With an

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example of a (translated) vignette we illustrate this data collection method in Appendix 1.

Results

Overall, 39% of the respondents preferred the view on good nursing home care that was based on a liberal interpretation, while 18% chose the Kantian view. The narrative approach corresponded with the moral views of 33% of the respondents. Finally, 10% chose the ethic of care view.

We compared the choice of view with some respondent characteristics. Twenty-nine per cent of the participants were between 31 and 35 years of age (range 24–56). Their years of working experience varied from three months (registered nursing home physician) to 20 years; 32% of the respondents had between 5 and 10 years' experience. Age and working experience had no significant influence on the choice of what is good nursing home care, and we did not find significant differences between women and men or between nurses and physicians (Table 1).

Preferences in case descriptions

We used logistic regression to analyse the responses to the question concerning which comment was the best reflection of the moral experience of caregivers in particular case descriptions (vignettes). The results showed the influence (predicted value) of (a combination of) systematically reordered variables on a

Table 1 Respondent characteristics per view

Characteristic	View (no. (%))				
	Liberal $n = 49$	Kantian $n = 22$	Narrative $n = 41$	Care ethic $n = 13$	Total $n = 125$
Sex					
Male	21 (43)	6 (27)	13 (32)	5 (38)	45 (36)
Female	28 (57)	16 (73)	28 (68)	8 (62)	80 (64)
Discipline					
Physician	13 (27)	2 (9)	11 (27)	5 (38)	31 (25)
Nurse	36 (73)	20 (91)	30 (73)	8 (62)	94 (75)
Ward					
Psychogeriatric	16 (33)	7 (32)	25 (61)*	5 (38)	53 (42)
Medical/rehabilitation	21 (43)	14 (64)**	13 (32)	4 (31)	52 (42)
Psychogeriatric and medical/rehabilitation	12 (24)***	1 (5)	3 (7)	4 (31)	20 (16)

*$p = 0.003$
**$p = 0.021$
***$p = 0.038$

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certain outcome, in this case the choice of one of the four interpretations of respect for patient autonomy (Table 2).

Figure 1 contains the results of the multivariate logistic regression analysis. We computed the predicted percentage value of the combinations of variables in the ten vignettes. This table shows the combination of circumstances under which the predicted value of each approach was highest and lowest.

The choice of a certain view on good care did not have a significant influence on the choice of a certain approach in the concrete cases.

The responses to the vignettes did not provide independent observations because, from each of the 125 respondents, 10 decisions were obtained. Results with a *p*-value just below 0.05 are not of great significance, but in most cases the *p*-value was lower than 0.03.

By computing the predicted percentage value of the combinations of variables in the ten vignettes we obtained insight into the combination of circumstances under which a certain approach was preferred by the majority of respondents. As the tables show, we found that:

- The highest predicted value for a liberal approach came from the vignette in which the patient was not competent and made a request that was not in accordance with the caregivers' duty of beneficence, although the workload was high.

Table 2 Predicted value (%) of variables for choice of view (vignettes)

Variable	View[a] (%)			
	Liberal $n = 288$	Kantian $n = 288$	Narrative $n = 394$	Care ethic $n = 277$
Patient's competence	*	*	*	*
Competent	16	31	43	10
Incompetent	28	18	24	30
Patient's request	*	**	***	*
Request	28	25	33	14
No request	5	14	26	55
Beneficence	**	*	*	*
Conflicting	28	36	23	13
In accordance	20	15	37	28
Workload	***			
High	26	23	30	21
Normal	21	23	33	24

[a]Total number of cases 1247; 3 missing values
*$p < 0.0001$
**$p < 0.001$
***$p < 0.05$

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	Beneficence	–	+
	Workload	+	–
Competence	Request		
–	–		Care ethic (58) Liberal (4)
	+	Liberal (44) Narrative (14)	Kantian (10)
+	–		
	+	Kantian (44) Care ethic (8)	Narrative (55)

Figure 1 Highest and lowest predicted values (%) per view per combination of variables (multivariate analysis)

- The Kantian approach had the highest predicted value in the case of a competent patient making a request that was contrary to beneficence. In this case, the workload was also high.
- The combination of variables that resulted in the highest predicted value for a narrative approach was a competent patient making a request that was in accordance with the caregivers' duty to be beneficent in a situation with a normal workload.
- Finally, the care ethic approach was preferred when the patient was incompetent, when the patient's request did not conflict with the caregivers' duty of beneficence, and the workload was normal.

Analysis: core elements of respect for autonomy

The task of analysing the intuitions of caregivers presented us with several problems. In general, respondents preferred the liberal view on good care. However, the results yielded no conclusion in terms of one view reflecting best the normative ideas of caregivers; after all, 39% is not very convincing. Thus, we must acknowledge that there is not one particular view that fits well enough into the nursing home setting. In addition, the view that is put forward in the literature as a good alternative for long-term care (namely an ethic of care) apparently does not appeal to caregivers as a general starting point of care. It is surprising that we found no significant relationship between opinions on the views on good care

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in general and the preferred comments on the vignettes. In other words, respondents who chose, for example, the narrative view on good care did not in general choose more often the vignette comments based on this approach. Another conspicuous result was that, in seven out of 10 vignettes, over 50% of the respondents made the same choice of comment (spread 52–70%). Finally, there were no other factors than the variables in the vignettes that seemed to influence the choice of a certain comment. We found, for example, no significant differences between answers given by doctors and nurses, or between men and women. Neither age nor years of working experience were associated with particular comments.

These results led us to drop our initial idea that identifying caregivers' moral judgements of the field would enable us to use one of the four approaches as the basis for a refined understanding of respect for autonomy in nursing home care. The moral judgements of caregivers are too diverse and these health care workers seemed to be attracted by elements from each approach according to certain conditions. This is understandable, given the differences in competence found in nursing home residents. It seems plausible to interpret respect for autonomy differently when dealing with a fully competent patient compared with a patient who is, for example, suffering from dementia. We think that respect for autonomy has to be understood in such a way that the core elements of this notion are preserved. At the same time, respect for autonomy can be meaningful in a nursing home setting only when it takes account of the limitations that most residents have. In our further analysis we therefore tried to understand the moral judgements by relating them to the core ideas of the different approaches.

We think that the following moral concepts or principles adequately describe the moral judgements of caregivers. First, the notion of freedom is important, especially in circumstances that seriously threaten a person's freedom. This is why the liberal approach is appealing in a situation where patients are not only limited in their competence but also want something that is not readily approved of by the caregivers. The second element that is relevant is reasonableness. It is a good thing to try to reason with patients about their needs and wishes. Thirdly, caregivers should try to provide care not only by reacting to the wishes of patients, but also by reflecting on the life story of each patient. Finally, care as a moral category is an element of respect for autonomy.

After identifying these principles as the four relevant elements of an adequate view on respect for autonomy, we could integrate them into an actual view. However, this cannot be the end of our moral reasoning. In order to arrive at a modest theory of respect for autonomy in nursing homes, we need to look at these elements from a critical perspective to avoid the pitfall of conservatism. We have already stated that it is not our intention simply to describe systematically the moral judgements of caregivers. In the next section we demonstrate how a normative view on respect for autonomy can be formulated.

Towards a modest theory of respect for patient autonomy in nursing homes

The moral judgements we identified in our empirical study provide a general framework for describing respect for autonomy. This is not to say that all the

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elements of this framework are equally important or desirable from a normative point of view. We think that there are reasons to make some adjustments to this framework. There is a certain heterogeneity among the principles that have to be taken into account. The idea that the life plan of a patient is the frame of reference for evaluating needs and wishes seems to be more or less an overarching principle. The principle of freedom can be reflected in an attitude of caregivers that is sympathetic towards the wishes of patients. Caregivers also have to be motivated to go the extra mile to protect patients' freedom when it is threatened. The idea that it is good to try to find out what is reasonable functions as a safeguard against negligence. When the wishes of competent patients cannot be understood by caregivers and seem to be contrary to the duty of beneficence, then respect for autonomy requires that they at least try to engage in conversation with patients about their motivations. If this step is omitted, patients are neglected instead of respected.

The most problematic principle of the four is, however, the one that places care as a moral category under the wings of the principle of autonomy. Care is usually seen as opposed to autonomy, or is at least considered to be exemplary of an attitude in which autonomy is not a central issue. Notwithstanding the fact that care as an element of respect for autonomy seems problematic, we think it helps to express certain notions that are relevant for respect. One example is that the needs of patients can never really be understood if we use as a starting point of our thinking an image of an 'ideal' person who is totally independent and mentally and physically fit to take control over his or her own life.[15] The concept of care is a way of introducing the relational aspect of respect for autonomy into our understanding of this principle.

Another notion concerns the role of caregivers. Care is not a one-way activity. Both the caregiver and the care receiver have their own roles in the process of care.[12] This has important implications for a view on the professional responsibilities of caregivers. A side-effect of the liberal understanding of respect for autonomy is the increase in action-guiding rules and protocols in health care. This implies a simplification of the role of professionals, because good care can never be contained in a set of rules that is applicable to all situations:

> That which surpasses the minimum norms cannot be caught in general rules, because what ought to be done and what can be done are too strongly dependent on the concrete situation and on the person of the caregiver and the care receiver.[16]

In a view that is inspired by an ethic of care, the complexity of shaping respect for autonomy in interaction with the patient is more obvious. This leads us to emphasize the importance of a good caregiver–patient relationship. In other words, the principles we have described so far can only result in respect for autonomy when caregivers are able and willing to put some emphasis on a particular one, depending on the patient and the circumstances.

Conclusion

In our study of respect for autonomy in nursing home care we started with empirical information on the moral judgements of caregivers. Contrary to what is some-

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times suggested in the ethics literature, we found that caregivers in nursing homes do not prefer a view on good care that is based solely on an ethic of care over a view based on a liberal understanding of this principle. Furthermore, we found no significant difference in moral judgements between men and women or between doctors and nurses. Surprisingly, there was also no significant correlation between the view on respect for autonomy in general and that in concrete case descriptions. Caregivers seem to value different notions that are related to respect for autonomy under different circumstances. This led us to the conclusion that a multidimensional understanding of this principle would best fit the context of the nursing home.

In such an alternative view on respect for autonomy, four moral principles are relevant, namely principles of: protection of freedom; reasonableness; people's choices as part of their life story; and the moral element of care being an essential part of respect for autonomy. These principles can be the framework for the further development of a modest normative theory of respect for autonomy in nursing homes, being refined and adjusted in a process of further normative reasoning. The core steps of this process are outlined in this article.

A concrete description of respect for autonomy in nursing homes can still be given in different ways. As long as each element is incorporated, this is not problematic. We do, however, want to end this article with a suggestion for the description of respect for autonomy in the nursing home.

Respect for autonomy implies that the personality of the patient, his or her life story, and the choices he or she makes are seen by caregivers as necessarily intertwined. Choices, needs and preferences are viewed and evaluated in the light of the life story. Caregivers have an active role in the process of care. With respect to the principle of autonomy, this means that they should have the expertise, the motivation and the responsibility to make respect for autonomy an element of everyday practice in the nursing home. An important element is the awareness of potential threats to autonomy in this setting and the value of freedom. At the same time, caregivers have to be sensitive to the competency of patients. When dealing with competent patients, respect for autonomy requires that caregivers can engage in conversation with them about the rational grounds for a choice or decision. However, it is sometimes necessary that caregivers have to take more initiative to support an incompetent patient. This can be realized in a caregiver–patient relationship that is based on mutual respect and trust. A caring attitude of professionals in nursing homes is therefore of the utmost importance.

This view on respect for autonomy is based on a combination of elements from theory and practice. It is hoped that the integration of theory and practice will enhance not only the understanding of respect for autonomy but also the way in which it is practised in day to day care in nursing homes.

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Appendix 1

Example of vignette

Mr J lives in the nursing home because he is suffering from Alzheimer's disease. He is confused and disorientated in time and place. In the last few days, Mr J has refused to get out of bed. If the nurses encourage him to get up he resists. Because Mr J stays in bed all day, there is an increased risk of bed sores developing.

Which comment do you prefer?

1) The question is whether this resident can comprehend the consequences of his choice. If he is capable of balancing the pros and cons, then his decision should be respected. If this is not the case, then the caregivers should ask themselves what would someone who is capable of understanding do in this situation?

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The caregivers should then act in concordance with the answer to this question.

2) We can decide only after the specific circumstances of this case are taken into account. The caregivers should first try to find out why he has this wish. In other words, what motivates this resident? They have to take into account information about the things that this resident values in life. In this way they can understand the situation better and decide on a way that best fits the individual circumstances of Mr J.
3) The caregivers are rightly worried about the welfare of this resident. He is confused and disorientated. They should (because of the risk of bed sores) try to communicate with this resident and make an effort to regain his trust. They should work towards getting him out of bed. If this resident trusts the caregivers, his resistance will diminish.
4) The expressed wishes of the caregivers should be the starting point of care. In principle, the wishes of Mr J, expressed in a very explicit fashion, should also be respected. Only if there is acute danger can caregivers consider choosing to protect the resident from himself. Until that is the case, the wishes of Mr J should weigh heaviest in the decision making.

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