



Equity

and human dignity in health care in Finland

Summary

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The main theme of the National Advisory Board on Health Care Ethics (ETENE) in 2000 was human dignity and equity in Finnish health care. On August 17, the Board held a seminar on topics connected with this basic theme. The presentations and discussions at the seminar, a summary of the seminar as a whole and a review of topics discussed at other meetings of ETENE are presented here to stimulate debate and provide a basis for discussion both for those working in health care and for the users of health care services, and also to serve as a bridge builder between different groups.

Key words: ethics, human rights, health care, human dignity, equality, rights, priority setting

FOREWORD

Our age is awash with topics that bounce momentarily to the surface, creating a brief ferment and perhaps even rather strongly expressed opinions, only to sink again and make way for the next topic to emerge. Debate jumps from issue to issue. Different forums have a different focus of interest. What shocks one person may to someone else be a normal part of everyday life. But there is also a need for discussion in which the participants take the time and effort to get to know their topic and seek genuine dialogue between the different parties and views expressed. Society studies and comments on itself through the flow of public debate.

Health care is a subject of relevance to all. It is a topic on which people have a wealth of experience and a variety of views. Public discussion of health care issues would seem rather to be increasing than decreasing. This is important, as health care uses up considerable public resources, while the issues of health and sickness are of fundamental importance to everyone's quality of life.

In 1998, the Finnish Government appointed the National Advisory Board on Health Care Ethics (ETENE). A broadly based body comprising representatives from a large range of different sectors and areas of experience, ETENE is charged with examining issues of health care ethics in Finnish society. The issues on its agenda vary across an enormous range of topics. The aim, however, is to examine them all from the perspective of a fairly general framework of values.

During 2000, the National Advisory Board on Health Care Ethics examined ethical issues in Fin-

nish health care, placing special stress on the issues of equity and human dignity. It held a internal seminar on this theme on August 17, 2000. A document was produced from the seminar to provide a basis for public debate on ethical issues of principle. The document invites contributions to the debate from all concerned parties: patients, health care professionals, decision-makers, the media and the general public.

The Board has also gathered together a number of concrete themes and perspectives relating to equity and human dignity in the health care sector which have played a key role in its own discussions during the first two years of its work.

Human dignity and equity are by no means straightforward concepts, and can be appealed to in conflicting ways. However, deliberately highlighting them reminds us that health care is in the final analysis all about the lives of individual people and how to take care of the common good and the equality of our citizens.

In view of the importance of these considerations, ETENE has decided to publish the documents from the above-mentioned seminar in order to facilitate broader debate. They do not contain many unambiguous statements; the focus is rather on presenting perspectives and framing questions that the Board wishes to raise and stress in public debate.

ETENE warmly welcomes all comments and ideas, either on these documents or in general on topics relating to health care ethics.

Mäntyharju, December 18, 2000

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Chairman of ETENE

Table of Contents

Summary	2
Foreword	3
Equity and Human Dignity in Health Care in Finland	5
The ethical debate	6
National Advisory Board on Health Care Ethics	6
Realism and idealism	7
Human dignity	7
Equity	9
Urgency and prognosis of treatment as ethical criteria	11
The importance of information	12
Limits and sources of health	12
Invitation to join the debate	12
Themes and Perspectives for the Public Debate	14
Equity and equality	14
Resources	14
Vulnerable groups	14
Working life	15
Quality and efficiency of care	15
Wellbeing at work in the health care sector	15
The importance of data collection in health care development	16
Cooperation and volunteers	16
Health care and faith in the future	16
Can We Define and Measure Equity in Health Care?	17
Introduction	17
Why in the headlines?	17
Equity assessment of the funding pool and its ramifications	18
Measuring equity	19
1. Distribution of services	19
2. Funding	19
Can equity assessment provide support for political decision-making?	19
Key Issues in Health Care Ethics	21
Introduction	21
Realism and idealism	21
Why the focus on human dignity and equity?	22
Issues related to human dignity	22
Issues related to equity	23
Autonomy, freedom and abandonment	24
Problems	24
In conclusion	24
Equity in Health Care	26
Underlying principles	26
Equal access to treatment	26
Equality in quality of treatment	27
Equality in individual care decisions	27
Appendix 1: Members of ETENE	29
Appendix 2: How to contact ETENE	30

EQUITY AND HUMAN DIGNITY IN HEALTH CARE IN FINLAND

We are living in the midst of rapid change both globally, nationally and locally. Many of the long-term effects of this process of change are barely, if at all, discernible today. Change always involves both opportunities and risks. For some people, change can easily mean danger and suffering. This is why we must make the effort to ensure that such people or groups of people do not end up suffering unreasonably as a consequence of change. Health care is an area which has to confront many of the problems and suffering caused by social change. The knowledge, values and choices of decision-makers have a major influence on how skilfully and humanely managed the process of change in practice is.

The present process of change is affecting many areas of life — but above all technology and the economy. With time, this will also have far-reaching implications for social policy and social institutions, and for our culture and values. Knowledge is the most important development capital. The generation and communication of knowledge has developed into an enormous system. Rapid production and dissemination of knowledge poses a risk of irrelevant, incomplete or simply erroneous information rapidly reaching an audience which is not necessarily equipped to judge the truth or importance of the information it receives. For many people this is a source of uncertainty. All levels of education should therefore devote greater attention to both the understanding and the critical evaluation of information.

The information society holds enormous potential for economic success and human development, but this will not come automatically, nor will it affect everyone in equal measure. As rapid access to and application of information takes on a key role in society, there is a danger that people who are unable to access or apply this information will become socially excluded.

Health care reflects the general trends within society. Scientific-technological change in particular has a powerful impact on health care, generating both new opportunities and, in many cases, also new costs. The evaluation of new health care procedures is vitally important. Health care is also influenced by changes in population structure, lifestyle and patterns of consumption. For example, the current ageing of the population and the rapid spread of single-person households will raise both expectations and the cost burden on the health care system.

Present-day health care ethics focus on two very different areas whose relationship to each other is essentially like the opposite ends of a U curve. At one end are the rapidly developing and changing applications of medical research and medical technology. This area is the focus of both unrealistic expectations and major commercial interests.

At the other end of the U curve are the various groups of patients with common, chronic and incurable illnesses, or who suffer from a complex web of social and health-related problems. These groups may seem to present difficult care problems, while the measurable results of treatment may be rather modest. This is also true of efforts to reduce the suffering of the terminally ill. In a society that worships competition, performance and peak achievements there is a danger that these types of patient may end up being excluded. But it is not only the patients themselves who are under threat of exclusion. Both their relatives and the health care professionals whose job it is to care for them can also easily end up in an unreasonably difficult and vulnerable position. Entire areas of life could become excluded from mainstream society.

This is therefore an appropriate time to discuss the present and future of Finnish health care, particularly from the angle of equity and human dignity.

The ethical debate

In social development, ethical vigilance manifests as an ongoing debate on values and choices in which each individual compares and reflects on his own experience and thought in juxtaposition to the experience and thought of others. Not without reason has it been observed that the credibility and viability of democratic society depend critically on the conduct of ethical debate both among members of the public and between members of the public and decision-makers. Finland still suffers from a dearth of creative thought on ethics and quality debate on contemporary ethical issues. The time has

come to broaden and deepen the debate.

In present-day society, health care phenomena and issues affect a whole range of different forums and groups. These, in turn, can have very different views on the ethical values that should be attached to different issues. By stimulating debate on ethics, we can bring the different values and experiences referred to above together within a single process. Never before has there been a need for such broad public debate on ethics as there is today. There are two main reasons for this:

1. It is an irrevocable fact that we are now living in a world of multiple truths. This is so both at the level of the global community and at home in our own society. Both ideologically and ethically our thought is longer underpinned by a unitary foundation and way of understanding. We now have to seek common goals and ethical principles from a base of different experiences, traditions and points of view. We have to build a world in which different convictions, sets of values and lifestyles can live safely together in creative dialogue.
2. Rapid technological development is taking place in specialized and fairly autonomous subcultures that are firmly entrenched in their own theoretical and linguistic worlds. It requires a major effort to really understand and form an opinion on, for instance, development trends in biotechnology, and to envisage what the future of this field is likely to be. It is, however, important to do so, as high technology has far-reaching implications — at least indirectly — for large numbers of people.

The practice of ethics involves above all lively, public and uncensored ethical debate in which each individual and group has the right to bring out their own experiences, thoughts and values. It is vital that everyone has the right to ask any question whatsoever and to make critical comments. We need a wealth of real-life stories to illustrate what is actually happening day-by-day on the health care front line. As elsewhere in human life, what is happening is generally both good and bad, because, as people, we live in the intersection between good and evil, under the shadow of perpetual moral conflict.

Democracy is the political system that provides the best framework for effective ethical debate. Someone once said that the human capacity for good makes democracy possible, while the human capacity for evil makes it essential.

A credible health care ethics must begin with the value of the individual human being and the communal nature of life, while using the democratic process to pursue the ideal of equity. An approach such as this is rooted in realities, does not deny ineradicable limitations, and is able to conceive of the human being as a moral subject capable of both good and evil.

National Advisory Board on Health Care Ethics

In autumn 1998, the Finnish Government appointed the National Advisory Board on Health Care Ethics (ETENE), whose work is based on the Act on the Status and Rights of Patients (785/1992) and the Decree on the National Advisory Board on Health

Care Ethics (494/1998) issued thereunder. ETENE's brief is to initiate both within its own ranks and broadly in society a debate on health care ethics focusing on topical issues in contemporary health care. Its membership is therefore drawn from a broad

range of people representing the experiences and perspectives of health care customers, providers and professionals, ethical and legal experts, and political decision-makers. Under the Decree, ETENE must include at least four members of Parliament in its ranks.

The focus of ETENE's work is strongly human-centred. Ethics are important to health care above all in order to ensure delivery of human rights in care provision and quality care in a safe and secure atmosphere. There is a danger that the experiences

and needs of patients are being lost under the weight of management structures, routines and technology. The obvious overburdening of health care staff also presents an ethical risk to patients. The condition of care systems and the treatment of patients serve as a gauge of how humane social policy is at any given time. A welfare society can be recognized by the fact that it harnesses economic success as the motor of social development. This is primarily the responsibility of political decision-makers on all levels from national politics to the smallest units of local government.

Realism and idealism

Ethics as a discipline exists in the tension between realism and idealism. On the one hand, part of its role is to consider ideals — 'the best possible world' — however naive or far-fetched this may seem. The ability to dream is essential to creative change. But, on the other hand, an ethics that fails to take account of prevailing realities and practical limitations will be of little practical use. The main problem with broad declarations and lofty ideas is that they have no practical effect. They merely exist in their own world of ideas.

Our ethics must be realistic. We must be prepared to examine ugly, controversial and unpleasant issues, because evil is the unavoidable complement of good. The concrete rooting of ethics in everyday life, the procurement of valid and rounded information on prevailing conditions, and the charting of practical alternatives are all very important issues. One of the signs of ethical responsibility in everyday life is the ability to minimize evil and to make difficult choices involving unwelcome but tolerable consequences.

In relation to the law, ethics has two main functions. On the one hand, the process of ethical debate and reflection precedes the later crystallization and enactment of legislation. The ethical process thus leads to concrete law. The legitimacy of society

requires that legislation be genuinely based on a living and respected moral reality. But on the other hand, ethical debate can also begin where the law leaves off. Ethical responsibility is not limited to legal responsibility. Every individual and community must generate an ethical understanding and autonomy that does not derive primarily from the hope of reward, fear of punishment or outside control, but from people's own will and commitment.

It is not realistic to expect that health care could survive as some sort of separate enclave abiding by an entirely different system of values from the rest of society. The values of the age — both good and bad — will inevitably permeate health care, if a little more slowly in the public than the private sector. However, this does not mean health care has to be merely a passive observer of what is happening in society. Those involved in the health care arena can join the debate and highlight the experiences and observations the health care sector has of Finnish society and its development. Health care professionals have a wealth of untapped knowledge, understanding and wisdom about life. They are aware in very concrete terms of the human costs of social change. It is in the interests of us all to harness this knowledge for common consideration and use.

Human dignity

Human dignity lies at the heart of all health care, constituting both its foundation and its purpose. Care systems, traditions and philosophies have arisen because individual human beings have been considered so valuable that they cannot just be left to the mercy of their sickness and suffering. We must

never lose track of this basic fact. Even care which skilfully utilizes the best tools of diagnosis and highly complex and advanced methods of treatment is inadequate if the individual person is not recognized, protected and respected. Nothing less is at stake here than the human rights of both patients and health

care staff. Finland's Act on the Status and Rights of Patients takes a clear and internationally progressive stand on behalf of the human dignity and self-determination of the patient.

One shadow hanging over human dignity is the public conception that only independent, productive, economically self-sufficient and ambitious people really matter. The increasing currency of this way of thinking means a growing burden of mental and emotional distress for certain individuals and groups in society. To some extent this distress is a general burden of loneliness arising from a variety of different causes. But to some extent it stems from the experience of failure — in many cases a cumulative series of failures — inability to cope, anxiety and exclusion. It is no wonder that care systems are having to cope with a constant and growing flood of deprivation and mental health problems. Health care workers see the other side of the current obsession with success and performance. Those who cannot 'make it' on these criteria have nowhere else to turn.

In health care, as elsewhere, 'interesting', 'cooperative' and 'readily treatable' patients tend to be given priority. On the other hand, 'awkward', 'hard-to-treat' patients with multiple problems are vulnerable to prejudiced attitudes and face the threat of exclusion.

Respect for human dignity and for the integrity of the individual are key issues. It is sometimes necessary to ask whether a particular treatment respects the human dignity of the patient. This is shown by complaints to the Office of the Parliamentary Ombudsman (?) over mistreatment of the elderly. In closed institutions, involuntary treatment, care of the mentally handicapped and institutional psychiatric care, too, we must give special attention to ensuring that treatment and care do not infringe upon the human dignity of the patients. We must ask whether quality requirements in these areas and the threshold of acceptability for methods of care experienced by patients as threatening have been lowered in comparison with other areas of health care. Is there something in the way institutions are run that patients experience as threatening to their human dignity?

From the point of view of ethics we must be aware of how easily people can be labelled by their moral,

social or mental health problems, or problems relating to their lifestyle. This is often followed by rejection or otherwise harsh or negative treatment. Such people include criminals, antisocial people, those with alcohol or drug-related problems and people with psychological problems. Discrimination is apparent both in attitudes and in the way such people are treated. There is rarely anyone to take their side.

Other groups whose human dignity is especially vulnerable include people in long-term geriatric care. Such old people can easily feel themselves a burden and abandoned. They are also vulnerable to mistreatment. The quality of life for people in long-term care and the provision of care specifically to support their quality of life are key issues in care ethics. One group at the other end of the age spectrum are children in need of paediatric psychiatric care, who often have to wait several years for treatment, by which time their symptoms have become chronic. The recession brought cuts in preventive work, or even made it in practice impossible, which will of course lead to increased costs in the future.

Material resources are important and are often clearly inadequate. Finnish society will be unable to cope with the health care challenges of the next few decades without the input of considerable extra resources. But money alone cannot solve problems of human dignity. Discussion of resources can often be a way to avoid difficult issues. We must create new practices and models of thinking, and a culture of genuine contact between people. The fringe areas of health care bring society face to face with its own distress and helplessness, from which we can all learn a great deal.

The right of self-determination is an essential cornerstone of care ethics. And it is very important how we interpret this in practice. The patient's right to self-determination confirmed in the Act on the Status and Rights of Patients means above all an emphasis on dialogue and contact between patients and the health care professionals charged with their care. The care relationship must be based on mutual trust and understanding. Unfortunately, the principle of autonomy is often not realized as we would hope. Paternalism and callous indifference both pose ethical risks in health care. If autonomy is interpreted in a strictly technical sense, there is a danger of

indifference and the transfer of responsibility from professional carer to patient. Sick, dependent and frightened people often suffer strong internal conflict and are unable to choose between the available alternatives. It is therefore important for health care professionals to be able to empathize with their patients, discuss the alternatives in understandable

language and help patients reach a decision. Genuine contact and the process of building trust are key issues here. For the sick and other people requiring care, independence is often highly restricted. This must be understood and acknowledged. Indifference leads to exclusion. The principle of patient autonomy does not reduce the responsibility of the professional.

Equity

The interpretation of the concept of equity in different situations varies depending on the surrounding society and its values. The endeavour to find a valid interpretation of equity in each situation lies at the very core of social policy. Human dignity and extending a helping hand to our fellows form both the foundation and the goal of health care. Health care is influenced by a whole range of internal and external factors: values and general attitudes within care, available resources, internal conflicts, and external forces such as the pharmaceutical industry, equipment manufacturers and various other outside interest groups. The majority decides what the minority can have. Knowledge on consumer rights and the techniques available to treat illness can raise both realistic and unrealistic expectations of health care delivery.

Section 19 of the Finnish Constitution guarantees the right to receive indispensable subsistence and care for all who cannot obtain for themselves the means necessary for a life of dignity. Government must guarantee adequate social and health care services for all. Government responsibilities are also stipulated in the Finnish Local Government Act, the Primary Health Care Act, the Act on Specialized Medical Care and the Act on the Status and Rights of Patients. A number of international conventions and the European Social Charter also define society's responsibilities towards its members.

Finnish society has gone through enormous changes in recent decades, and, as a consequence, there has also been a fundamental change in the Finnish system of health care. Social systems all over the world have experienced a radical transformation, and the cumulative effect of all this on Finnish society has been considerable. The medicalization of life seen in a growing overemphasis on medical and health care perspectives has given rise to new demands on the health care system. It is expected to provide

solutions to all sorts of problems that do not necessarily have anything to do with the basic functions of medicine and health care. Although health care is currently the focus of a lot of fear and anxiety, the overall situation in nursing and care systems in Finland is not that bad. This does not, of course, mean there are no problems or that certain individuals or groups are not facing a clear danger of exclusion.

Health care productivity can be measured in a number of ways, but the key issue is whether the system really fosters health, genuine care, security and quality of life. Is the right to care determined according to need, and which rights are themselves dependent on the system? How can we foster wellbeing, equity and human dignity, qualities not necessarily susceptible to quantitative measurement?

Health care and patient care have experienced a notable change in the increasing emphasis being attached to the interests of service purchasers. In the paternalistic system of old, it was the health care provider who primarily defined the needs of the patient, seen as the 'object' of treatment. But nowadays the purchasers of health care have a fairly broad say in what services they require. It is therefore essential to identify the real demand for services in different situations and locations. We should be aiming towards a health care system characterized by partnership and cooperation between the various stakeholders. Health care cannot be merely the passive fulfilment of people's unlimited needs. Nowadays, care also benefits from the involvement of patients' and relatives' organizations and a whole range of other communities and individuals engaged in voluntary work. In the case of many illnesses, peer group support among the patients has proved to be very valuable.

With regard to equity, key issues are equal treatment, non-discrimination and respect for human dignity. Equal treatment is reflected in issues such as access to care: do people have equal access to care on the basis of their state of health irrespective of their circumstances, the area in which they live or other background factors? Differences between geographical areas undermine the principle of equality. People can also easily be stigmatized by negative social stereotypes associated with their lifestyles and problems. Long-term care carries the implicit threat of gradual social death.

Access to health care services varies between different groups of the population, while some illnesses would also seem to place sufferers in a disadvantageous position compared to those suffering from other illnesses. Psychiatric services vary from area to area in both quantity and quality, and there is inadequate welfare provision for substance abusers. It is also the case that some small population groups — such as children in care — find themselves in a different position from the rest of society. Such inequality often stems from unconscious prejudice that leads to problems being brushed aside casually without much thought.

In practice, issues of principle relating to equality and non-discrimination arise primarily in individual decisions on care, in questions such as whether a person has been left without a certain treatment on the grounds of age, mental handicap or multiple disability. The risks of treatment can increase with age, and some treatments are not suitable for old people, but leaving someone without treatment purely on the grounds of age is clearly discriminatory. Each case should be resolved individually, taking into account all relevant factors.

Some health care services can be divided in such a way as to allow a relatively simple quantitative assessment of equity, while some require the balancing of a number of qualitative factors. The first group would all seem to involve some sort of life-threatening illness (e.g. heart attack) and diagnosis based on definite biochemical quantities (e.g.

reduced kidney function) or other unambiguous laboratory results (e.g. cancer). In contrast, the latter group is characterized by differences within the medical profession on the need for treatment, or else diagnosis based on other than numerical quantities. In the future, we can expect the gradual harmonization of diagnostic criteria to facilitate greater equity in the distribution of services. It is therefore vitally important to develop national recommendations on care.

The legislative safeguards for ensuring the equity of the health care system are in practice rather toothless. The Act on the Status and Rights of Patients sets out the principles of good care, but failure to observe these principles rarely leads to any consequences. However, there are cautionary examples from around the world of what bringing the courts into health care can mean in practice. Court proceedings on patients' rights can stimulate valuable public debate. But they also deal with some extremely sensitive areas, as ill health is a very personal and delicate issue. We must therefore bear in mind the possible implications of court proceedings for the privacy of patients and their relatives.

Equity and non-discrimination are essential pillars of our society. We are entitled to health care and treatment when sick on the basis of the nature of our illness, our need for treatment and the effectiveness of the proposed treatment, irrespective of the municipality in which we live, our social status or other aspects of our lives. The mention in the Act on the Status and Rights of Patients that care must be provided within the scope of the currently available health care resources has given rise to a lot of differing interpretations. It is therefore worth pointing out that the Act in no way reduces or removes the responsibility of the municipalities to provide primary health care and specialized medical care as stipulated in, for example, the Primary Health Care Act and the Act on Specialized Medical Care. The idea is rather to develop the quality of health care operations.

Currently topical equity issues include:

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1. Working life is now very demanding. It has become a rather merciless discarder and consumer of human beings. Some employers are also keen to get access to the health records of their employees or prospective employees. At the same time, some people of working age have been pushed more

or less permanently outside the labour market, which of course undermines their confidence and leads to exclusion. This in turn has implications for their health.

2. Medicine, nursing and biotechnology are also to some extent a large international business with its own laws and values which are not necessarily in harmony with the social goals of equity and justice.
3. The illusion of the completely altruistic motives of carers and researchers has been shattered. Shady dealings and abuses are known to take place. The accumulation and use of funds must be properly supervised.
4. There is no easy way to interlink private and public sector services in a fair way. Competition is an important motor of development, but can also easily exacerbate differences in consumption. The growth in economic inequality observable elsewhere in society will inevitably also be reflected in health care.
5. The growing development gap between regions and the continuing drift of population into growth centres will exacerbate the problem of regional inequities in health care provision.

Urgency and prognosis of treatment as ethical criteria

The debate on health care priorities has focused on studies of effectiveness and the drafting of common health care recommendations as a rational and realistic way to control costs, improve quality and reduce inequities in the health care system. The gradual harmonizing of diagnostic criteria can also help to increase equity in the distribution of services. We must gather comprehensive and reliable information on the use of resources, treatment provided and treatment criteria, and on the long-term results of treatment. Open, analytical debate is essential.

An ethically important principle is to acquire as reliable information as possible on the prognosis of treatment in different situations. In practice, however, things are not that simple. In setting priorities for effective treatment we must not forget that the value of human care, closeness and warmth is not susceptible to quantitative measurement. Moreover, measurements of effectiveness often concentrate solely on cost-effectiveness, mortality rates and life expectancy; quality of life is less often taken into consideration.

Common health care recommendations can bring equity and equality to the health care field. However, it is worth giving some thought as to how binding such recommendations can be in individual cases. Each patient is a unique individual in a unique life situation. Recommendations can therefore provide only a general guideline, not detailed instructions for treating an individual patient.

Under the law, urgent treatment takes priority. It is fundamental to people's sense of security that they can be confident they will receive essential treatment without delay. This principle can, however, create problems, as urgency can be hard to define.

It has been suggested that we should perhaps consider dropping the concept of urgent treatment, or making it somehow more susceptible to rational definition. The problem is tied up with recent attempts to link the concept of subjective right to the traditional special status held by urgent treatment. Proponents of such a move suggest urgent treatment should be the (only) special responsibility of the municipal health care system — the responsibility for providing other treatment would then only extend to the limits of the available funding. The concept of subjective right has not traditionally been a part of the health care system, being a borrowing from the legislation on daycare and on services and assistance for the disabled. The problem is that it could lead to an artificial tension between urgent treatment and other treatment. On one hand, linking the concept of subjective right to the existing concept of urgent treatment could lead to a situation in which everything possible has to be done under the heading of urgent treatment. On the other hand, however, practical experience of the way the legislation on services and assistance for the disabled has been applied in some municipalities would suggest there is a danger that some municipalities would interpret their responsibility as extending no further than the provision of urgent treatment.

The importance of information

In ethical terms it is important for society in general, and for patients, their relatives and patient organizations in particular, to have as much information as possible on treatments and care systems, and also on the rights of the patient. We are now in the situation that a large number of people have almost unrestricted access to an enormous quantity of information on medicine, nursing, the law and society in general. The Internet has made it possible for people to access information from all over the world. It is valuable to be able to access reliable, up-to-date information in this way, but it

can also be confusing and requires the reassessment of a whole range of issues. From the point of view of ethics, we should strive to ensure that this increase in information also leads to an increase in understanding and a strengthening of care relationships without unreasonable disputes over loss of face or suspicions between patients and the health care professionals charged with their care. This presents a challenge for all sides, as it will inevitably lead to a restructuring of roles and structures of interaction.

Limits and sources of health

The health care system cannot solve all our problems, not even all our health-related problems. Health is a matter for us all, and the promotion of health is a joint venture requiring input from many sectors of society. Moreover, it is not the health care system as a structure which has the most decisive impact on our health and wellbeing; what really matters is the people who work in it. Thus, it is also of fundamental importance ethically to ensure that workers in the health care sector are valued and to take care of their wellbeing, working conditions and ability to cope at work.

We must speak up on behalf of a caring culture, a sense of community and an attitude that values social security and solidarity. Wisdom and compassion are the key qualities in any ethics. Wisdom means knowledge integrated by our values into our experience of life, while compassion means the ability to see and experience things from other people's point of view. There are no external methods or resources that can compensate for the loss of these vital qualities. We must speak up on their behalf, as they are fundamental to the very survival of our society and culture. It is the job of society to guarantee legality, security, basic equity and the protection of the weak.

It is important to remember that, even if the available resources were not as limited as they have now turned out to be, the very nature of ethics itself involves a basic tension requiring the constant balancing of different quality perspectives. The core concepts here are the common good, the rights of the individual, and equity. If we are to provide for social wellbeing and a truly human quality of life in the long term, a viable social ethics must protect all of these values.

No health care system can meet all our needs and expectations, let alone free us from the limitations inherent in human life, despite the rosy visions of science fiction. Nature, history and the universe itself are all on a much vaster scale. The individual human being is a fleeting and fragile figure in the great flow of life. All existence is transient. To deny this would be both dishonest and unethical.

Ethics can never be a closed book, as it deals with incomplete, limited and constantly changing processes. Ethics must live in the present even when it can only perceive a part of that present. Realism, the urge to learn and a willingness to accept the facts are excellent allies in this endeavour.

Invitation to join the debate

This document based on the discussions conducted by the National Advisory Board on Health Care Ethics is being issued to stimulate an open public

debate, to which we invite all those involved in health care, decision-makers, the media and the general public. The aim of the debate is to develop Finnish

health care in an ethically responsible direction.

We are simultaneously issuing a separate document presenting a number of themes and perspectives

relating to equity and human dignity in health care that have been prominent in our discussions during the first two years of the Board's work. We welcome further debate on these themes too.

Helsinki December 12, 2001

National Advisory Board on Health Care Ethics

Martti Lindqvist
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THEMES AND PERSPECTIVES FOR THE PUBLIC DEBATE

During 2000, the National Advisory Board on Health Care Ethics examined ethical issues in Finnish health care, placing special stress on the issues of equity and human dignity. It held a closed seminar on this theme on August 17, 2000. A final document (?) was produced from the seminar to provide a basis for public debate on ethical issues of principle. The document invites contributions to the debate from all concerned parties: patients, health care professionals, decision-makers, the media and the

general public.

The Board has also gathered together a number of concrete themes and perspectives relating to equity and human dignity in the health care sector which have played a key role in its own discussions during the first two years of its work.

The Board should like to draw particular attention to the following issues:

Equity and equality

The differences in development between Finnish municipalities caused by the rapid pace of social change have led or are leading to health care inequalities between people living in different parts of the country. Medical tests, services and treatment may be given under different criteria in different municipalities. Government, both local and central, must face its responsibility in a situation where many municipalities are struggling against almost insurmountable difficulties in the effort to provide essential services. Responsibility lies with both local government (the municipalities) and central

government. We must consider municipality by municipality such factors as the impact of age structure and unemployment on both resources and the level of service demand. Society cannot leave the residents of declining municipalities without essential services. The issue is one of equity, equality and securing the foundations of the welfare state. Government must ensure the development of health care in a way that respects human dignity and complies with both the Finnish Constitution and international conventions on human rights.

Resources

The cuts in health expenditure justified by appeal to the economic recession continued long after Finland had already moved on to a period of strong growth, growth which has now continued for an exceptionally long period. Attempts have been made to rationalize a number of functions, and cost-effectiveness is certainly important in health care, as in other areas. Even so, it is clear that the health care sector must be prepared for a growth in service demand and an associated rise in costs in the years and decades which lie ahead. This is due above all

to the coming changes in population structure and morbidity. Short-sighted savings could with time prove expensive. Under-resourced health budgets cannot be ethically acceptable. Moreover, a recent ruling by the Supreme Administrative Court (794/3/99 27.11.2000) requires the municipalities to arrange for the provision of adequate social and health care services for local residents. The decisions of today will determine the foundations of the care systems of the future. Wealth and comprehensive, quality health care both today and in the future.

Vulnerable groups

The general growth in social and economic inequality in recent years has also meant that certain groups of people in the health care sector have become

extremely vulnerable and prone to exclusion. Some of these people simply cannot meet the requirements that the present day seems to demand of people.

Such groups include the socially excluded, people with problems of addiction, asocial groups and the homeless. Others are people who have been marginalized on account of age or illness: long-term geriatric patients, adults and children with mental health problems and socially excluded young people. Experts tell us that it is the situation of the weakest people in Finnish society that is deteriorating fastest. This should serve as an ethical wake-up call. The growing problems of young people also present a major challenge for health care in both prevention and treatment. Increased substance abuse, in

particular, is a serious social and health problem.

Meeting the problems of the socially excluded and those facing the threat of exclusion will require action both at the broader political level and within the health care system, and also an attitude of responsibility towards our neighbours on the part of the general public. Care and compassion are the most fundamental ethical resources we have. Systems have a limited ability to help people. We always need the help and care of our fellows.

Working life

Contemporary working life is extremely demanding and performance-centred. At the same time, some people of working age have been pushed more or less permanently outside the labour market. Both these factors create social and health-related problems that require action. Employees are expected to display constant flexibility, assimilation of new ideas and fulfilment of performance targets. Many employees can adapt to these demands, but for others they are too much, and this leads to symptoms of stress, exhaustion and depression, and

perhaps eventually to the end of their working life. Stress at work and unemployment both also feed the problem of alcohol and drug abuse. It is particularly important to consider the long-term risks posed by the increasing pressures of working life. This will require a thorough dialogue on concrete issues between health care experts and the representatives of both sides of working life. Effective occupational health care can be a key factor in reducing risks and supporting wellbeing at work.

Quality and efficiency of care

The ongoing structural changes in society and in care systems are giving rise to a number of ethical problems. For example, the running down of institutional psychiatric care led to serious problems in non-institutional care due to inadequate resourcing and preparation. Similar questions could also arise elsewhere – for example, in care for the elderly or the disabled. These questions need to be addressed comprehensively, and this will require additional input into research.

and the patients' experience of quality. These are all important in their own right, and together they give rise to quality care in an ethical sense.

Any analysis of the quality of care involves several levels: scientific and technical quality, quality in costs,

It is important that we research the efficiency of care. We must also continue the debate on how to measure efficiency and remember that from the point of view of the patient's subjective experience the sense of being cared for and taken seriously are of prime importance. Human contact and a caring attitude must not be sacrificed for an overly rationalist approach.

Wellbeing at work in the health care sector

Health care professionals nowadays are under enormous pressure in their work. This is due in part to changes in the structure of society, in population structure and in morbidity, but also to rationalization measures and cuts in expenditure. Problems are caused by poor working conditions, inappropriate staffing levels, a lack of opportunities for continuing

education, and poor management. The past few years have also seen an enormous increase in the use of short-term contracts for health care personnel. It is both unfair and, from the point of view of effective health care provision, unwise to squander in this way the most important human resources and skills in the health care sector. In the absence of

radical change, the long-term effects of the present burden on health care personnel could be very serious indeed. What staff can manage temporarily through a special effort cannot be taken as a general

norm for work on a permanent basis. The full human cost of constant overwork will only become apparent years, or perhaps even decades, from now.

The importance of data collection in health care development

Information technology nowadays provides a considerable extra resource for the day-to-day work of health care professionals. Even primary health care can now take advantage of comprehensive, quality databases from both Finland and abroad. And one of the main areas of development within health care today is precisely the development of information systems.

The importance of data collection extends also to the statistical information essential in health care

administration and in providing a base for balanced development. It is vital that the data collected is both comprehensive and up-to-date. At present, too much has to be done based on assumptions and guesses. At national level, at least, some information is produced too slowly, hampering the development of effective monitoring and measurement. What is needed is an effective system for ongoing accumulation of data for monitoring the state of the health care system.

Cooperation and volunteers

Our care systems alone are unable to cope with the constantly growing challenge of providing care and solace for people in contemporary society. The challenge comes both from the concrete change in society and from the accompanying revolution in lifestyles and values. Caring about and for one's neighbour is neither as easy nor, at the level of attitudes, as obvious as it once was in the closely

knit rural society of the past. Peer support and the altruistic work of both relatives and volunteers is very important in relieving human suffering and providing support. Alongside the development of effective treatments and the professional competence of health care workers, we must also seek partnership between others involved in providing care or supporting the care process.

Health care and faith in the future

Loneliness is the great epidemic of our age, and this makes many people fear for the future. In their minds' eye, they can see themselves alone and abandoned in their old age or if they should become seriously ill. Or they may instead be worried about the fate of their parents or their children and grandchildren. Some people find it hard to imagine what sort of times and conditions are lying ahead. Most simply cannot understand the issues discussed by experts in specialized fields. They find both the language used and the issues themselves frightening. With this in mind, it is understandable that people fear a future in which they could be left entirely without treatment, or else be subjected to a kind of

treatment they neither want nor approve. It is therefore vitally important for discussions on science, technology and planning to be conducted in a way people can understand. We must be able to demonstrate to people that they will continue to receive humane treatment and care in the future as well. We are all entitled to know our rights and the main ethical principles underlying medical care.

A healthy community is based on people valuing and caring for each other. Health care forms an integral part of this process, and in the years and decades lying ahead we must do everything we can to ensure it retains this position.

CAN WE DEFINE AND MEASURE EQUITY IN HEALTH CARE?

Introduction

In this essay I consider:

1. why health care equity appears to be a growing concern;
2. whether there are any readily acceptable dimensions for quantifying equity;
3. whether there are any reliable scales suitable for presenting these dimensions; and
4. whether information quantified in this way can be used to support decision-making on health care, and whether it is being used in this way in Finland.

Finnish law defines health care equity as an aspect of equality between citizens. Equality applies to the distribution of services among the population and provides everybody the opportunity for care according to their level of need at any given time. The law accepts that the overall volume of health care is necessarily limited by the resources available to the municipalities. In addition, the law gives priority to urgent treatment and goes so far as to give those requiring such treatment a subjective right to treatment.

In addition to equitable satisfaction of the demand

for care, the concept of equity can also be extended to cover the way in which resources are gathered for the collective funding of services. (From here on I refer to this collective funding with the concept of funding ‘pool’.) Neither the law nor any other norm has a word to say on this. The law also says nothing on the definition of available resources per se, or on how to define their adequacy. Still to be considered is whether there is any ethical problem attaching to the self-financing of health care services (i.e. financing that comes from outside tax-based funding systems) and the services funded in this way.

Why in the headlines?

The debate on health care equity is an inheritance from the 1990s, when publicly funded health care had to carry its share of the burdens of the recession. Finnish health care expenditure shrank more quickly during the first half of the decade than that of any other industrial country has ever done in peacetime. This was accompanied by a simultaneous increase in the technical means of treatment.

By the end of the 1990s the technical means for increasing efficiency had been more or less used up: treatment was transferred to outpatient clinics and surgical units, large hospital units were closed, and treatment periods were reduced in the direction of ‘norms’ adopted from other countries (especially the United States).

When the technical means of increasing efficiency had been largely used up, the focus shifted to

allocative efficiency. With government help, the Finnish Medical Society Duodecim organized two seminars on priority setting in national health care, which approved the principle of setting priorities as an idea. Equitable prioritization was seen as based around an application of utilitarianism aimed at maximizing the health benefit, understood as the overall cost-effectiveness of the system as a whole. Although approval of this general aim is important for coherent ethical debate, many factors in the equation currently exist only on the level of ideas.

During the recession, the general public had to be made aware that there were unavoidable limits to health care funding and that — in the spirit of the Committee on Priorities in the Health Care — care would in the future have to be ranked in order of priority. On hearing this, many must have begun to fear that old age, the contribution of patients’ own

choices in generating certain illnesses, ability to pay and other such factors could form obstacles to receiving the best possible treatment.

Now is also an appropriate moment to consider the issue of equity in light of the redistribution of income currently under way in Finnish society. If we are to

believe the media, Finnish incomes policy has turned a corner: after decades of reduction, income differentials have begun a steep rise. This also makes people wonder whether ordinary members of the public will still get access to treatment when they need it.

Equity assessment of the funding pool and its ramifications

Equity can easily be presented as an entirely volatile mental construct, and the assessment and measurement of equity thus as an impossible task. I do not entirely agree with this view.

In my opinion the whole problem of health care equity is closely linked to the existence of the third party to the equation, the funding pool. We do not worry in the same way about equity in housing (as long as everyone has some sort of roof over their head), nutrition (as long as nobody starves to death) or clothing (as long as every Finn has at least something to wear). All three areas we have simply left to the mechanisms of the market. In these areas the market is seen as by far the best way to arrange for the distribution of commodities in society. According to the general perception, only those in immediate danger require some sort of direct support in order to afford such commodities, rationally functioning markets being sufficient to meet the needs of everyone else. In practice, nobody discusses equality in reference to these issues.

Why is this so? The decisive factor cannot be the threat these problems pose to the health or life of the individual, as lack of housing, clothing and food at latitudes over 60° north will statistically speaking lead to death more quickly than lack of health care services. The difference is actually best explained by the inefficiency of the market as a mechanism for distributing health care services: demand for services is, at the level of the individual, typically unpredictable, the costs considerable, and the average consumer largely dependant on the opinion of experts in seeking the appropriate services. And health care experts can scarcely be equated with sales personnel in food or clothing stores.

Thus, all post-industrial societies gather health care resources into a common pool by some sort of collective decision. The subsequent disbursement of

funds from this common pool is triggered by the health need of a 'stakeholder' in the pool, but still requires specification by an expert — the doctor — before final disbursement can take place.

In respect of the dimensions of equity, the funding pool is an essential structure. Equity can in principle touch on two distinct processes: 1) how resources are gathered into the pool, and 2) how the resources thus gathered are subsequently used. Special consideration should also be given to considering whether members of the public should be entitled to use their own legally earned income according to their own discretion to purchase health care services from outside the common pool. Some may consider this question entirely superfluous, as the answer is so obviously "yes".

It is nevertheless worth posing the question of people's use of their own private resources in very clear terms. If we approve such use, we thereby also approve the principle of inequality in health care services. Furthermore, we also approve the inevitable consequence that in a market-based democratic system the debate on equity must perforce be restricted to discussion of the common pool — or pools, if, as in Finland, funds are collected and disbursed in more than one way — the flows of money into the pool, and the services funded from it. The third consequence is that services produced outside the pool can pose a threat to the volume of operations within the pool. If the overall volume of health care were to be limited by a scarcity of certain production factors, for example a shortage of doctors, this could threaten the overall volume of services provided within the pool, and by extension access to these services. The pool would either have to reduce its service output or acquire increased resources via the political process. The relative level of resources within the pool would not affect the equity of its service provision; instead of plenty, the

pool would merely move over to distributing scarcity.

Measuring equity

1. Distribution of services

Gavin Mooney has presented his well-known multilevel interpretation of equity in service distribution. In the present context, a recognisably Finnish interpretation of equity would be that the pool is distributing services in an equitable manner when it *satisfies* the same health needs of different people in the same way. But it is worth noting that Finnish law is less strict in its definition of equity. It is sufficient that people have *equal opportunities* to receive services; with the exception of urgent treatment, the law says nothing of satisfaction.

Some of the health care services funded from the Finnish pool are distributed more or less equitably, some not. The former are characterized by life-threatening illness (e.g. heart attack) and diagnosis

based on definite biochemical quantities (e.g. reduced kidney function) or other unambiguous laboratory results (e.g. cancer). The latter group of services, distributed on average inequitably, is in contrast characterized by differences within the medical profession on the need for treatment, or diagnosis based not on numerical quantities, but on hermeneutic interpretation. As the inequitable distribution of services is not due to deliberate malevolence, we can expect the gradual harmonization of diagnostic criteria in the future to facilitate greater equity in the distribution of these services too. In this sense, we can put our hope in the development and harmonization of national and international recommendations on care.

2. Funding

The normative basis that we can use in assessing funding equity is, if anything, even shakier. Some analysts have sought, and derived, assistance from international comparisons. These have shown that tax-funded systems are either neutral or slightly progressive, social insurance systems slightly regressive, and voluntary insurance systems (United States) clearly regressive in their funding effect. If desired, we can measure the equity of funding by the relative distribution of the funding burden across income classes. It would also be possible to set the equity goal of Finnish health care funding as a neutral funding effect. (Such neutrality would, however, not alter health care's position as a massive system of income transfer due to the mirror-like social distribution of income differentials and service needs.)

This can be summed up by saying that the pool operates on a distinctly egalitarian principle: from each according to their ability, to each according to their needs.

A glance at the break-down of funding in the 1990s indicates a clear change: growth in patients' own share of the costs of medicines and travel expenses, the shift in the tax burden from taxes on work to taxes on consumption (value-added tax) and the cuts in government grants to the local authorities combined to turn a marginally progressive system of health care funding into a slightly regressive one. Assessed thus, the aim of equitable funding as defined above can be said to have retreated slightly during the past decade.

Can equity assessment provide support for political decision-making?

In a democracy, the political system uses the legislative process to channel public opinion, and especially public interpretations of equity, into social praxis. Viewed thus, it would seem natural for health care equity, too, to be effectively monitored by the machinery of representative democracy. It would also seem natural that both the equitable distribution

of services and the neutrality of funding could be accepted as some sort of norms in a society such as Finland, marked by an internationally unusually large measure of agreement on the provision and funding of health care services.

Even so, this assessment is only partly true. Both

politicians and the general public have at times found it hard to understand that the debate on equity can only refer to funding pools, that Finland has several such pools, and that the regressive element in funding can also be increased or reduced by decisions at municipal level. There is a dearth of analytical debate on all levels. On the contrary, there is an almost convulsive wish to adhere to the status quo, and some people have clearly not grasped the changes taking place in the world.

One example of this analytical weakness and an accompanying paralysis in decision-making is the increasingly serious shortage of doctors in Finland. At the same time as the public sector is suffering from a flight of doctors to the private sector, the private sector is being publicly supported through tax breaks. Thus, public 'decisions' are simultaneously pushing doctors out of the public sector and drawing them into the private, leaving in their wake complaints about both a lack of doctors and a growing inequality in health care. What, then, to do about this? As I outlined above, we all have the right to use our own legally acquired assets as we see fit, provided we harm no-one in the process. To recap, private medical services undoubtedly have a place in a good society, and those who wish to seek services in the private sector must be afforded the opportunity to take out insurance to cover their possible service needs. But, whereas in other Western countries private health insurance is voluntary and confers no right to tax relief (which is always regressive in its effects), in Finland subsidy is drawn from all taxpayers in the form of distrainable taxation. Every year, 70—84% of people use no private services, but most of this group, too, will contribute to funding these services.

The clearest, quickest and politically most acceptable solution would be to make payment of the insurance contributions conferring entitlement to reimbursement of private medical costs voluntary. This would place funding and service distribution in the private pool on an equitable footing and bring Finnish practice into line with other Western countries. The consequent reduction in subsidy for the private sector would result in lower private sector pay for doctors, reducing the attraction of the sector and increasing the supply of doctors for the public sector while at the same time bringing about a measurable increase

in the equity of the service system.

The KELA (Social Insurance Institution) funding pool, on the other hand, presents more of a problem than the pool funded by the local government municipalities. In addition to the services already mentioned, KELA also reimburses travelling expenses and medicine costs and pays a variety of daily allowances to compensate for loss of earnings. It is very important to note that reimbursement of travelling expenses and medicine costs is, from the perspective of equity, quite a different matter from the reimbursement of doctor's fees. Reimbursement of travelling expenses represents an attempt to enable people living in outlying areas to gain access to health services of any sort. In contrast, as the private sector has not so far offered any reimbursable service forms that the public sector does not also provide, patients' turning to the private sector for services represents a matter of preference between forms of service rather than a straight choice between access to service or no service at all. There is thus a real difference in equity between reimbursement of travelling expenses and reimbursement of doctors' fees.

The difference is, however, reduced to some extent by the 2001 Budget, which brings a major slice of dental care within the KELA funding pool, as the public sector is unable to offer an adequate volume of services. Admittedly, this has also been claimed for several years now in respect of the services of consulting physicians, as much of a third of which are KELA-supported. However, the distribution of these services is so skewed both regionally — the net recipients of KELA funding are under 50 municipalities grouped around the university hospitals, while the poorest 400 municipalities are net contributors — and in terms of consulting speciality, that there are good grounds to doubt the validity of the claim.

As rapidly updatable information is readily available on the flows of money and services under the various funding pools, this information can be put to good use in assessing the equity of the system. Decisions on normative issues, such as the acceptability of funding neutrality, must of course be left to our representative political institutions.

KEY ISSUES IN HEALTH CARE ETHICS

Introduction

Many slogans and characterizations have been used in an attempt to encapsulate the age in which we live, all of which capture something of its kaleidoscopic appearance. However, all of these images are to some extent incomplete. There is always another side to things, something different and opposite. This is due in part to the pace of change, and in part to the fact that we have entered an age in which the world — including Finland — is different to different people. This is why ethical debate is so important, as there is no longer a single correct and complete description of the world or of ethics. We can only continue with this shared process and endeavour to sustain creative and determined debate.

Even so, I shall take the liberty here to say a few words about my view of the age in which we live.

The most visible features of our times are on the one hand a techno-economic rationality that has also developed into a criterion of the good, and on the other hand a transient and instrumentalizing lifestyle centred on enjoyment and pleasure. People appear as their social roles, which are constantly changing, and through which it is hard grasp the real person. Some have made the constant changing of role identities into a way of life. There is also an expectation of performance, efficiency and a constant drive onwards and upwards, while on the other hand we are adrift in the transient moment, unconnected to the past or the future. The market has no native land, and the marketplace of today is global. Its morals are shaped by the rules and customs governing trade at any given time.

Market valuation easily spills over into human relationships, too, and into other non-material values such as culture and religion. People are willing to pay for what is in demand and in short supply. That which is in overabundance and is overlooked arouses no interest or demand. This market orientation in the prioritization of values relegates the everyday to

the status of something dull and marginal. This is accompanied by an accumulating burden of mental and spiritual distress. In part, this is an immense weight of loneliness generated from many very different contributing factors, and in part, a multifaceted, and for many people constantly accumulating burden of failure, inability to cope, anxiety and a sense of being left behind. In the light of all this, it is no wonder our care systems are facing a continuing and growing flood of deprivation and mental health problems.

I find myself troubled by the still continuing references to the recession when discussing the health care problems of today. The recession ended years ago. We are now in a period of growth and for the most part facing the problems associated with such times. The talk of recession is mere obfuscation.

However, I have no wish to moan about the times we are living in. Each generation lives in its own age. There have been both better and worse times in the past. But this time is ours, and we must base our actions on the realities of the present.

Realism and idealism

Ethics exists in the tension between realism and idealism. On the one hand, it ought to expend a lot of energy on considering ideals — ‘the best possible world’ — however naive this may seem. But, on the other hand, an ethics that fails to take account of

prevailing realities and genuine limitations will be of little practical use. The main problem with broad declarations and lofty ideas is that they have no practical effect. They merely exist in their own world of ideas.

An effective ethics must often demonstrate a cold-blooded realism. We must be prepared to examine ugly, controversial and unpleasant issues, because evil is the unavoidable shadow of good. The concrete rooting of ethics in everyday life, the procurement of valid and rounded information on prevailing conditions, and the charting of practical alternatives are all very important issues.

In relation to the law, ethics has two main functions. On the one hand, the process of ethical debate and reflection precedes the later crystallization and enactment of legislation. The ethical process thus leads to concrete law. The legitimacy of society requires that legislation be genuinely based on a living and respected moral reality. But on the other hand, ethical debate can also begin where the law leaves off. Ethical responsibility is not limited to legal responsibility. Therefore, every individual and community must generate an ethical understanding and autonomy that does not derive primarily from

the hope of reward, fear of punishment or outside control, but from people's own will and commitment. The more such 'natural legitimacy' is undermined, the more we will need legal controls and all the related consequences.

It is unrealistic to expect that health care could survive as some sort of separate enclave abiding by a different system of values or different rules of the game from the rest of society. The values of the age will inevitably permeate health care as well, if a little more slowly in the public than the private sector. However, this does not mean health care has to be merely a passive observer of what is happening in society. Those involved in the health care arena can join the debate and highlight the experiences and observations the sector has of Finnish society and its development. Health care professionals have a wealth of untapped knowledge, understanding and wisdom about life.

Why the focus on human dignity and equity?

Human dignity lies at the heart of all health care, constituting both its foundation and its purpose. Care systems, traditions and philosophies have arisen because individual human beings have been considered so valuable that they cannot just be left to the mercy of their sickness and suffering. Even care which utilizes the best tools of diagnosis and highly complex and advanced methods of treatment must never remove the individual human being from the heart of the care process. In actual fact, this heart embraces both those giving care and those receiving it. Finland's Act on the Status and Rights of Patients provides a solid legal basis for this view. It also provides much of the foundation for our work in ETENE. We must never allow ourselves to get so enraptured with the cutting edge of research, media sensations or the issues raised by huge amounts of money that we forget the importance of caring for

people in the everyday world and on the margins of society. This approach resolves the majority of the most important questions relating to human dignity.

And what about equity, or, as it is more commonly referred to in the political arena, justice? A small word, perhaps, but one which looms large; it is constantly being bandied about by politicians, but somehow always seems to defy precise definition. Every age must define for itself its own interpretation of justice, and this inevitably places justice at the heart of political discourse. Health care professionals have perhaps been too flexible and uncritical in the face of the growing inequality clearly visible at present both as a general trend in society as a whole, and especially within the health care system itself. It is time to speak of justice.

Issues related to human dignity

The first shadow hanging over human dignity comes from the public conception that only independent, productive, economically self-sufficient and ambitious people really matter. Health care gets to see the other side of the coin, the people who cannot manage on these criteria. At the same time, within the health care system itself, we find a somewhat

similar dynamic around the idea of the 'interesting, cooperative and readily treatable' patient. Even the care system itself generates its own outcasts and 'enemies'. These are often awkward, hard-to-treat patients with multiple problems, who are vulnerable to prejudiced attitudes. In these cases, the carer's shadow falls between them and those in need of

help.

Ethically important issues from the perspective of human dignity in Finnish health care include at least the following:

- The labelling of people on account of a moral, social, lifestyle or mental health problem, and consequent harsh or unfriendly treatment (e.g. criminals, antisocial people, people with alcohol or drug problems, or people with serious psychological symptoms). Discrimination is evident both in attitudes and at the level of decision-making.
- There are evident problems of human dignity in the conditions of care and attitudes towards chronic geriatric patients. The problem of being socially 'buried alive'.

A quote from the Finnish bishops' statement '*kohti yhteistä hyvää*' (towards the common good) from 1999:

"There is more to life than buying and selling, consumption and markets. The human being is also a giver and receiver of gifts, a carer and nurturer, a playful companion."

Issues related to equity

If we view the present situation globally, we cannot fail to notice how poverty, inequality, ignorance and injustice are throughout the world the main causes of underdevelopment, sickness, poor health care, suffering and early death. Although here in Finland the situation is not so stark, the basic mechanisms are the same. When people lose their faith and are forced to live in absolute poverty, there's precious little that can decisively improve the level of health and care. The example of Russia demonstrates that even relatively technologically developed societies can take a turn for the worse. Development is not always a one-way street.

I agree with those who have drawn attention to the problem posed by the division of our country into 2/3 who feel they are doing well and keeping abreast of developments and 1/3, comprising a broad range of different sorts of people, who have in fact very

Ethical problems relating to equity include:

- Working life has become extremely demanding, separating people out and acting as a fairly merciless consumer of human beings. Employers are very keen to get hold of employees' health data.
- Medical science, medical care and biotechnology are an enormous international business with their own practices and values that do not necessarily chime with the strivings of societies towards equity and justice.
- The illusion of the altruism of carers and researchers has been shattered. Financial irregularities and abuses are well known.
- The equitable dovetailing of private and public sector services is no easy task.

The widening economic gulf between regions of the country and the continuing flood of people into population and growth centres is exacerbating the problem of inequities between regions.

Autonomy, freedom and abandonment

Health care ethics in western countries has perhaps been too narrow in concentrating almost exclusively on the principles of autonomy and self-determination, which, despite their importance, are in danger of degenerating into a purely formal legalese. The concept of a free and independent individual directing his own destiny is historically speaking rather young. Certainly, human dignity has been emphasized for thousands of years. Christianity in particular raised it as a central theme two thousand years ago, but, until the Enlightenment and the French Revolution, the individual was really viewed as an inseparable part of his own community, estate, destiny and the eternal world order. He could be his own self only within the parameters of these spheres.

It is thus no surprise that the present day has adopted as the centrepiece of its ideology of progress the freedom and right to self-determination of the individual human being. According to this way of thinking, the human person is an open book, and through his choices writes his own history. He is radically responsible for both the happiness and the unhappiness of his life. The current success philosophies and free competition liturgies are a direct application of the modern intoxication with freedom.

This has also left its mark on the philosophy and ethics of medical care. After the Second World War,

the individual's right to freely agree or refuse tests or treatment became the ethical foundation for all medical tests and treatment. Historically, this represented a major step forwards compared with the previous highly reactionary and patronising practices of treatment and care.

In recent decades, as the world has become more technical and economic perspectives have been emphasized to an extreme degree, the principle of freedom has taken on a very mechanical interpretation. The consent of the patient is increasingly seen as merely a routine part of a technical treatment process. The patient is furnished with factual information on his illness and the available treatments on the assumption that he will be capable of deciding on his own treatment. In Finland, the Act on the Status and Rights of Patients passed in 1992 is based on this key principle.

I do not seek to criticize the principle of self-determination, which protects the patient from abuses and is intended to give him an active role in treatment decisions. But I believe it is important to understand that help for a human being cannot be based on just a single, isolated principle — and far less on its mechanical application. Alongside self-determination, the principles of the common good, community and equity, among others, demand to be taken just as seriously.

Problems

The information society paradoxically gives rise to a problem of ignorance. Because knowledge is money and power, people are increasingly excluded by their ignorance and lack of competence.

People excluded in this way easily become prey to dependency, depression and loneliness. The logic is

self-fulfilling.

Depression and psychological and social deprivation lead to a cycle of problems. People begin to repeat their failures and then seek relief through 'solutions' such as alcohol and drugs.

In conclusion

Above all else, we must speak up for a caring culture, an approach to life that emphasizes a sense of community and social solidarity. There are no outside means or resources that can replace the loss of such vital features. We are actually speaking here on behalf of factors fundamental to the very survival of our society and culture. It is the role of society to ensure

the rule of law, security, basic justice and protection of the weak.

It is important to remember that even if resources were not as limited as they have proved to be, the very nature of ethics involves a basic tension that requires the balancing of different quality

perspectives. The core concepts in this tension are the common good, the rights of the individual and equity. If we are to have a chance of preserving the wellbeing of our society and sustaining a human quality of life, our social ethics must protect all these values.

No health care system can meet all our needs and expectations, let alone free us from the limitations

inherent in human life, despite the rosy visions of science fiction. Nature, history and the universe itself are all on a much vaster scale. The individual human being is but a fleeting and fragile figure in the great flow of life. All existence is transient. To deny this would be both dishonest and unethical.

Realism, the urge to learn and a willingness to accept the facts are excellent allies for an effective ethics.

EQUITY IN HEALTH CARE

Underlying principles

The underlying principles on which I base my assessment of health care equity are the fundamental rights guaranteed in the Finnish Constitution. It is, after all, the job of the Ombudsman to ensure the implementation of these constitutional rights by those carrying out public duties. Viewed from this angle, equity in health care essentially means equality: equality in access to services and treatment, equality in individual treatment solutions, and equality in the quality of care provided. Equality is particularly important for the members of vulnerable groups: people who are weak or vulnerable for a variety of reasons, old people, the disabled, children and all who are unable to take care of themselves.

A number of WHO publications also set out from the principle that equity in health care means equal access to the available treatment for those with equal needs, equal use of services by those with equal needs, and equal quality of care for all. The point of equity as an objective is to reduce unnecessary, avoidable, unreasonable and unfair differences in health (Margaret Whitehead: The concepts and principles of equity and health. Copenhagen World Health Organization, Regional Office for Europe, 1990).

Equal access to treatment

The right to equal access to treatment can be derived from sections 6, 7 and 19 of the Constitution. Equal treatment and the inviolability of human dignity are cornerstones of our system of justice. There is nothing in health care legislation that would justify

derogation from these principles. For example, in the area of primary health care the criteria for acceptance for treatment mentioned in the legislation are the nature of the illness and the need for tests, treatment and medical rehabilitation.

It is nevertheless clear that, for instance geographically speaking, people do not enjoy equal access to treatment. This can be readily illustrated by a number of issues that have come to light during the course of my own work:

- for some illnesses there is regional variation in the per capita numbers requiring treatment;
- there are significant regional differences in involuntary psychiatric care and access to care for children and young people; in some areas there have been cases of people having to wait up to six months for treatment, while in others adult psychiatric care or placement in a reformatory are seen as alternatives to psychiatric care specifically tailored to the young;
- there have been serious inadequacies in the provision of treatment for gravely psychotic and violent young people and young people suffering problems of alcohol and drug abuse, including the type of inequality outlined above;
- moreover, there has been absolutely no provision of specialist care facilities for children and young people needing forensic psychiatric care, or catering to the care needs of hard-to-treat or dangerous children and young people;
- there are also regional and other differences in provision of transport for mental health patients: the long distances involved or other reasons have at times led to the provision of transport by the police instead of in an ambulance;
- the treatment provided for drug and alcohol-related illnesses has in general been both inadequate in volume and ineffective in content; it is worth considering the relative significance in this respect of the inherent difficulty of treating such cases, inadequate information on the demand for services and the criminalization of drug abuse.

Equality in quality of treatment

Equality in the quality of treatment received is hard to assess, as the treatment required inevitably varies from one illness to another. It is, however, surely reasonable to expect a certain minimum level of quality from all treatment. At the very least, treatment should not violate human dignity.

I present below some useful examples to illustrate the problems experienced by people in the vulnerable groups referred to above:

- studies have revealed mistreatment of old people in social welfare and health care institutions, including neglecting to ensure adequate intake of liquids and food, and neglect of basic hygiene and safety; it can also include rudeness, indifference and unfriendliness;
- in involuntary psychiatric care, isolation is used in order to restrain aggressive patients and control their destructive behaviour; at its worst this can mean isolation in a very small, bare, foul-smelling room, from where the patient cannot communicate with care personnel other than by shouting or banging on the door; isolation can also take the form of strapping patients to their bed for days on end;
- the wards in long-term psychiatric care can still be large and noisy, and, depending on staffing levels or other factors, patients may be unable to get out of the ward each day to take exercise in the open air;
- there are also similar problems in institutions providing special care for the mentally handicapped.

In such cases, we may well ask whether the quality of, for example, care for the elderly or specialist psychiatric care is really acceptable. The answer is clear: in view of the wealth and standard of living of our country, care of this nature cannot be considered legally acceptable.

I should like to emphasize that one of the functions of health care is to care and provide solace for the incurably ill and to alleviate pain and suffering; it is not only concerned with prevention and cure. For this very reason, it is vital to demand quality not only when we are endeavouring and able to heal the sick (e.g. when treatment is machine-dominated, acute and 'dramatic'). Quality and effective care are just as important in situations where the focus is on providing solace, and indeed always where care

focuses on vulnerable groups such as those mentioned in my examples above.

The issue in the problems highlighted by my examples could also of course simply be a case of established practices and approaches to care, as studies have shown is indeed the case in respect of the isolating of patients in involuntary psychiatric care. There are clearly regional variations in practice, and this has been shown to be due to just such differences in established practices and traditions of care. This brings us back once again to the question of regional differences. Given that isolation represents a considerable interference in a person's freedom and integrity, there is surely no justification for the regional differences that exist in isolation practices (e.g. isolation in a room/strapping to a bed).

Equality in individual care decisions

And what of equality in individual care solutions? Do old people, people with disabilities, or any other people suffer discrimination on account of their personal characteristics in contravention of their

constitutional rights?

In my work I have come across such claims by individuals, as the following cases show:

- a 78-year-old patient was refused dialysis; the doctor initially justified this decision by reference solely to the available financial resources, only later adding the further justification of treatment-related reasons;
- observed flaws in tests and treatment for a patient's heart disease were claimed to have derived from the attitudes of the health care staff towards the patient's age and dementia (there were undoubtedly shortcomings in the treatment provided, but these could not be shown to derive from

the reasons claimed; admittedly, one of the doctors who had treated the patient said in defence of his/her own conduct that the hospital did not have the financial resources to implant a pacemaker in every “demented old person”). The ‘demented old person’ in this case was actually a 60-year-old employed woman whose paramnesia was largely due to her depression, and partly to her chronic heart disease, of which she later died;

- there have also been a number of other cases in which a doctor has expressed the opinion that it was for the best for the patients themselves or for their relatives that a hard-to-treat, perhaps multiply handicapped or aged relative had died, thereby relieving their relatives of a number of worries;
- some discussions on medical law and ethics have raised the proposal that patients’ ‘utility’ to their families or to society as a whole should be one of the criteria of selection for treatment.

In my opinion such views are not acceptable from the equality perspective.

I believe it is important for people to be able to trust in the realization of equity and equality in care solutions. This is one of the essential requirements for the credibility of the entire health care system. I also take the view that we cannot accept as an underlying principle that individual doctors’ own assessment of the ethical foundations of their work can be used as the basis for individual care solutions.

Equality and the prohibition of discrimination have been reinforced, making them together one of the main principles in the Constitution of our country. This being the case, we can presumably agree that the only prioritization in individual care solutions that is consistent with our values and our thinking on fundamental rights is one which focuses on the illness, the need for treatment and the effectiveness of treatment. This leaves us with the question: can this be realized in practice, and, if so, how?

I consider equality in care solutions to be of central importance to the issue of equity in health care, an issue directly related to the implementation of constitutional rights. I consider it particularly important that those patients who are unable to defend or supervise their own interests are not placed at a disadvantage to others. All possible steps should be taken to reinforce equality in decisions on treatment and care. Each decision affects a valuable and unique human life.

I refer here to the section on health care in the Parliamentary Ombudsman’s Annual Report 1999, which discusses cases relating to this theme. The Annual Report can be read and printed off from the Parliamentary Ombudsman’s website at **www.eduskunta.fi**.

Appendix: Members of ETENE:

National Advisory Board on Health Care Ethics (ETENE) 1.10.1998-1.10.2002

Chairman:

Docent Martti Lindqvist
Mäntyharju

Members:

M. Sc. Sinikka Lyllys
Mäntyharju

Social Worker Tarja Sipponen
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Chief Doctor Markku Oinaala
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M.D., Ph.D. Tapio Tervo
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Director of social affairs and health Juha Metso
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Chief Physician Helena Kääriäinen
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Deputy Chief of Dept. Marjatta Blanco Sequeiros
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Emeritus professor Erik Anttinen
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Assistant professor, University of Helsinki

Professor Raimo Lahti
University of Helsinki

Justice Marita Liljeström
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Docent, research director Anneli Sarvimäki
Kuntokallio, Helsinki

Hospital chaplain Sirkku Eho
Rovaniemi

MP Riitta Korhonen
Parliament of Finland

MP Tuula Haatainen
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MP Anne Huotari
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