Part I *Theoretical and Conceptual Considerations*

1. *Health, Autonomy and Quality of Life: Some Basic Concepts in the Theory of Health Care and the Care of Older People*

Lennart Nordenfelt

Introduction

In this first chapter a number of basic concepts related to health care and the care of older people are analysed. The analysis focuses particularly on the concepts of quality of life and dignity. These two concepts, however, are not the only ones to be considered in a situation of care. There are other values with which we are perhaps better acquainted and which must play an important role. Among these are health, autonomy and integrity. In this chapter I present some of these values and analyse them to a certain extent. This should make it easier to comprehend the more complicated concepts of quality of life and dignity.

The discussion of quality of life is included in this first chapter since it is so closely related to health, which is the first concept to be studied. The discussion of dignity is held over to the next chapter, where it can be explored in greater detail; this is necessary because the analysis is largely original and some of the ideas are presented here for the first time.

1.1 Health

The most basic of concepts in health care is the concept of health itself. Health is considered by many people, particularly in modern times, to be one of the most precious values in life. They believe that health, and longevity, should be protected and enhanced as much as possible. Thus, the art and science of medicine has received a crucial place in modern society, both Western and Eastern. Doctors are dignitaries. In most countries they are highly regarded and well paid. In some circles they have replaced the priests or even the gods of olden times.

However, one may wonder why health is mentioned in the context of values. Although health is highly regarded it is, one might argue, a state of body or mind that can be scientifically assessed. A doctor or a nurse can investigate a body using modern equipment, taking blood pressure, checking the blood sedimentation rate or using X-ray diagnostics. In such a way health can be exactly determined. This is the view of some experts, in particular some physicians. It is also the view of certain influential philosophers of health.

The most famous protagonist of this view, Christopher Boorse (1977, 1997), defines disease in the following way:

> A disease is a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.

The notion of functional ability, in this theory, is in turn related to the person's survival and reproduction, i.e. their fitness. The same idea can be formulated in the following positive terms:

> A person is completely healthy if, and only if, all their organs function with at least typical efficiency (in relation to survival and reproduction).

However, other experts in the field, both doctors and ethicists, consider that attributing health to a person is not just a matter of scientific investigation. One must also assess how the person feels and what they are able to do in life. It is only when we have knowledge about this *holistic state* of the person that we can attribute health or ill health to them. The healthy person is the person who feels well and can do whatever is needed in their daily life. Moreover, according to this analysis, by designating a state of the whole person as healthy, we have also claimed that this state is a *good* state. Thus we have attributed a value to the person in question. This idea can be developed in at least two directions. Here I will consider, first, health understood as well-being and, second, health understood as a person's ability to realise personal goals.

1.1.1 Health as well-being

It is an important aspect of health that the body and mind are well, in both order and function. But we may ask about the criteria for such well-functioning. How do we know that the body and mind are functioning well? When is the body in balance?

A traditional answer is that the person's subjective well-being is the ultimate criterion (Canguilhem 1978). Simply put: when a person feels well, then they are healthy. This statement certainly entails problems, since a person can feel well and still have a serious disease in its initial stage. The general idea can, however, be modified to cover this case. The individual with a serious disease will sooner or later have negative experiences such as pain, fatigue or mental suffering. Thus the ultimate criterion of a person's health is their present or future well-being. (For a different approach suggesting that complete health is compatible with the existence of disease, see Nordenfelt 1995, 2000.)

It is difficult to characterise the well-being that constitutes health. If we include too much in the concept, there is a risk of identifying health with happiness. Indeed, an

accusation commonly directed against the famous WHO definition (1948) is that it falls into this trap. Many critics say that health cannot reasonably be identical with complete physical, mental and social well-being. The absurd conclusion of this conception might be that everyone who is not completely successful in life would be deemed unhealthy.

Some authors (Leder 1990; Gadamer 1993) have pointed out that phenomenological health (or health as it is experienced) tends to remain as a forgotten background. In daily life, health is hardly recognised at all by its subjects. People are reminded of their previous state of health only when it is disrupted – when they experience the pain, nausea or mental suffering of illness. Health is 'felt' only in special circumstances, the obvious example being after periods of illness when the person experiences relief in contrast to their previous suffering.

Thus, although well-being or absence of ill-being is an important trait in health, most modern positive characterisations of health have focused on other traits. One such trait is health as a condition for action, i.e. ability.

1.1.2 Health as ability

A number of authors in modern philosophy of health have emphasised the place of health as a foundation for achievement (Parsons 1972; Whitbeck 1981; Seedhouse 1986; Fulford 1989; Pörn 1993; Nordenfelt 1995). In fact they argue, partly in different ways, that ability/disability is the core dimension determining health or ill health. A healthy person has the ability to perform the actions they need to perform, but an unhealthy person is prevented from performing one or more of these actions. There is a connection between this conception and the one that illness entails suffering. Disability is often the result of feelings such as pain, fatigue or nausea.

The formidable task for these theorists is to characterise the set of actions that a healthy person should be able to perform. Parsons (1972) and Whitbeck (1981) refer to the subject's wants, i.e. the healthy person's being able to do what they want, Seedhouse (1986) to the person's conscious choices, and Fulford (1989) to such actions as could be classified as 'ordinary activities'. I myself settle for what I call the subject's *vital goals*. These goals need not be consciously chosen (babies and people with dementia also have vital goals). They have the status of vital goals because they are states of being that are necessary conditions for the person's happiness in the long run. Health in my theory is thus conceptually related to, but not identical with, happiness. Let me expand on this.

It is plausible to believe that whatever the adequate answer to the question of the nature of health should be, it will be an answer on an abstract level, capable of being summarised in terms of certain general goals. The question to be put should then rather be formulated in the following terms: what are the goals that a healthy person must be able to realise through their actions?

My general proposal (2001, p. 9, slightly revised) is as follows:

> A is completely healthy if, and only if, A is in a bodily and mental state which is such that A has at least the second-order ability (i.e. an ability to acquire an ability) to realise all his/her vital goals given a set of standard or otherwise reasonable circumstances.

Let me now clarify and to some extent defend this proposal by commenting on the crucial clauses concerning vital goals and second-order ability. I will be brief with

regard to the first clause and instead concentrate on the relation between health and second-order ability.

What are the vital goals of a human being? And is there just one set of vital goals? A person's vital goal, I suggest, is a state of affairs that is necessary for their minimal long-term happiness. As a consequence of this interpretation, many of the things that human beings hope to realise or maintain form part of their vital goals. More precisely, most states that have a high priority on a person's scale of preferences are included in their vital goals. Examples of such vital goals might be passing an exam, or getting married and having children, as well as simply maintaining existing conditions such as retaining one's job and remaining in touch with one's nearest and dearest.

However, certain things that people happen to want do not form part of their vital goals. First, we have trivial wants. We may casually want something, but if we don't get it, it doesn't matter much. Second, people may sometimes have counterproductive wants. They may want to get drunk, but getting drunk is not a vital goal. Instead of contributing to long-term happiness, being drunk contributes in the long run to suffering and thereby unhappiness. Third, we may have irrational wants, i.e. wants that are in conflict with other, more important wants. As soon as someone recognises this conflict, they normally realise that the more important wants are the only candidates for vital goals.

On the other hand, some things that we do not want may be included in our set of vital goals. Completely apathetic or lazy people who do not have any conscious goals whatsoever will soon realise that this creates suffering for them. This will be particularly salient if they do not even seek food or shelter. Getting these basic issues sorted out must certainly form part of long-term minimal happiness, and such basic requirements are among everyone's vital goals.

A crucial observation to be made here, then, is that a vital goal of A need not be wanted by A at a particular moment. A vital goal is thus a technical concept, not identical to the ordinary-language notion of a goal. (For a further discussion, see Nordenfelt 2001.)

I will now turn to the idea of health as a second-order ability. To be healthy, I propose, is to have the second-order ability to realise one's vital goals. Consider the following situation. A refugee from, say, an African country has just moved to Sweden. In his native country he had his own business, which he managed well enough to sustain himself and his family. When he arrives in Sweden he is no longer able to lead such a life. He does not know Swedish culture, particularly the Swedish language, so to begin with he cannot make any arrangements for establishing a business in Sweden. In his home country he lived relatively well, but in Sweden he is disabled. But would we say that this man is healthy in his native country, and becomes ill upon arriving in Sweden? No, it seems more plausible to say that as long as he has the second-order ability to run a business in Sweden, then he remains healthy. This means that as long as the immigrant has the ability to learn the Swedish language and the ability to learn how to cope in Swedish society, then he is a completely healthy person. In general, then, disability that is due solely to lack of training is not an indication of illness. We have reason to speak of illness only if the training process has in turn been prevented by internal factors, in which case there is a second-order disability.

But what about the typical case of illness that is due to an organic disease? Consider the following example. A woman has a first-order ability to perform her professional

activities. Then she becomes ill, and as a result loses her first-order ability. But would it be true to say that she no longer has the second-order ability to do her work?

It is easy to be misled here and identify two pairs of concepts that should be kept distinct: one pair is first- and second-order ability, the other is having a basic competence and having the power to execute it. We normally ascribe a basic competence to someone when they know how to do something. According to our previous definition, this need not be true of second-order ability. The immigrant to Sweden has not previously learnt anything about Sweden and does not have the necessary basic competence for making his living in Sweden. He may, however, have the requisite second-order ability.

It is crucial to recognise that a person who has a basic competence vis-à-vis a certain action F need not even have a second-order ability with regard to F. Consider the case of a professional footballer who has broken his leg. Obviously, until he has physically recovered he does not have the first-order ability to play football. Still, we would say that throughout the period of illness he has a basic competence to play football. He knows how to play football. But, while lying in bed or walking on crutches, does he have the second-order ability to play football? No, because having the second-order ability to play football means having the first-order ability to follow a training programme that leads to a first-order ability to play football. But the person who is confined to bed is clearly not in a position to follow such a programme; and so we may say of the footballer that he is ill. The same reasoning may be applied to all paradigm cases of illness due to disease or impairment. During an acute phase of illness, however short it may be, the subject has lost both the first- and second-order ability to perform the actions with respect to which they are disabled.

To this analysis of ability must be added a few remarks about the *circumstances* under which a person can be said to have an ability. It is evident that health cannot be the ability to reach vital goals in all kinds of circumstances. If that were the case then nobody would be completely healthy. There is always some conceivable circumstance in which one cannot reach one's vital goals. The outbreak of a natural catastrophe is one example. Another is that a person may be physically or legally prevented by other people from performing the actions necessary for the achievement of their vital goals. Nor could the ability to realise one's vital goals given just one set of circumstances constitute health. If that were the case, then almost everybody would emerge as completely healthy. Consider the case where an individual is almost completely dependent on the help of someone else in their endeavour to achieve a goal. We can imagine a paraplegic person who is supported in their attempts to reach various destinations; a personal assistant may help in various ways and physically transport the person. If it is true to say that the paraplegic person has the ability to travel wherever they need to go, then we should ascribe health to them. This is clearly counter-intuitive: we do not assess a person as being healthy if they require such extreme support.

So how should these circumstances be defined? One plausible idea is that the circumstances that we normally have in mind in a health assessment are those that are in some way *standard* in our culture. A person who cannot walk on an ordinary pavement is certainly disabled with regard to a standard situation. Likewise, to take an animal example, a dog that cannot run on an ordinary, well-kept lawn is disabled. In both cases, unless there are other impediments, we can draw medical conclusions. The person and the dog are unhealthy.

The way we devise such a standard (which is normally done implicitly) is not via statistics. A situation that is statistically normal in a specific geographical region at a particular time may turn out to be *unreasonable*. In certain countries the political and cultural situation may be such that it is unreasonable to judge the health of its inhabitants given this situation. It may, for instance, be impossible at the moment (January 2009) to work as a teacher in Gaza. But it would be unreasonable to say that the unemployed trained teacher in Gaza is unhealthy for this reason. In this case the circumstances in Gaza are unreasonable.

Although it is evident that health, as ordinarily understood, is connected with ability, and ill health with disability, one may still doubt whether the ability/disability dimension can remain the sole criterion of health/ill health. An important argument concerns those disabled people who are not ill, according to common understanding, and who do not consider themselves to be ill. According to the ability theories of health, these people should be classified as unhealthy.

One answer to this question (Nordenfelt 2001) is that disabled people (given that their disability is assessed in relation to their individual vital goals) are all unhealthy. However, they are not all ill and they do not all have diseases. Another answer, proposed by Fredrik Svenaeus (2001), is that there is a phenomenological difference between the disabled unhealthy person and the disabled healthy person. The unhealthy person has a feeling of not being 'at home' with regard to their present state of body or mind. This feeling is not present for disabled people in general.

I cannot enter further into the difficult discussion about the nature of health here. Suffice it to say that we frequently use the term 'health' in an evaluative sense. When we talk about the desirable state of a human being we may use the terms 'health' and 'healthy'. Health in this sense plays an important role in health care. It defines the goal of care and the framework within which care should be performed. Therefore we can say that health is the basic value in health care.

To summarise: health is the bodily and mental state of a person, often characterised by the person's well-being and, almost universally, by their ability to realise vital goals.

1.2 Quality of life

1.2.1 Introduction

Questions about the relationships between the concepts of health and quality of life have plagued philosophers and empirical researchers in the field of health care for a long time (Nordenfelt 2006). Although much has already been written to clarify the topic, rather little has happened in the field of applications. Much production of instruments is still going on, as if the discussion had not taken place. There is good reason, then, to pursue the philosophical analysis of the topic and also to remind ourselves of the ethical consequences of assessing the quality of people's lives, not least in a situation where this kind of assessment is being made in different ways in different settings and in different parts of the world. In such situations there is hardly any basis for comparing results, but if such a comparison is made notwithstanding, the results can be disastrous.

We can discern three age-old intellectual traditions within which the idea of the good life has been interpreted in quite different ways (Sandöe 1999). The three competing ideas are *perfectionism*, the idea that a person lives a good life when they realise important human potentials; *hedonism*, the idea that a person lives a good life when they seek out certain pleasant states and avoid painful and unpleasant ones; and finally *preferentialism*, the idea that a person lives a good life when they manage to get what they want. These ideas indicate quite different ways of pursuing the good life, and as a consequence the ways by which we can judge the quality of a person's life must be quite different.

But an important question, of course, is why we are investigating the nature of the good life. Perhaps the context can help us in assessing this. As Georg Henrik von Wright pointed out in a classic work (1963), there is a great variety of goodness. The goodness of a good person is different from the goodness of a heart or the goodness of a knife. And a person can be good in several ways: good manners, a good intellect or good sporting ability, for example. It is obvious that there is a multiplicity of dimensions of goodness. But is it reasonable to believe that we can be asking questions about all these dimensions in the discussion about quality of life?

A primary observation is that we must concentrate on a dimension pertaining to human beings. The people who request assessments of quality of life, for instance politicians and researchers in medicine and the social sciences, are asking for the quality of the life of a *human being*. Moreover, the quality should concern the human being as a whole. Still, when we focus on medicine and social affairs the quality of life does not include all aspects of a person (see Nordenfelt 1994). The questions asked within these discourses do not, for instance, concern the moral value of the person in question, nor do they concern aesthetic or intellectual values. It is salient that the concern is rather about what could, at least vaguely, be called the *welfare* of the person. Central in these discourses are questions about how life (in the form of external and internal events) is treating the person. Questions about how the person lives their life, in the sense of how they plan and make choices in life, are less central. Questions like these would of course be particularly pertinent if the discourse concerned moral or intellectual aspects of life.

When one narrows the scope somewhat in this way, it seems that perfectionism is not such a plausible candidate for interpreting the modern notion of quality of life. The traditional, classic version of perfectionism (Aristotle 1934) is indeed an all-encompassing idea about the good life but it has a very strong moral foundation. Moreover, its basic tenet is that *eudaimonia*, the perfect life, consists mainly in the person's virtuous activity.

But even if we focus on welfare we are left with a broad concept, and we can still disagree about what welfare ultimately is. We can wonder whether it has to do primarily with the possession of certain objective properties such as money, a job, freedom from political oppression or freedom from disease, or with an individual's judgement of their situation, or with the presence of certain pleasant mental states in the individual.

Observe that the answer to the conceptual question concerns whether welfare *consists in* certain objective factors, or in such factors as are positively judged by the subject, or in certain pleasant mental states of the subject. Taking a definite stand on this issue does not prevent us from observing the variety of empirical connections between these three

ontological categories. One obvious connection is that certain external states of affairs, such as money and a good job, are normally preferred by the subject and normally contribute causally to their pleasure. In such cases there is a congruence in practice between the main theories. A judgement about the presence of high quality of life would be similar from whichever platform we were to judge. But, of course, this need not always be the case.

Much of the present discussion on quality of life in the fields of medicine and social policy focuses on choices between these three theoretical platforms. There seems, however, to be a reasonable consensus that we should not ask for a purely objective measure. We should reconsider the motivation for the introduction of the 'quality of life' concept. The concept was introduced, in medicine, as a supplement to ordinary medical 'objective' judgements of people's health. Doctors and researchers explicitly wanted to know whether the functional improvement of a heart or a lung had really improved the life of the individual. The objective anatomical and functional measure had always been there, but now there was a need for information that went beyond this basic biological knowledge. This new knowledge might still contain certain objective features, but then on the molar level of the person. It might concern abilities such as the ability to walk or use one's hands, but it must also include certain mental features of the person such as preferences, attitudes and emotions.

This argument implies that the shift within medicine to considering the quality of a person's life (from roughly a welfare point of view) means a step away from a biological objectivistic position. Similarly, the concept of 'quality of life' was introduced into social policy as a supplement to the welfare studies in terms of standard of living that had previously been prevalent. A good example of this type of study is the Swedish Annual Surveys of Living Conditions, where facts concerning work, income, housing, education and social mobility are characterised with the help of statistical data (*Living Conditions and Inequality 1975–1995*, Report 91, Statistics Sweden).

One could then ask: What are the reasons for preferring one sense of quality of life to the other? What should our criterion for choice be? Should we make an ordinary-language analysis of the general concept of welfare and examine our intuitions about this concept? Or should we analyse the medical and social contexts in great detail and see what kind of measure is actually being asked for? This method is sometimes preferred (see Birnbacher 1999). For a long time researchers in the field of medicine and social policy used traditional medical and social indicators for measuring people's health and welfare. Now they want to know *how people themselves assess their lives*. Birnbacher asserts, for instance, that there is really a call for an assessment of the subject's own assessment of their state of health or welfare.

If this is in fact the case, the question has been simplified and the theoretical problems have been considerably diminished. In the case where the term 'quality of life' indeed *means*, and should be interpreted as, the subject's assessment of their own situation, then the basic conceptual problem has come much closer to its solution. However, significant problems remain, and they are not just technical. Let me just mention two major problem areas here. The first concerns whether individuals are to be asked to assess their situation in the sense of describing the situation in as neutral a way as possible, or whether they are to evaluate it in normative terms. To put it concretely: is the individual to say, 'I cannot move around as much as I could before', or, 'My present

disability makes my life miserable'. It is clear that the same 'objective' disability can mean quite different things to different people. The second major question concerns the question of whether quality of life measures should be partial or total. Should individuals assess their total state of health or total welfare situation, or just certain relevant parts? Can the parts be isolated? Is it reasonable to try to isolate them?

I would argue strongly for adopting a subjectivist and preferentialist interpretation of quality of life, since a subjectively evaluated quality of life is a universal value. Moreover, I would say that a subjectivist concept is largely independent of changing social and cultural values. A further pragmatic reason is that a subjectivist approach is preferable because test *instruments* must ultimately be based on the subject's evaluations. This means, moreover, that these instruments must be individualised to a much greater extent than they normally are now.

An interesting ethical argument for adopting a subjectivist concept of quality of life is also possible. It is clear that the subjectivist approach has anti-paternalistic potential. It is much more in line with respecting the patient as a person to ask how they regard a particular treatment, or how they assess their state of well-being. Indeed, it is difficult to involve patients in decisions about treatment, as the principle of autonomy requires, unless they can first assess their condition.

There is an important set of arguments, then, for adopting a subjectivist and preferentialist notion of quality of life in the contexts of medicine and social policy. Some theoreticians in the field have indeed adopted this notion and have consequently constructed measuring instruments based exclusively on it (see, for instance, 'The General Well-Being Schedule' and 'The Quality of Life Index', McDowell & Newell 1987, pp. 125–133 and 209–213).

It is salient, however, that most instruments, in particular those used for measurement in health care, are much less clear in their conceptual underpinning. They normally contain a substantial element of subjective assessment (in either the hedonistic or the preferential sense). But in addition there are normally elements of an objective kind, for instance in terms of objective symptoms or disabilities (e.g. the modern instrument EuroQuol, Williams 1995). The latter statement can perhaps be countered by noting that it is normally individuals who are asked to make 'objective' assessments about their own symptoms or abilities. On the other hand, these individuals are not normally then asked to evaluate the impact of such a symptom or disability. One may wonder what the constructors of such instruments think they are doing. Do they believe that it is not necessary to be clear about the basic concept? Or do they think that there is a merit in mixing concepts in one and the same instrument?

For my present purposes I will adopt a subjectivist notion of quality of life which I call *happiness with life.*

1.2.2 The concept of happiness

My basic intuition concerning happiness is the following:

> Sara is happy with her life as a whole if, and only if, Sara wants her life-conditions to be exactly as she finds them to be.

A way of expressing this intuition is to say that there is an equilibrium between Sara's wants and reality as she finds it. I call this notion *happiness as equilibrium*. It follows from

this characterisation that happiness must be a dimensional concept. Sara is more or less happy with life according to the degree of agreement between the state of the world as she sees it and her wants. Moreover, she can be completely happy with life only if her life-conditions are exactly as she wants them to be. Similarly, she is completely unhappy with life only if nothing in her life is as she wants it to be. There is, then, a continuum from complete happiness to complete unhappiness. This continuum must be distinguished from any particular state of happiness.

The opposition between happiness and unhappiness is of a contradictory kind. This means that the continuum can be divided into two mutually exclusive parts: one part of happiness and another part of unhappiness. Later I shall try to characterise the point at which happiness and unhappiness meet. I shall suggest a notion of minimal happiness based on the concept of a high-priority want.

To the global notion of happiness with life corresponds a molecular notion of happiness with a particular fact. Sara can, for instance, be happy with the fact that she has passed an exam. She is happy because she wanted to pass this exam. In general, Sara is happy with every fact that constitutes the satisfaction of a want of hers. In a way global happiness with life constitutes the sum of molecular happiness with particular facts. The sum, however, cannot be derived in a simple arithmetical way.

Our general happiness or unhappiness concerning life is dependent, not so much on the number of things that we are happy about, but on what kinds of things we are happy about, in particular on what we consider to be important in life. To most of us it is more important to become a parent than to have a nice day out in the countryside. A father's happiness about his newborn baby influences his general happiness much more than his happiness about the beautiful weather. I shall return to this in a more systematic way later on.

1.2.3 The reference of happiness to different points in time

I said that Sara is happy now if the state of the world is as she wishes it to be. This reference to the present is important and requires further comment. It is plausible to think in the following way: if happiness is connected with the fact that wants have been satisfied, then happiness ought to be connected with the past. That person is happy, one might think, whose wants in the past, including the most recent past, have been realised. I can easily show that this idea is not sufficient to explain the nature of happiness. Consider the following case:

> A small boy has wanted for a long time to have an electric train. He has wanted this intensely and told his parents about his desire. He is given this toy train as a Christmas present. He certainly becomes very happy. However, after a short while he becomes terribly bored. He finds that there is in fact very little that he can do with the toy. His happiness has very quickly been transformed into boredom.

What has happened, if we wish to describe this situation in more abstract terms? It is true that the boy has had a want from the past satisfied. However, this want no longer exists. At the present moment there is no want for the train; therefore the presence of the train cannot satisfy a want on the part of the boy; therefore it cannot contribute to his happiness.

The important and indeed well-known lesson to be learnt from this example is that the satisfaction of wants can be followed by emotions such as disappointment, boredom and regret. Therefore the wants whose satisfaction should constitute happiness must refer to the present. The reference to the present solves a further problem that is often mentioned in dissertations about happiness. A person can say, 'I am happy about the gift that I have received, but I had never expected to receive it and I had never wanted it.' It can very well happen that something new occurs in one's life and one may not even have known of its existence; therefore one cannot have wanted it in the past. But when it occurs, one may quite strongly want to hold on to it – one likes it, as we say. Thus its existence at the present time contributes to one's happiness.

But what about wants which are directed towards the distant future? Do they have anything to do with one's happiness? Consider a young man who is planning his life. He intends to marry in ten years, he plans to complete an education that takes at least five years, and after that he wishes to enter upon a long career as, say, a lawyer. In short, he has many wants referring to the very distant future. By definition, these wants cannot be satisfied now. If they could, they would not be wants directed towards the future. But what does that mean for the happiness of the young man? Is he extremely unhappy? A moment's reflection shows that this would be an absurd conclusion.

Again, this case shows that happiness is dependent on those wants that refer to the present. And indeed, wants that are directed towards the future sometimes have important implications for the present. In order to take one's law degree in five years' time it may be necessary to begin the relevant education right away. Therefore this future-directed want implies a present-directed want and if this present-directed want is not satisfied now, then the person has reason to be unhappy.

1.2.4 The dependence of happiness on belief and knowledge

In order to be able to want something, one must be a minimally intellectual creature. One cannot want to have a car unless one can imagine a car. One cannot want to take an exam if one does not know anything about exams and their relevance for certain professional careers.

This truth has immediate consequences for the concept of happiness that I am attempting to establish. I cannot be happy about a gift unless, at least, I believe that I have received this gift. The sources of this belief, however, can be of various kinds and various validities. Most importantly, they can be either true or false.

If John is happy about an event, then John believes (or knows) that this event has occurred and that this constitutes the satisfaction of a want of his. But as I said before, this belief need not agree with reality; what it agrees with is John's perception and awareness of reality.

John may have good reasons for his beliefs. He may have observed the occurrence of the event in question, or he may have perfectly trustworthy informants. In such a case we could say that John's happiness is rationally founded. Some authors require such a rational foundation in order for the happiness to be a real human good or to be considered to constitute a high degree of quality of life. The Swedish philosopher Bengt Brülde (1998, 2007) argues strongly for the requirement of rationality. It proves, however, to be quite difficult to spell out exactly what this requirement involves. See Egonsson (2006) for a thorough analysis of this problem.

The concept of happiness to be established is thus cognitive. This leads us to a reflection on other positive, non-cognitive, states of mind. What is the relation of each to happiness?

1.2.5 On happiness and pleasure

What is the relation between pleasure and happiness? Let me try to answer this question by considering what can be a reason for wanting something. Why do we want to have something – why, in general, do we want something to be the case? We can give many answers to such 'why' questions, and they can be different for different people. But there is a typical answer to such questions: I want *x* because *x* gives me immediate pleasure. This is a way of terminating the series of 'why' questions. There is no point in asking further questions.

There is a famous theory called *psychological hedonism* which states something as strong as the following: all our wants refer ultimately to a state of pleasure of some kind. The pleasure need not be the immediate reason; the chain often has more than one link. It can have the following structure:

I want to have a car at hand to be able to get to the theatre.
I want to get to the theatre to see an interesting play.
I want to see this play for the sake of intellectual pleasure.

This hierarchy of wants that terminates with the want for pleasure is indeed typical. I do not, however, as the psychological hedonists do, consider it to be the only kind of hierarchy that there is.

Pleasures are states of mind that are typically wanted for their own sake. This does not, however, mean that pleasure is identical with happiness, nor that a person who experiences strong pleasure is automatically happy. A person is of course normally happy about pleasure, or about the absence of pain, but there are cases where this need not be so. Consider the case where the pleasure is a sign that something dangerous is going on – the pleasure involved in taking a drug, for instance. The addict may be conscious of the fact that after a while the pleasure will be gone and the future suffering will be great. Hence, although at a particular moment the addict may experience intense pleasure, they may at the same time be deeply unhappy.

Conversely, pain and suffering are states of mind that are typically unwanted. Normally, a person in great pain is unhappy about their state of mind. But again this need not be so. The pain or suffering may be a sign that something positive is coming. For example, a surgical operation may be quite painful. However, if the patient believes that the operation is an effective measure and that they will soon be healthy, then the pain is easily endurable and can coexist with great happiness.

1.2.6 On different degrees of happiness

I have said that happiness can be viewed as a dimension. A person can be more or less happy. But how should we understand this dimension? And what determines a person's degree of happiness?

Since happiness is conceptually connected to the agreement or disagreement between a person's wants and reality as they find it, it is tempting to relate happiness to the

number of wants that have been realised. Suppose that John has 100 wants and that 90 of them have materialised. Suppose, on the other hand, that Sara has as many wants but that only 10 of them are realised. According to a simple arithmetical calculation, John's happiness ought to be 9/10 of the possible total happiness, whereas Sara only reaches 1/10 of total happiness. Hence John must be much happier than Sara.

A moment's reflection shows that this reasoning must be a caricature, for a number of reasons. One important reason has to do with the idea of a want-unit. What is *one* want as opposed to a number of wants? Is my want now to scratch my nose to be compared to my want to protect my family from harm? And what about a hierarchy of wants? Consider the case of going to the theatre presented above. Are we talking there about three wants or just about one basic want?

I have said enough to introduce some major problems, but I shall not go deeper into them now. It is not necessary for my main reasoning, which will completely avoid the counting of wants. Instead, I shall introduce the idea that there are wants of higher and lower *priority*. It is the degree of priority that determines whether or not great happiness will result from the satisfaction of a want.

Some of our wants are of vital importance to us. To most of us it is very important that our family should be well and successful. Our own health is also of great importance. So is the fact that our professional situation is all right, and perhaps also that the political situation is tolerable. The fact that these conditions hold has considerably higher priority than most other things we wish to do or have at a particular moment.

Thus there must be a scale of priority or importance along which we can rank our wants. This ranking is practically never explicit, nor is it particularly clear when we try to visualise it. Certainly there is no 'naturally' given cardinal order for these wants. We cannot say that it is five times more important that our children are alive than that our own health is in order. But what, then, can we say about this scale of priority that certainly exists in every human being? First, how can we know that a certain want of Sara's has a higher priority than another, or what the criterion for this is? I suggest the following characterisation:

> Sara's want to have x has a higher priority for her than Sara's want to have y if, and only if, in a choice between x and y, where both cannot be realised, Sara would prefer x.

With this formulation I can keep the connection to my basic analysis of the concept of happiness. I said that Sara is happy about life if, and only if, Sara wants the conditions of life to be exactly as she finds them to be. We can now say that Sara is happier about a situation x than about another situation y and explain it by simply saying that Sara prefers x to y.

Given this explication, we seem to have an intrapersonal instrument for comparison. We can understand how to analyse and also in principle how to get to know that an individual is happier now than they were before. But do we now have an instrument for a comparison between different people? How shall we explicate the idea that Smith is happier than Brown, or for that matter that Smith and Brown are equally happy? The analysis given above will allow us to do this only under very specific circumstances. Assume that Smith and Brown have exactly the same profile of wants. That is, they have exactly the same wants and their priorities among the wants are identical. Thus

we know that, if Smith prefers x, Brown must also do so (given that x and y are total situations). Assume now that Smith is in a situation x and Brown is in y. Then it follows that Smith is happier than Brown.

A pragmatic method for interpersonal comparison of happiness would then be to describe their respective life situations to the people involved. To make it as simple as possible: we compare the happiness of two people, John and Sara. We describe John's situation meticulously to Sara, and vice versa. It appears that John prefers his own situation to Sara's and that Sara prefers John's situation to her own. Then we have reason to say that John is happier than Sara.

Having described this procedure for interpersonal comparison, I must point out two great difficulties in practice. 'Preference' in this context is an ideal concept. We must be talking about an ideal situation of choice, where the individual has complete self-knowledge and can foresee such things as risk of disappointment or boredom. It is certainly true that people normally lack this self-knowledge in actual situations of choice. It is also important to stress that one has to compare people's total situations in order to be sure that the result mirrors their states of happiness. Smith who is in situation x need not be happier than Brown who is in y (even if both of them prefer x to y) if x and y do not cover total life situations. If x and y only affect some part of their lives, for instance professional life and state of health, then it is always possible that something unhappy has occurred to Smith in some other sphere of his life. He may have lost some close relative, which has caused him deep grief.

In general it is easy to go wrong when one dreams about another person's life situation and prefers it to one's own. It was easy to prefer the life of Aristotle Onassis to one's own. But one must remember that his life-situation consisted not only of his money and his yachts but also his poor health and his love problems.

How, then, should we treat all those cases where people's goal profiles differ and where a comparison between the life situations of two people does not result in both agreeing on which situation to prefer? Can we then ever say that one person is happier than another?

My general conclusion is that there are many cases where the happiness of one person and that of another are incommensurable. In these cases – for theoretical as well as practical reasons – we simply cannot say that one person is happier than the other. There is one important exception to this, however. This is the case where John finds his situation unacceptable, while Sara finds hers acceptable. In this case Sara is clearly happier than John. And we can say this even if Sara were to prefer John's situation to her own, and John were to prefer his to Sara's.

The notion of *acceptability* indicates where the line is between happiness and unhappiness on the happiness scale. For every human being there is a level that marks the transition from happiness to unhappiness. Below this level the situation is so far from satisfactory that it is not acceptable to the individual. They are unhappy. Just above this level the situation is acceptable; they are minimally happy.

We can make a preliminary characterisation of this line in the following way: in order for John to be at least minimally happy, then all those conditions that have a high priority for John, in an absolute sense of the word, must have materialised.

Where this line goes in any concrete sense must vary greatly between different people. People have different temperaments and character traits. Impatient or spoilt

people become unhappy for the most trivial reasons. For such people almost every want has a high priority. Patient or stoic people, on the other hand, can meet most adversities without falling below the 'acceptable' level. To such people very few things in life have a high priority.

This observation about the dependence of happiness on how we set our priorities contains a key to happiness which I have hitherto not recognised. To influence a person's happiness means not only to try to realise states of affairs in their external or internal situation. It equally entails influencing their profile of wants. The person who has a low profile, the person with the smallest number of high-priority wants, has, in one sense, the greatest chance of becoming happy.

1.2.7 On the relation between health and quality of life

I suggest here an interpretation of quality of life such that there is a clear distinction between health and quality of life. In fact, it is only if we can find a substantial difference between them that we need both concepts.

It is easy to see that health and quality of life are different when we consider that quality of life may involve matters external to the individual. A person is said to have a high quality of life if they possess great wealth or have good opportunities to travel and have a great variety of experiences. Health does not have to do with such external facts.

In another usage of the term, which I think is the basic one, quality of life refers to a person's degree of happiness. An extremely happy person has a high quality of life; an unhappy person has a low quality of life. We can distinguish health from quality of life in this usage too. A healthy person need not be happy. Consider the healthy man who has just lost one of his children. This man is extremely unhappy as a result, but his health may very well remain intact. Conversely, consider an old woman who is dying and does not have many more days to live. She may be dying in a peaceful way; she may have her family with her all the time and may be pleased with the fact that she has lived a long and successful life. She may be very ill, but at the same time quite happy.

Thus health is different from quality of life, but the two are related. It is significant that health *normally* contributes to a high quality of life and that ill health *normally* contributes to a low quality of life. The value of health is therefore connected to the value of quality of life.

We can say that quality of life is a value that lies beyond health. In health care, for instance, we may contribute to a person's quality of life *by* enhancing their health. This is a typical way of improving quality of life, but it is not the only way. Quality of life can be enhanced more directly. A dying person may be in great pain, and such pain can be suppressed by pain-killing drugs. As a result the quality of life of the person, but hardly their health, will be enhanced. Many acts of care, however, do not directly involve the physical treatment of a body. They may be acts of charity and kindness, or acts of encouragement and consolation. Such acts can moderate a patient's unhappiness and increase their level of happiness.

Therefore quality of life, in the sense of happiness, can also be a direct goal of health care. (See also in this context the Final Report of the Swedish Parliamentary Priorities Commission: *Priorities in Health Care: Ethics, Economy, Implementation*, Government

Official Reports 1995:5, where quality of life is given the status of a goal of medicine alongside the traditional goal of health.) This does not mean that all kinds of enhancement of happiness are proper parts of health care. Intervention in a person's financial situation falls outside its remit; so does intervention in their love life.

Quality of life in the happiness sense seems to be closely related to the satisfaction of the person's deepest wants. To put it simply: a person is happy with life when their deepest wants are satisfied or there is a good prospect that they will be satisfied.

1.3 Autonomy

1.3.1 Introduction

Autonomy derives from two Greek words, *auto* meaning self and *nomos* meaning rule or law. Literally, then, autonomy has to do with setting rules for oneself. This literal sense is also the basic one adopted by the philosopher Immanuel Kant (1724–1804); see Kant (1997). To him, the autonomy of the human being is one of the most characteristic properties of humanity. Human beings, in contradistinction to animals, have autonomy, entailing the power to set rules for themselves. They create their own ethics and legal systems. 'Autonomy indicates the ability of the human being to be a self-legislative rational being, having the capacity to recognise the universal validity of moral law without being determined by outer heteronomous conditions for action' (Rendtorff & Kemp 2000, p. 26).

In modern medical ethics a much wider concept of autonomy has emerged. Autonomy in this sense concerns individuals' general ability to handle their own affairs, in particular their ability and opportunity to decide for themselves. Thus autonomy has become a general concept of power, freedom and independence. 'For many people today, moral autonomy is a question of free moral choice according to a set of values that the individual finds right and just. And to be morally autonomous is related to sincere choice and personal decision-making' (Rendtorff & Kemp 2000, p. 27).

Some recent studies in medical ethics have emphasised that the moral choice need not be individual. In many instances, both in health care and in ordinary life, decision-making is shared between two or more people. Zeiler (2005) gives a detailed analysis of the case where a couple together make the crucial decision of having pre-implantation genetic screening and possibly having a fertilised egg implanted in the woman's uterus. Here Zeiler emphasises that the decision is shared and the question of whether such a choice is autonomous or not concerns the couple as a unit and not the individuals separately. The issue of couplehood is also raised in the context of the Home project. Hellström (2005) describes how a couple where one of the spouses is demented share much of the decision-making and act together. For details of this study, see Chapter 5 of this book.

We commonly say that we have a duty to respect a person's autonomy. (For the sake of simplicity, in the following I will stay with the case of individual decision and action.) This is shorthand for saying that we must respect a person's *right* to autonomy. What we mean then is that we must respect every individual's right to decide for themself. This is central in the setting of medical care and the care of older people. Everyone has in principle the right to decide with regard to their own affairs. Everyone has the right

to choose what to wear, how to spend their days, where to travel, and so on. All patients also have crucial rights with regard to their treatment and care. In particular, they have the right to refuse treatment and care. In principle, no treatment or care can be forced upon anyone. This rule is included in the health-care legislation of many Western countries, although there are, however, justified exceptions to this rule dealing with the care and treatment of babies and of people with dementia or psychosis.

Autonomy, in the sense of ability and opportunity for decision, has gradually become an extremely important value in medicine and care in general. There is perhaps a special emphasis on this value at the present time. Up to the Second World War, medical treatment and care almost totally lacked respect for patient autonomy. We can say that the system of health care in those days was *paternalistic*.

1.3.2 Paternalism and autonomy

Consider now the following slightly paradoxical dictum that can be heard defended in contemporary medical and social ethics (cf. for instance Seedhouse 1991, pp. 113–119):

> It is sometimes right to violate a person's autonomy in order to increase his or her future autonomy.

What does this mean? Is it indeed a paradox? And does the word 'autonomy' mean the same thing both times it is used? To illustrate this, consider the usual situation in schools, where the teachers have quite a paternalistic attitude towards their students. The latter are always being told by their teachers what to do and what to study. In spite of some recent changes, the students have rather little to say about how their education should be planned and carried out. This situation prevails for quite a long period of children's lives. Thus we can say that for rather a long time they have little autonomy. Perhaps we might even say that their autonomy is being violated during this period. On the other hand, this type of paternalistic education is normally defended. Most of us would argue that the intention behind traditional school education is benevolent. Some people would even say that the institution of the school is working for the autonomy of the pupils in the long run. The school is designed to prepare the children to become autonomous adults.

It is easy to construct similar examples from medical ethics. The doctor, or the health-care worker in general, may enforce a certain treatment on a particular patient, and thereby violate the patient's autonomy, but does so in the name of this patient's future autonomy. Without the treatment, the health worker says, the patient will, for instance, not be able to form autonomous decisions in the future.

I think we understand the reasoning here quite well. Especially in our role as parents, we are all too familiar with it. But there are a number of puzzling theoretical issues that need clarification here. Perhaps the most important question is the following: Is the autonomy that we say is being violated the same thing as the autonomy of the future autonomous agent? My main task in the present section is to discuss this problem.

First, we need to make the well-known distinction between autonomy as a theoretical property and autonomy as a normative property. Or, to put it more clearly: we should distinguish between, on the one hand, a person's property and, on the other hand, their right to have this property.

When we violate a pupil's or patient's autonomy, strictly speaking we violate their right to have or execute this autonomy. On the other hand, when we raise the level of a person's autonomy, we do not, at least not in the examples cited, increase this person's right to autonomy but rather we increase the amount to which some theoretical property is instanced in the person.

Of course, we can also conceive of a case of raising or enforcing the right to autonomy, for instance when we campaign politically for patients' rights, or when, as legislators, we actually enforce the rights of certain groups of people. But in our example this is not the case. When we educate or cure people and claim that we thus raise the level of their autonomy, we are not raising the level of their political rights. Instead, we are trying to raise the level of some theoretical property of the people in question.

But what is this property? And are we talking about the same property in the first use of the word as in the second? Do we have the right to autonomy in the same sense as when we say that we wish to see somebody's autonomy increased? These are my principal questions.

Let me analyse this stepwise. Consider first what is being violated in the medical ethics case. Assume that some health-care officials initiate an inoculation programme without consulting any members of the community, or even their political representatives. We then accuse the officials of violating the people's autonomy. What do we mean? In what sense has the autonomy of the members of the community been violated?

The obvious answer is that the health officials have violated the people's right to decide about their own situation. They have prevented them from making an autonomous decision in this particular case of disease prevention. There may even be two elements in this violation of the people's rights. First, there is a lack of information about the planned measures; second, there is an attempt to force the people to comply with these measures.

There are then two rather specific rights that are violated: the right to be informed about a matter of vital concern to oneself and the right to decide concerning this matter. The violation entails that these rights are prevented from being executed in this situation. The violation does not, however, affect the existence of the rights. In fact, in order to be able to talk about a violation of a right we must presuppose the existence of this right.

Let me now turn to an analysis of the theoretical property of autonomy. What is it to be an autonomous agent? The etymological basis is of importance here, as emphasised by Dworkin (1976) among others. 'Autonomy' means self-government. The autonomous person can govern their own life. This can have a number of implications, of which the most important seem to be that the autonomous person makes their own decisions, not forced by any other person. Moreover, the autonomous person acts according to these decisions. No other person prevents them from executing the decisions. This is a minimal definition of autonomy as freedom to decide and act.

So far I have only discussed freedom in so-called interactional terms, i.e. in terms of freedom from human intervention. The concept can, however, be generalised to cover freedom from all kinds of intervention. The autonomous person is then not forced by any external force whatsoever, be it human or non-human. Examples of non-human forces are acts performed by other living beings, such as apes or dogs, and by natural forces such as hurricanes and earthquakes.

Now we have a slightly broader notion of autonomy as freedom from external intervention in deciding and acting. It is likely that autonomy as a right is normally seen to be connected to this sense. This right would reasonably exclude most instances of human interaction of the coercive kind. It is doubtful, however, whether it should also cover most non-human interaction. I think that the right extends only to such non-human interference as could reasonably be prevented by human measures. Certain natural catastrophes would presumably fall outside the framework.

A full philosophical analysis of this kind of freedom requires more. Dworkin, who has contributed much to this analysis, notes that freedom from interference must not entail that one could not be influenced by other agents. The autonomy that we wish to establish in the context of rights must be compatible with receiving information and even recommendations from other agents. The important feature is that we, as agents, should be able to evaluate the information and recommendations in the light of our basic values.

Freedom from external interference, however, need not be the whole story. In order to be an autonomous agent in the full-blown sense of the word one must not be disturbed by internal interference either. By this I mean interference from intoxication by alcohol or drugs, or indeed the abstinence from such substances. A person who is in a state of abstinence and craves more drugs does not, we would say, have the free will to act. The agent in such a case does not have the opportunity for free deliberation. The urge for the drugs and thereby for a continuation of the self-destructive life is too strong.

But from here it is not a big step to the kind of internal interference that is constituted by mental illness. Someone with severe schizophrenia may be unable to reflect upon their situation and weigh alternatives in the light of their deepest values. Mental illness can disable a person with regard to decision-making capacity as well as capacity for action. But mental illness is only the most radical compromiser of autonomy: it is a typical feature of all kinds of diseases that they compromise ability in some way. When one is ill, one is typically unable to do what one wants to do. In fact, one is prevented from realising one's intentions. One's freedom to act is gone. Hence one's autonomy in this extended sense is compromised.

1.3.3 Two notions of autonomy

At this stage of the argument we are not far from identifying the notion of autonomy with the notion of power to act or indeed with the notion of health (in the holistic sense of the word) that some theorists today propose. According to one such notion, which I endorse and have presented more fully above, a person is in complete health if, and only if, given standard or otherwise accepted circumstances, they can realise all their vital goals.

This extended interpretation of autonomy is not far-fetched. David Seedhouse (1988, pp. 132–133) uses the expression 'creating autonomy'. Here he identifies the work for health with the creation of autonomy. The discussion is elaborated in Seedhouse (1991).

But now the central questions of this discussion need to be raised again. The first question relates directly to my initial statement that it is sometimes right to violate a person's autonomy in order to raise the level of their future autonomy. I asked: Do we mean the same by 'autonomy' in the two uses of the word here? The second question is: If we do not mean the same, would it make sense to make a similar claim with an identical meaning in the two uses of 'autonomy'?

As I said, I think that it is relatively easy to identify the ordinary meaning of 'respecting a person's right to autonomy' in the context of medical ethics. The sense normally is: respect this person's right to decide about the measures which are being proposed in order to contribute to their health.

What can we mean, then, when we say that we create autonomy? This is much less clear unless we make some stipulations. One way of interpreting the term is to confine its use to the area of decision-making. In the school situation we may, for instance, justify our paternalism by saying that our education system makes the children much better equipped in the future to make decisions independently of other people. Another, rather extreme, interpretation would encompass the agent's general ability to perform actions. This is the sense partly referred to by Seedhouse in the work cited above. 'The idea of autonomy makes full sense only when it is thought of in terms of being able to do in the widest sense' (Seedhouse 1991). Creating autonomy, according to this interpretation, is partly tantamount to raising the level of a person's general health in a holistic sense of the word 'health' (see my analysis of health above). Observe, however, that autonomy here entails more. Autonomy does not only entail the person's internal *ability* to act, it also entails the person's *opportunity* to act.

An obvious conclusion to be drawn from this analysis is that there must be a difference between the two uses of the word 'autonomy'. Even if the creation of autonomy refers only to the person's ability to make independent decisions, there could be a difference. To respect autonomy in a particular case may concern something very limited, i.e. a right to decide on a particular matter. The creation of autonomy, on the other hand, concerns a *general* ability to make certain kinds of decisions.

A further observation is that when we respect a person's right to decide on a particular matter, we primarily see to it that we ourselves, as external agents, do not prevent the person from forming a decision of their own. Contributing to the creation of a person's autonomy, on the other hand, normally only deals with the strengthening of the person's internal ability to form decisions. The creation of autonomy can hardly include possible future interference in the decision-making on the part of external agents. We can hardly, by any measures that we take today, prevent the appearance of paternalistic officials or doctors in the future. Thus in a sense there is no such thing as creating complete autonomy for the future.

Initially, I also asked the following question. Would it make sense to say: respect a person's right to autonomy in the full-blown sense of autonomy? To elaborate, could we sensibly say: respect a person's right to have the power to work, love and play? And what does it entail? Does such respect, for instance, entail active help and active support from us in the execution of such a power? I merely raise these questions here: a detailed answer would require space that goes beyond the scope of this chapter.

Let me now summarise. A person's 'right to autonomy' in the standard context of medical ethics refers to a person's right to make decisions of their own without being forced by some external agent or some non-human circumstance that could reasonably be prevented by external agents, concerning a health-care or health-promotive measure. It is easy to apply this principle *mutatis mutandis* to the care of older people.

The idea of creating autonomy, on the other hand, which is now being introduced in medical philosophy, refers to the creation of a general ability (and the corresponding opportunity) on the part of the subject, an ability which includes the ability to make

Table 1.1 The various senses of autonomy

Autonomy as a theoretical property	Autonomy as a right
Ability and opportunity to make an informed decision	The right to make an informed decision
General ability and freedom to execute this general ability	The right to execute and develop a general ability in a permissive and supportive environment

independent decisions but which may also include the ability to work, play and love.

The various senses of autonomy analysed in this section can be summarised as a matrix (Table 1.1).

1.4 Integrity

Let me also briefly introduce a further value, integrity, which has a prominent place in health care and the care of older people. This value is closely related to autonomy and can be analysed as a special case of autonomy. The word *integrity* is derived from the Latin *integer*, which means 'whole' or 'undamaged'. To violate the integrity of a person is to violate the wholeness of this person, i.e. it entails hurting them.

There is a value, then, attached to the person's wholeness or identity (a concept that I will return to). This identity can be violated in many ways, some of which have been discussed with regard to health care. The most obvious infringement is the physical one, for instance when the person is intentionally assaulted and hurt. But there are many other possibilities. A person can be debased by improper treatment, for instance by being left naked in front of strangers or being verbally insulted.

Moreover, the person's private arena can be intruded upon. We think that everybody has a right to privacy and that it is an infringement to enter the private arena without permission. This right is particularly obvious when we are talking about the person's property. We cannot enter a person's home without permission and we cannot just seize any of their belongings. But this is not the whole story. Privacy is also a more general concept. We think that everybody has a right to some privacy even in a hospital or a residential home. Although patients may only be allotted a very limited physical space, such as a bed and a bedside table, which they do not own in a legal sense, they can claim a moral right to this space. Any intrusion into this space is a violation unless the patient gives consent or in an emergency situation.

There is a further aspect of integrity that is of particular importance in health care and the care of older people. Much information about people belongs to their private sphere. Doctors and nurses get to know a lot about their patients, including intimate information. This information does not deal only with the physical and mental condition of the patient: it may also concern social circumstances, such as family relationships and the work situation. This is information that people often wish to keep confidential, and revealing it is a serious infringement of their integrity. It is significant that the rule

about confidentiality is one of the oldest in the history of medical ethics: it already exists in the ancient Hippocratic oath dating perhaps from the fourth century BC.

The concept of integrity can be widened further to include the individual's life story and life context. Respect for integrity can thus be understood as 'respect for the unity of a life story, a life-context and a life-totality by which we recognise the identity of the other' (Rendtorff & Kemp 2000, p. 39) (see my discussion of dignity of identity, Chapter 2, section 2.2).

1.5 Final remarks on the basic values

How are the values discussed here related to each other? I have already noted the salient relation between health and happiness. Health is causally contributory to a high degree of happiness, but it is neither a necessary nor a sufficient cause of a high degree of happiness. Are there any similar connections between integrity and autonomy on the one hand and quality of life on the other? There are relationships, but they are partly different from the case of health. With integrity and autonomy the most obvious relationship is that somebody respects the integrity and autonomy of the subject in question and the subject's quality of life is enhanced as a result of the respect shown. In the case of autonomy understood as capacity and freedom almost on a par with health, there is a further relationship to note. The person who feels that they are capable and free may be content with the situation and thus have an enhanced quality of life. For a confirmation of such relationships, consider some of the empirical results in Chapter 9.

The relation between integrity and autonomy is salient. Respecting a person's integrity can be looked upon as a special case of respecting autonomy. To respect a person's integrity is at least partially to respect that person's right to decide about their private affairs, including their private space.

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