

WHAT DOES IT MEAN TO BE A VIRTUOUS PATIENT?

VIRTUE FROM THE PATIENT'S PERSPECTIVE.

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Abstract *This paper shifts the focus of biomedical ethics away from the dilemmas of doctors and towards patients and their responses to chronic illness. It explores the possible virtues needed to flourish despite ongoing pain and disability. An empirical study, investigating patients' perspectives on the role of character in illness, revealed that patients valued qualities such as courage, realism, self-respect, a sense of humour, hope and the ability to maintain good relationships with others. Such qualities may characterise the "virtuous patient". These findings carry a number of practical implications for the pastoral care of those suffering from chronic illnesses. These include working towards the empowerment of patients, and an appreciation of the healing force of humour and the value of communication, all of which assist patients in their efforts to maintain their self-respect, their sense of a role in their community, and a sense of purpose in their lives.*

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Virtue and the chronically ill patient

Biomedical ethics has tended to concentrate on the dilemmas facing doctors in crises associated with acute illness. The intention of this essay is to move the focus of ethical debate away from the actions of professional decision-makers, important though this sphere of debate is, and towards the patient. A consideration of discrete actions may be relevant in a discussion of acute illness but less so when we consider chronic illness. The chronically ill patient lives with illness on a regular or even daily basis. The actions of health professionals may be able to do little more than alleviate their suffering to a degree. This is a situation in which cure is less important than care, and in which actions are less important than attitudes. Our focus here is therefore no longer on discrete actions but on the personal qualities that a chronically ill person must draw on or develop in order to live a happy or fulfilling life despite physical disability. This is the realm of virtue ethics, a philosophical theory concerned with the character of the moral agent rather than their actions. Virtue ethics is concerned not with the question "What should I do?" but rather "How should I live?", and virtues are developed throughout the course of human life. This concept is particularly important when one considers the chronically ill

patient. Such a patient shoulders an ongoing physical and mental burden that continually threatens their happiness and forces them to draw upon their own personal and moral resources. It is our hypothesis that a "virtuous patient" is someone who possesses or develops the virtues in order to participate in their own recovery or to maintain a satisfying and productive life despite continuing adversity.

But who would qualify as a "virtuous patient"? On first reflection, a virtuous patient might be conceived of as someone who is passive and compliant – manifesting stoical qualities which are at odds with the emerging emphasis on the "expert patient". The expert patient is proactive, assertive, informed, and not afraid to challenge medical authority. However, these two conceptualisations of patient character are not necessarily entirely at odds. Virtue is a much richer concept than modern usage of the word implies. It encompasses many qualities of character and intellect, and virtue in action is a subtle concept. Aristotle (see e.g. Ross's translation, 1980) defined a virtue as any state of character, displayed in the right situation to the right degree. For him, a virtue lies in a balance between a vice of deficiency and a vice of excess. For example, the virtue of courage lies in a mean between the vices of cowardice and rashness. For Aristotle, the virtuous person is someone who sees or perceives what is good, fine or right to do in

any given situation and acts accordingly. If a person possesses and exercises the virtues this will enable them to flourish; if they are developing and exercising vices they will fail to find happiness and fulfilment.

We will briefly discuss the very small body of modern writing on the virtues of patients; key contributions being by Earl Shelp, Karen Lebacqz and Stanley Hauerwas. Shelp (1984), in a journal article entitled "Courage: a neglected virtue in the patient-physician relationship", presents courage as an important moral virtue for patients and practitioners alike. To this he adds the desirability of the patient-specific excellence of compliance, exercised to a reasonable degree and evidencing a desire to get well and assume a degree of responsibility within health care. He also discusses the patient-specific excellence of gratitude, a "thankful appreciation for benefits received". More generally, Shelp holds that patients have a duty to develop character in a manner appropriate to the successful negotiation of human existence.

Lebacqz (1985), in a chapter in Earl Shelp's edited volume, *Virtue and Medicine*, concurs with Aristotle's assumptions that virtue is a mean between extremes, and that 'virtues are not simply character traits but responses to situations' and thus are developed as life progresses. She describes experiences associated with illness, and finds that these may be summed up as threats to the self, which require changes in the self-concept. Part of this threat is that illness forces a new social role upon a person. Lebacqz defines the virtues of the patient as "qualities of excellence in response to the stresses of pain, discomfort, physical limitation, loss of autonomy, violation of privacy, vulnerability, and loss of self". She goes on to identify three virtues - fortitude, prudence and hope - as central to the task of being a virtuous patient, and contrasts these qualities with the stereotype of the virtuous patient as compliant, cheerful and uncomplaining.

Fortitude consists partly of enduring that which cannot be changed and remaining 'quiet of heart', but at the same time being able to rage against the situation and reassert one's autonomy. These paradoxical responses can result in the acceptance which is fortitude. The virtue of prudence, on the other hand, requires listening to the body, realistic adjustment to new limitations and the formation of a new self-

concept. It also involves bringing balance to one's life by developing a new awareness of the value of things, and a reaching out to others which avoids social isolation and self-absorption. Hope is a virtue which enables people to look for 'meaning to emerge out of the chaos, pain and sense of injustice' associated with illness. Lebacqz notes that an enabler of hope is often a sense of humour, not only because it relieves stress, but because it is a way of transcending illness and renewing courage. However, Lebacqz does not believe that this list of virtues should necessarily apply to all people confronted with illness, and emphasises the cultural relativity of virtue. She also resists the notion of a unifying 'virtue', although some notion of personal integrity, incorporating realism and optimism might serve as such.

Hauerwas (1997) also addresses the issue of virtue and illness, from a Christian perspective, in a chapter in *Christians among the Virtues*, entitled 'Practising patience: how Christians should be sick'. He writes in reaction to the impatience of contemporary society, in which people are unwilling to be frustrated by the failures of their bodies. Hauerwas reasserts the importance of the term 'patient' (as opposed to the more autonomous sounding 'client') and combines it with an advocacy for the Christian virtue of patience. Christian patience in the face of illness is not false optimism, but nor is it a fatalistic despair of worldly things. Instead being patient enables us to achieve certain good ends, despite our fear and suffering. Firstly, such patience helps us to 'love the great good things our bodies make possible', without hating our bodies because they are the instances of our death; secondly, it helps us to reach out to others in love, even though we know that such love must result in sadness and loss through their, or our, death; and, thirdly, it gives value to our time and our space, enabling us to engage in 'worthy activities' that have significance, even though they will not endure, and enabling us to share these with our children and pass on a heritage to them of memories and exemplary activities.

As a complement to these theoretical accounts of the virtuous patient, we wish to discuss an empirical investigation of virtue and illness, the first of its kind. We will reflect on the results of a multinational study of patients with chronic illness which sought to reveal patients' own perspectives on the moral and personal qualities that they feel are rele-

want to their experience of illness. What virtues or vices do patients feel are important in the context of chronic illness?

An empirical study into virtues and illness

For the past three years the authors have been project co-ordinator and project officer respectively for a study funded by the BIOMED II research programme of the European Commission, entitled ‘The relevance of virtue ethics to patients with chronic illness’. The main empirical work documented the illness experiences of patients with four chronic conditions: rheumatoid arthritis, endometriosis, end-stage renal disease and mood disorder. Three research centres took part in the empirical aspect of the project: Bristol (UK), Nijmegen (Netherlands) and Rome (Italy). Two others centres, Copenhagen (Denmark) and Cardiff (UK), participated in theoretical analysis and interpretation of the findings.

Method

A qualitative research approach was adopted, in which individual interviews were conducted with small groups of patients in each diagnostic group. The interviews were conversational, but focussed on the concept of ‘living well’ with a chronic condition. Patients were asked to discuss not simply coping strategies, but ways in which they felt they could continue to live lives of value and fulfilment, and any personal qualities or attitudes that helped them to do so. The interviews were audio-recorded and transcribed. Table 1 gives demographic details of the patient participants:

The transcripts were subjected to Interpretative Phenomenological Analysis (IPA), a qualitative analytical method used to identify recurrent themes in narratives (Smith, Jarman and Osborn, 1999). The focus of the analysis was on ‘living well through chronic illness’. The transcripts were explored for descriptions or explanations of characteristics or personal qualities that participants felt they possessed, which were relevant to how they faced the challenges their condition posed. Each transcript was examined individually, and significant words, phrases or explanations were noted. These were then given a code capturing the meaning of the content of the text portion. The recurrence of certain codes across interviews indicates emerging themes; codes appearing together frequently indicate an interrelation between themes.

Several main themes emerged from analyses of the interviews in each diagnostic group, and these are summarised in Table 2 below. Some themes were specific only to that diagnostic group; however, a number of themes common to all four groups were discovered. The themes reflect not only virtues that have developed as a consequence of the onset of illness, but also existing virtues that are drawn upon in order to face the challenge of illness. We also touch upon the possibility of the development of vices as a consequence of the hardships of illness. The themes common to all the diagnostic groups may suggest what qualities may be key to the virtuous patient.

Table 1

Diagnostic group	Interview location	No. of interviews	Age range	Patient gender
Rheumatoid arthritis	Bristol	10	20-68	7F 3M
Endometriosis	Bristol	12	31-55	12F
End-stage renal disease	Nijmegen	7	55-82	2M 5F
Mood disorder	Rome	15	28-64	6M 9F

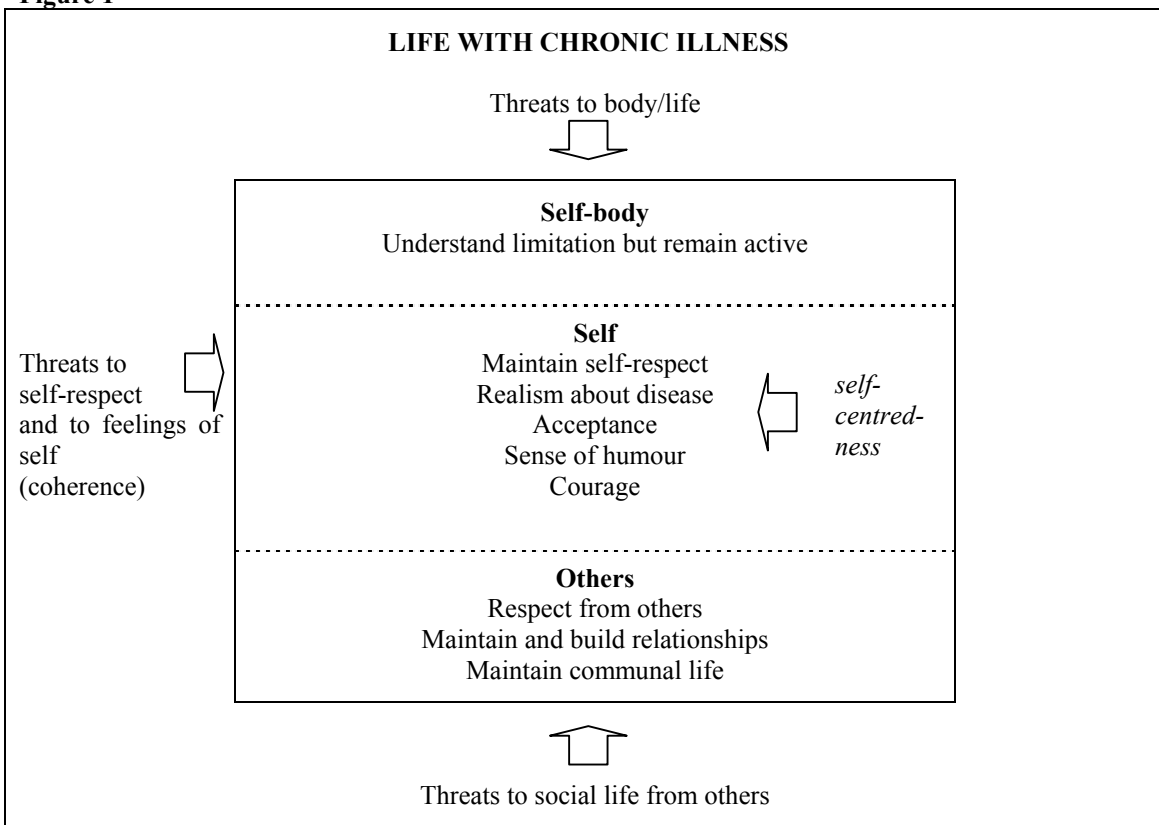
Table 2

THEMES MENTIONED				
Rheumatoid arthritis	Endometriosis	Chronic renal failure	Mood disorder	Common main themes
POSITIVE TRAITS				
<i>Traits related to the self</i>				
Strength Optimism Sense of humour Acceptance Future goals Self-identity Threats to self-worth and dignity	Enduring Accepting Being self-directing Keeping a sense of purpose in one's life Putting other considerations ahead of one's illness Being cheerful and positive	Bearing-endurance-perseverance Second-nature-habitation-balancing-deciding Sense of reality Gratitude-hope Awareness of finitude Acceptance-acquiescence	Realism about the disease Acceptance Insight Self-awareness Refusal to surrender Sense of humour Respect for own dignity	Acceptance Sense of humour Maintain self respect Courage / perseverance
<i>Traits relating to the relationship between the self and the physical body</i>				
Listening to your body Perspective Expectations		Vitality-being active-being able to enjoy-happiness		Understand limitation but remain active
<i>Traits related to the relationship between the self and others</i>				
Participation in the present Responsibilities Respect from others Respect for others	Getting others to acknowledge one's illness experience Assertive Better at communicating	Sense of community-relationships with other people Faith	Capacity to develop trust and friendship Ability to maintain interests Ability to make use of social network Taking care of others Humility – acknowledging need for others	Maintain and build relationships
NEGATIVE TRAITS				
Intolerant of stupidity More bad-tempered Not as sociable Bitter Unsympathetic	More impatient More short-tempered Less sympathetic to others' problems Bad at communicating		Too strong sense of duty Self-conceit	More self-centred (in a negative way)

The common themes (in the right hand column) were used to construct a model of chronic illness and virtue. The model is thus based on four moral challenges identified: 1) maintaining self-respect, 2) being courageous, 3) maintaining good relationships with others and participating in the community, and 4) being realistic.

Figure 1 below represents the dynamic interrelationship between the threats or challenges of the illness and the core values and aspirations of the individual. Three of the threats are external (threats to physical capacity, threats to self-respect and threats to social life), while one is an internal threat - self-centredness - which isolates the individual, and stops them maintaining good relationships with others.

Figure 1



It should be emphasised that this is just one possible way of constructing a model from data provided by the interview transcripts, and it is acknowledged that the construction of a model is biased by the theoretical stance of the interpreter. For example, it could be just as valid to see two complementary sets of virtues – self-regarding and other-regarding. Equally we might have interpreted the findings in the style of Aristotle by identifying the ‘cardinal virtues’ of courage, prudence, temperance and justice as these are expressed in the patients’ realistic approach to their ill bodies and their endeavours to

maintain good social relationships. Finally an interpretation in terms of the theological virtues of faith, hope and love could be seen to fit the empirical data also, since the patients are clearly reflecting on all three of these in their awareness of what they need to persevere despite their illness.

Nonetheless, when patient representatives in the study were presented with the analysis of the findings, they agreed with the themes uncovered, which lends support to the two following conclusions: firstly, that this study demonstrates that virtue can be

explored empirically, by allowing patients' own narratives to highlight the possible virtues relevant to chronic illness. Secondly, the identification of similar challenging experiences across chronic conditions supports a tentative hypothesis that possessing courage, realism, self-respect, a sense of humour, hope and the desire to maintain good relationships with others are all aspects of the virtuous patient. In agreement with theoretical accounts of the virtuous patient, such as Karen Lebacqz's, the findings oppose the idea that the virtuous patient is compliant, unassertive and unrealistically cheerful.

Pastoral implications

We believe that our research findings carry a number of important practical implications for the pastoral care of those suffering from chronic illnesses, whether they are in hospital or at home.

Firstly, pastoral work should seek to empower patients, by helping to bring out those strengths, which allow threats to self-respect to be diminished. In the hospital context chaplains should be alert to the potentially demeaning and depersonalising aspects of institutional care and should beware of inadvertently re-enforcing the stereotype of the virtuous patient as compliant, uncomplaining and cheerful. Particular caution is needed in relation to the idea that patience is a Christian virtue! While this is true in a sense, as Hauerwas powerfully argues, we also need to remember that anger can be a virtuous and healing response to the injustice of illness (see Campbell, 1986). The account of fortitude by Lebacqz, combining quietness of heart with a liberating rage, seems closest to the experience of the people we studied.

Secondly, solemnity should not be confused with virtue. In a book written thirty years ago, Heije Faber suggested that the image of the clown was appropriate for the hospital chaplain (Faber, 1971 as cited by Campbell, 1986). The clown stands apart from the powers of the hospital, seems like a bumbling amateur, yet releases the healing force of laughter. These insights are perhaps even more relevant today, as medicine has become more and more technical and pressure on beds makes the humane side of medicine harder to maintain. For the people we studied, humour was a powerful aid to maintaining realism and courage, and the threat of self-centredness, a potent enemy of virtue, was often

dispelled by being able to relax in the company of others. So the very simplicity of pastoral care, its just "being there" and having time to spend with people, is a real ally of virtue. This should not of course be confused with the "keep cheery" type of chaplaincy, which confuses jokiness with genuine conversation.

Thirdly, we would stress the sense of isolation, loneliness and exclusion from the community, which many people feel when they have to live with enduring pain or disability. It is at this point that pastoral care of those at home is especially important. Many of the people in our study felt misunderstood by the community around them and they found it hard to maintain a social life and a circle of friends. The effect of such isolation on one's sense of self worth can be devastating. For them, the important thing is not just being cared *for*, but being cared *about*, still having a respected place in society and a role to play as a member of the community. An effective pastoral care of those at home is one which enhances the moral agency still very much part of ill people's deepest wishes for themselves. How this is done will require imagination and flexibility, but the central question of virtue ethics should guide all our efforts to help such people retain a sense of moral worth and agency: The question is not, what shall I *do*? Rather, it is, how shall I *live*?

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