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Understanding respect: learning from patients

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Abstract

Background—The importance of respecting patients and participants in clinical research is widely recognised. However, what it means to respect persons beyond recognising them as autonomous is unclear, and little is known about what patients find to be respectful.

Objective—To understand patients' conceptions of respect and what it means to be respected by medical providers.

Design—Qualitative study from an academic cardiology clinic, using semistructured interviews with 18 survivors of sudden cardiac death.

Results—Patients believed that respecting persons incorporates the following major elements: empathy, care, autonomy, provision of information, recognition of individuality, dignity and attention to needs.

Conclusions—Making patients feel respected, or valued as a person, is a multi-faceted task that involves more than recognising autonomy. While patients' views of respect do not determine what respect means, these patients expressed important intuitions that may be of substantial conceptual relevance.

We all agree that respect is morally important. We expect it in our everyday interactions, and physicians and patients alike recognise its centrality to the clinical relationship. In addition to the direct moral importance of respectful treatment, there are data suggesting its indirect importance as well. Recent studies have reported, for example, that patients who perceive they are being treated respectfully may experience improved clinical outcomes and greater satisfaction with their care.^{1,2} Ensuring or improving respect in clinical and research relationships is surely an important goal, but it will be difficult to accomplish without knowing more about respect and what it means to be respectful.

Respect as a concept is poorly defined, and confusion about its meaning is compounded by the striking difference between the use of respect in ordinary language and the discussion of respect for persons in the bioethics and philosophy literature.³ While we use *respect* quite broadly in ordinary language, the ethical principle of respect for persons is often treated as almost exclusively requiring respect for autonomy.^{4–6} Some ethicists have argued that

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respecting persons involves much more than respecting autonomy,²³⁷⁸ but exactly what it requires in the setting of medical care and clinical research remains unclear.

We know particularly little about what patients consider to be respectful treatment. While some ethicists may argue that patients' views play no role in defining fundamental philosophical concepts,⁹ there are two important reasons to investigate patients' conceptions of respect. First, respecting patients surely must involve considering what they find to be respectful, and it may not always be apparent what patients consider to be respectful behaviour. Particularly in settings of acute illness, many patients are significantly incapacitated and unable to communicate but may have strong views on how they would want to be treated. Second, patients' views may reveal important aspects of respect that physicians and bioethicists have not recognised. This exploratory study investigates the meaning of respect to one population of patients—those who have survived sudden cardiac arrest.

METHODS

Study participants were adult patients in an academic cardiology clinic who had experienced sudden cardiac death and received an implantable cardioverter defibrillator for secondary prophylaxis of ventricular arrhythmias. This population was chosen because the study involved examining patients' attitudes toward research conducted in emergency settings as well as their views on respect. Eligible patients were identified through appointment lists and the electronic patient record. A convenience sample was selected. African-American and younger patients were over-sampled, because the majority of eligible patients in the clinic population were white and older. Clinic staff then called selected patients to ask if they would discuss participation with the investigator (ND), and recruitment continued until informational redundancy—the point at which further data collection fails to identify new themes or information—was reached. Spouses were invited to participate if they wished, because their views were considered relevant and important. This study was considered exempt from review by the Johns Hopkins Bloomberg School of Public Health Committee on Human Research. All participants interviewed in person provided written informed consent; those interviewed by telephone did so orally. All patients were assigned a unique identifier number at the time of enrolment, by which quotations are identified in this article.

Interviews were semistructured, and all but two were conducted by ND in person in a conference room or separate waiting area; the other two were conducted by telephone. Most lasted 30 to 60 minutes and were recorded digitally. One was not recorded, because of equipment failure, but extensive notes were taken in order to include those data. Upon completion, all interviews were transcribed and imported into a qualitative data software package (QSR N6) for analysis.

Questions were designed to elicit patients' views on and experiences of respect or disrespect in medical or non-medical contexts, including in the context of resuscitation. Examples of interview questions are listed in box 1. Patients' views on research in emergency settings were also solicited but are reported elsewhere.

The study's analytic aim—consistent with the method of qualitative description¹⁰—was primarily to describe the range and nature of views on respect. Analysis was conducted over the course of the study, with codes representing distinct thematic content developed by reviewing transcripts. Codes were merged or eliminated if they did not represent coherent or distinct content. The major headings below represent the salient thematic categories. In order to ensure reliable interpretation, on two occasions (once early on and once after all interviews were completed), several colleagues reviewed two transcripts each and provided

interpretations of participants' comments in major thematic categories. Any differences were discussed, and investigators refined analysis of relevant transcripts. Consistent with the methodology used, results are reported thematically, with frequent incorporation of direct quotations and limited reporting of frequencies of particular responses, to convey a general sense of the distribution of views among the population.¹¹

RESULTS

Thirty-seven eligible patients were identified, 31 of whom were contacted. Three were not contacted because the clinic staff believed they were unable or unwilling to be interviewed, and three could not be reached by telephone or letter. Twenty-two of the 31 were willing to complete the interview. Nineteen interviews were conducted; three willing patients were not interviewed because informational redundancy was reached before their clinic visit. Of the 19 interviewees, one was not asked about respect because of time constraints; that interview was eliminated from this analysis, leaving a total population for this analysis of 18 patients and four spouses. Equal numbers of male and female patients were enrolled. Three patients and two spouses were African-American; all others were Caucasian. Most had attended at least some college and were at least 60 years of age. The average time since cardiac arrest was 8 years.

The following elements represent the salient themes of patients' views regarding respect: attention to needs, empathy, care, autonomy, recognition of individuality, information provision and dignity. Examples of each of these elements are listed in box 2. The first element was most widely mentioned by patients. The order of the other elements of respect does not reflect frequency of responses. Rather, the elements are clustered by thematic similarity.

Attention to needs

The most widely cited element of respect, mentioned in some form by most patients, was simply paying attention to their needs. Some mentioned physical needs:

I asked [the nurse] if I could have a little bit of water and she just totally ignored me, just turned her back and said, "You can't have anything right now." (837)

Another recounted being left unattended on an examination table for an extended period, unable to sit up because of recent abdominal surgery.

Several patients emphasised the importance of physicians' listening to them and taking them seriously. One woman felt that a former physician had not acknowledged symptoms of depression after myocardial infarction. Another patient said a physician attributed a cough to smoking despite her insistence that it was different. She was later hospitalised with pneumonia. Patients also stated a need to be included in and recognised as a part of conversations that take place about them.

At least talk to me and tell me what you're saying and you're telling these interns, you may be telling these interns that I'm dying ... (428)

Empathy

Half of patients interviewed emphasised empathy as one important element of respect.

When someone's respectful of another person, they are taking into account what that other person may be thinking or feeling. Trying to see things from their perspective ... what would it feel like if, you know, I touched this person with my

cold hands. Okay, that wouldn't be very good, you know, I wouldn't like that on me so let me warm this up. (259)

I think doctors and the nurses should be conscious of the speed in which they move and the speed with which they talk and how they pick up things and look at their beeper and all of those machinations because it makes you feel like a cow, one of the minions, and that's not a good thing. (546)

For these patients, empathy was an important part of respecting them as valuable persons. Interestingly, of the nine patients whose comments reflected a concern for empathy, six were women.

Care

Six patients, four of whom were women, suggested that care is an important element of respect. Although closely related to empathy, comments reflecting a concern for care as part of respect were distinct. Comments about empathy focused on doctors' and nurses' recognition of the effects of their actions on patients; comments expressing the importance of care reflected an emphasis on doctors' and nurses' concern for patients' emotional and physical well-being:

There's a certain amount of detachment I know [doctors] have to have to function. But if you're gonna treat patients, you gotta care about them and you've got to let them know you care about them because if you don't, they feel like a slab of meat. (019)

For that patient, a physician who once came to the hospital late at night to visit her exemplified the care component of respect. Another felt respected by a doctor who hugged her. As her husband stated,

He showed that he cared about you as opposed to you being a number or another paycheck. (*Husband of a patient*, 428)

Autonomy

In much of the literature, autonomy is taken to be the primary concern of respect, and seven patients explicitly indicated that respect involves recognising them as autonomous by allowing them to make their own decisions or translating their values into decisions:

You tell the patient the risks that are involved so that they can make the decision and not the doctors make the decision for the patient. (261)

One patient recalled discussing with doctors whether to implant an implantable cardioverter defibrillator. He felt respected by their acknowledgment that the decision was his to make based on his values.

In contrast to empathy and care, autonomy was more commonly emphasised by men than women.

Individuality

Closely connected to the concept of autonomy, just over half of patients stated that an important component of respect is recognising patients as unique individuals with particular preferences about how they want to be treated. One couple cited physicians' willingness to facilitate clergy visits during a recent admission. Others stated that doctors who fail to review their charts or do not attempt to understand them as unique fail to respect them as individuals.

To me respectful conduct is that you're not a number and a case. You're a person, and there's a difference between a case and a person ... So respectful means some knowledge of the background, the living background of the patient. (195)

Information

Half of patients emphasised that respect involves paying attention to their particular need for information about their health:

... to let them know everything, you know, what they're going to deal with, what's going on ... Be honest and truthful with them. (360)

While related to autonomy, these patients' desire for information was independent of any particular decision. The provision of information itself was considered an important component of respect.

Dignity

More than half of patients stressed what may best be termed recognition of their dignity as a principal component of respect. While many of the other themes raised are closely connected to dignity, these patients' suggestions were distinct:

When I'm in the ER, stripped naked, crucified, tied down, etc, they never close the curtain, because the head ER man has to stand at the foot of the bed and say what to do next ... I feel it would be more respectful if he were aware that I am stark naked in an ER and people are walking by and there's a lot of excitement ... (605)

Well, I certainly wouldn't want them having a yuk over me (while unconscious) whether it's the way or how I'm dressed or whether it's one of my physical attributes or lack thereof. I would like, I guess, [for them to] treat me the same as if I were conscious. (127)

Interestingly, two male patients and one husband of a patient explicitly denied the importance of these dignity-related concerns in the setting of unconsciousness, emphasising instead the importance of competent medical care.

A different sense in which patients expressed concern for dignity had to do with doctors' not looking down upon them, but rather recognising them as adults of equal intelligence or status.

I think some people tend to think that you're old and can't comprehend so they talk to you like you're a baby or a child. Like [my husband] said, he's not a first grader or in kindergarten. Not every old person is like that, just because you're in your 60s. (*Wife of a patient*, 461)

DISCUSSION

This exploratory study offers important insights that are highly relevant to discussions of respect for persons, widely considered to be one of the fundamental principles of bioethics. First, it provides information useful to clinicians and researchers about what makes patients feel respected and reveals that this is a multi-faceted and individualised task. For some, it may involve primarily expressions of care and an empathic response. For others, the most important aspect of respect may be providing information and allowing them to make autonomous decisions.

The extent to which these participants' conceptions of respect truly differ is difficult to assess, as this study did not ask patients to consider forms of respect that they did not raise

spontaneously. The goal was simply to explore patients' own impressions and conceptions. In this regard, one interesting finding is the apparent difference in views between men and women. While one should not overinterpret this finding in this very small sample, the fact that more men emphasised autonomy-related concerns and more women gave definitions of respect related to empathy and care is in keeping with long-held views of masculine and feminine orientations to moral considerations. In fact, inattention to considerations of care and empathy as important moral considerations is a common criticism of feminine theorists against much of ethical theory in general, and the features of respect suggested by these patients' responses are consistent with the views of some advocates of care ethics.⁷¹²¹³ Furthermore, these data reinforce the potential importance of efforts to promote gender sensitivity and awareness in clinical contexts.¹⁴ The data should not, however, be taken to suggest that women do not consider respect to entail acknowledgment of autonomy or that men do not prioritise empathy and care. Additionally, men and women did not differ significantly with regard to other elements of respect that emerged through these interviews

Indeed, most respondents mentioned several different forms of respect, though certain forms were more immediately apparent or particularly operative for some individuals. Given that there are numerous aspects of persons that are important and valuable, it seems only proper that respecting persons will require many different kinds of attitudes and behaviours on the part of doctors.²¹⁵¹⁶ Each of the components discussed here, however, was mentioned by multiple participants, and we believe that attention to each of these components is likely to result in behaviour that meets most patients' conceptions of respectful treatment.

In addition to their practical utility in helping to identify types of behaviour likely to be considered respectful by patients, we believe that these data carry important conceptual implications. In particular, they suggest a need for a broader understanding of what it means to respect persons than is evident in traditional philosophical accounts that emphasise autonomy and decision-making. Consistent with the work of some recent scholars, they suggest that elements of care, empathy, dignity, provision of information and attention to needs, all manifested by numerous forms of behaviour and mentioned by many of these patients, may be important components of what it means to respect patients as persons.²⁷¹⁵¹⁷ Patients often described these elements as ways to recognise persons as the valuable persons that they are. If respecting persons is essentially about treating persons *as persons* and recognising them as valuable and important—as conceptually it seems to be—these elements deserve serious consideration in refining our operative account of respect for persons.

Exactly how these patients' intuitions about respect ought to impact on substantive ethical judgments about the content of the principle of respect for persons is an interesting philosophical question, significant examination of which is beyond the scope of this paper. It is clearly the case, however, that different philosophical traditions will make different use of these data.¹⁸ One of us, for example, has proposed an account of respect for persons that includes many of the considerations raised by these patients as important respect-driven demands on two grounds.¹⁹ First, to the extent that respecting persons involves taking into account persons' concerns, respect demands recognition of concerns that persons express. Second, these patients' concerns reveal important intuitions that have often not been considered in ethical theory but ought to be at least considered (even if ultimately dismissed). Implicit in both of these reasons is the view that fundamental philosophical concepts should not be determined by public opinion.⁹ In other philosophical traditions, particularly more procedurally or experientially driven ethical theory such as dialogical or practical hermeneutical ethics, the fact that patients raise these concerns as morally important concerns about respect carries important moral weight, provided these views are solicited in the context of appropriate dialogue. In addition, to the extent that mutual respect

is viewed as a pre-condition for appropriate ethical decision-making procedures, conceptions of respect may help to identify and define the appropriate procedural conditions. Redefinition of a *principle* of respect for persons, however, would be less important on these accounts, given the fact that these traditions generally do not attempt to define and establish abstract principles.²⁰⁻²²

Finally, many of these patients' views are already universally considered to be morally important, even if not traditionally considered to be within the domain of respect for persons. No one would dispute, for example, that attending to patients' needs, caring about them or recognising them as individuals is morally important. However, considering attention to needs, recognition of individuality, care and empathy to be duties of respect grounds these responsibilities in a fundamental moral principle and emphasises that they are serious considerations necessary to treating persons as the valuable and important beings that they are. Responsibilities of respect are not just theoretically fundamental; they carry significant moral weight.

Limitations

This study population was small and relatively homogeneous with regard to age, race and educational status. Participants also have access to medical care at an urban academic centre and reported high satisfaction with their care. These factors may limit the transferability of findings to other populations. Studying other populations' views will help to generate a fuller understanding of expressions of respect, as different cultures and social groups may express respect differently. In particular, it would be interesting and helpful to study conceptions of respect among people living in cultures that may be less individualistic. While thus not representative of all conceptions of respect, there are no reasons to think that the patients interviewed here have idiosyncratic understandings of respect among patients treated in US urban academic centres, even if the behaviours they take to be reflective of respect may differ to some extent from those of other populations.

CONCLUSIONS

This qualitative study is exploratory and provides important ground work for those attempting to enhance the extent to which patients feel respected in medical encounters, as well as those seeking to understand the nature of respect itself. We all agree that respect is important. These data suggest that respecting patients incorporates considerations of empathy, care, individuality, dignity and attention to needs, in addition to recognition of autonomous agency and provision of information. Further research will be integral to elucidating behaviours that express recognition or disregard for these considerations in medicine and research and to understanding how different situations tend to promote or hinder respectful behaviours.

Examples of questions about respect

- ▶ I am interested in learning about what people think it means to be respectful. Can you describe to me what you think respectful behavior is?
- ▶ Can you give me some examples of things that you think would be respectful or disrespectful? They can be related to medicine or not.
- ▶ Can you tell me about some examples of ways in which you have been treated with respect?
- ▶ Can you tell me about some examples of ways in which you have been treated disrespectfully?

- ▶ When you had a cardiac arrest, you were unconscious. Can you describe to me how to treat someone who is unconscious respectfully? What kinds of things would be disrespectful?

Examples of forms of respect

Attention to needs

- ▶ [The nurse] stole packages you crush to make ice, because when I arrested, I landed on my head and it hurt. The only thing that would give me any relief at all was that cold pack. (283)
- ▶ I'm in a conference with three or four doctors and they're talking among themselves, it's like I'm right here, you can ask me a question. You can talk to me. I believe I am the person you're discussing the problem about and things like that. (461)
- ▶ I asked [the nurse] if I could have a little bit of water and she just totally ignored me, just turned her back and said, "You can't have anything right now." (837)

Empathy

- ▶ For doctors and nurses to know that you're here cause you're sick, you're not just here because you want to pay a visit or come see somebody. You're sick and you don't feel good and if a pain or something occurs to you in the middle of the night and you holler, you don't want to be hollered at and told that it's three o'clock in the morning. (461)
- ▶ When someone's respectful of another person, they are taking into account what that other person may be thinking or feeling. Trying to see things from their perspective ... what would it feel like if, you know, I touched this person with my cold hands. Okay, that wouldn't be very good, you know, I wouldn't like that on me so let me warm this up. (259)
- ▶ I think doctors and the nurses should be conscious of the speed in which they move and the speed with which they talk and how they pick up things and look at their beeper and all of those machinations because it makes you feel like a cow, one of the minions, and that's not a good thing. (546)

Care

- ▶ There's a certain amount of detachment I know [doctors] have to have to function. But if you're gonna treat patients, you gotta care about them and you've got to let them know you care about them because if you don't, they feel like a slab of meat. (019)
- ▶ I think definitely the way they speak to a patient is very important. I've had some doctors who just kinda make you feel like they don't really care. They're cold, bedside manner is respectful. (360)
- ▶ He showed concern. He showed that he cared about you as opposed to you being a number or another paycheck, or how you feeling and so on, etc, etc, etc. You know, warmth in the voice, general attitude, body language. (*Husband of a patient*, 428)

Autonomy

- ▶ But here you're getting into the respect of the patient ... here's a patient caught in between and they're saying we advise you that you should do this or should consider it. They didn't say we advise you to do it, they say we advise you to consider it. (195)
- ▶ You tell the patient the risks that are involved so that they can make the decision and not the doctors make the decision for the patient. (261)
- ▶ I think you would have to think about the wishes of those people and still from your professional standpoint, I think you should be able to explain to them you know the possibilities of what's going on and try to weigh out your opinions with their opinions and come up with a decision. (916)

Individuality

- ▶ To me respectful conduct is that you're not a number and a case. You're a person, and there's a difference between a case and a person ... So respectful means some knowledge of the background, the living background of the patient. (195)
- ▶ The clergy would come in, they respected the clergy coming in. We had, they wanted bedside prayer, they were respectful of that. They stood back until we were done. It just made the whole atmosphere in the room more positive for us. (*Wife of a patient*, 261)
- ▶ He says, "Go home and decorate a room and you'll feel better." Well I was a career person and I just had to quit my job and so decorating rooms was not exactly what I had in mind. (605)

Information

- ▶ It's important to a patient to know what the doctor is doing to them and why they're doing it because otherwise ... particularly with my background, I can think of a thousand things, you know, if they don't tell me. (019)
- ▶ To be decent to them, to speak to them like they're a normal person, not talk down to them, definitely to let them know everything, you know, what they're going to deal with, what's going on, stuff like that. Be honest and truthful with them. (360)

Dignity

- ▶ Not making the assumption that oh he's an idiot, doesn't know what I'm talking about. He won't understand my big words. (069)
- ▶ When I'm in the ER, stripped naked, crucified, tied down, etc, they never close the curtain, because the head ER man has to stand at the foot of the bed and say what to do next ... I feel it would be more respectful if he were aware that I am stark naked in an ER and people are walking by and there's a lot of excitement ... (605)
- ▶ Well, I certainly wouldn't want them having a yuk over me (while unconscious) whether it's the way or how I'm dressed or whether it's one of my physical attributes or lack thereof. I would like, I guess, [for them to] treat me the same as if I were conscious. (127)

Numbers in italics are unique identifier numbers assigned to each patient.

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