

Ethical dilemmas in community mental health care

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Ethical dilemmas in community mental health care is the focus of this article. The dilemmas are derived from a discussion of the results of a qualitative research project that took place in five countries of the European Union. The different stakeholders are confronted with the following dilemmas: community care *versus* hospital care (clients); a life with care *versus* a life without care (informal carers); stimulation of the client toward greater responsibility *versus* protection against such responsibility (professionals); budgetary control *versus* financial incentives (policy makers), and respect for the client *versus* particular private needs (neighbourhood residents). These dilemmas are interpreted against the background of a value based ethical model. This model offers an integral approach to the dilemmas and can be used to determine policy. The dilemmas are discussed here as the result of conflicting values—namely autonomy and privacy, support and safety, justice and participation, and trust and solidarity.

Institute. This project focused on the ethical aspects of deinstitutionalisation in mental health care. Five European countries participated: Belgium, England, Greece, Italy, and The Netherlands.

In order to structure the discussion on community care the method of concept mapping was used. This method combines a group process with multivariate statistical analyses and concludes with a group interpretation of the resulting conceptual map. In each participating country a common set of 86 statements on critical elements of “good care” for persons with severe mental health problems were proposed to representatives of the five stakeholder groups. In total, 113 individuals from the five countries participated in the concept mapping: 26 clients, 21 family members, 25 professionals, 19 policy makers, and 22 members of the social environment. The participants first prioritised the 86 statements by rating them on a scale of importance. They then organised the statements into domains or clusters, which together represent for them the key aspects of “good care”.^{2,3}

The results were then processed statistically and represented in the form of a “concept map”. The 86 statements on good care fell into nine distinct clusters. These clusters were given the following names: working alliance, tailored care focusing on empowerment, rehabilitation, high quality professionals, needs of informal carers, accountable mental health care, effective treatment, accessible community care, and attitude of professional helpers. The results of the analysis of the concept of good care, as represented in the concept map, have been summarised by J van Weeghel and C Van Audenhove:

1. Good care is associated with a trusting and stimulating relationship between individual clients and their professional helpers;
2. Good care is seen as effective treatment, tailored to individual needs;
3. Good care presupposes the local availability of comprehensive services, which must be fully accessible to all those who need them, and
4. Finally, good care is associated with the care provided by the client’s family or other informal carers, whose need for information and support must also be addressed.⁴

In order to interpret the results, meetings were organised in the five participating countries and representatives of each stakeholder group were invited to take part. The primary aim of these meetings was to determine the major ethical dilemmas confronting each of the representatives.

Mental health care has been characterised in recent decades by a continuing process of deinstitutionalisation and the emergence of community care. The term deinstitutionalisation is used to describe the relocation of patients from large scale psychiatric institutions into the community. “Community care”, on the other hand, represents the provision of alternative psychiatric services intended to maintain appropriate support for the client together with his social network. Its main goal is to empower persons with psychiatric problems, enabling them to become fully participating members of the community.¹ This movement, however, implies a number of ethical dilemmas related to the partners or stakeholders in the context of community care—namely, clients, informal carers, professionals, policy makers, and neighbourhood residents.

In the present article the authors will provide an ethical reflection on the results of a European qualitative research project. We will begin, therefore, with a presentation of the research findings and then will develop a value based ethical model. The remainder of the article will discuss the ethical dilemmas confronting the various stakeholders.

A EUROPEAN RESEARCH PROJECT

From 1998 to 2001 the authors participated in the European research project, which was part of the Biomed Two programme, led by the Trimbos

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Following these meetings, the participating researchers collated the results and these were then discussed according to their similarities and differences. A comparison of the ethical dilemmas evident in the different countries was far from simple. Most dilemmas were common to all the countries involved, but some were specific to one or other specific country. Moreover, the dilemmas were expressed in different terms and emerged in a variety of forms and in various degrees of severity. A survey was made by D Bauduin, A McCulloch, and A Liégeois.⁵

Based on the survey, the authors were able to deduce one major ethical dilemma for each group of stakeholders:

1. For the clients: care in the community *versus* continued care in a psychiatric hospital;
2. For the informal carers: care of the mentally sick person *versus* a life without the duty to provide care;
3. For the professionals: stimulation of the client toward increased responsibility *versus* protection against increased responsibility;
4. For the policy makers: setting aside budgetary resources *versus* the provision of further financial incentives for community care, and
5. For the neighbourhood residents: respect for the client's particularity *versus* respect for their own particular needs.⁶

AN ETHICAL MODEL

a. The need for an ethical model

Although it goes without saying that a model is necessary in order to provide an ethical interpretation of the dilemmas outlined above, the development of an appropriate model considered relevant by policy makers remains a particularly difficult task. Policy makers tend to expect ethical reflection not only to take place on the personal and interpersonal levels but also to contribute to the feasibility of the organisation and evaluation of mental health care. The problem is thus evident: policy makers insist that information must be quantifiable, but ethical reflection is ultimately qualitative by nature and cannot, without difficulty, be reduced to quantifiable data.

Ethical interpretation among policy makers thus tends, for the most part, to be based on consequentialist or utilitarian models. Such an approach consists of an assessment of the positive and the negative consequences of a particular intervention in terms of its utility. Two principles are dominant in this method: effectiveness and efficiency. Effectiveness means that the interventions have to produce a successful result that is wanted or intended. The interventions have to be justified by evidence based medicine. This means that the interventions have proved their utility according to a statistical comparison of their positive and negative effects. Consequently, interventions have to be efficient. Efficiency means that the interventions have to be effective without waste of money or time. Efficiency is thus identical with cost effectiveness. The interventions are justified by a cost benefit analysis. Ethical evaluation is based, therefore, on the application of these two principles.

The present authors are of the opinion, however, that such a consequentialist or utilitarian ethical approach tends to fall short in the context of mental health care. The principles of effectiveness and efficiency do not do justice to all of the dimensions of "good care". The latter is an all inclusive concept that can be viewed from a variety of different perspectives. Effectiveness and efficiency tend to be the primary concern of the policy makers and therefore to dominate their perspective on good care. The perspectives of the clients, the informal and professional carers, and the

neighbourhood residents are afforded insufficient attention and are only considered indirectly, if at all.

An alternative ethical model is thus clearly necessary. Such a model will be obliged to meet two preconditions. In order to counter the critique outlined above it will have to do sufficient justice to the various perspectives associated with good care in all their diversity. Our alternative model ought thus to be an integral model. At the same time, however, it will also have to fulfil the expectations of the policy makers, in particular with respect to the feasibility of ethical reflection. As a consequence, our alternative model ought therefore to be a workable/operational model. A reasonable combination of the integral and the workable characteristics of the model is far from easy to achieve.

G Thornicroft and M Tansella have already tried to make ethical principles operational. They propose a five stage procedure:

1. An identification and selection of the ethical principles;
2. A proposition of specific definitions of these principles;
3. A validation of these selections and definitions;
4. A translation of the principles into outcome measures, and
5. An implementation of these outcome measures in research.⁷

In their paper the authors addressed the first two of these five stages and applied them in an effort to translate the given principles into outcome measures for mental health service research.

The present article will propose a similar procedure. We will suggest an ethical model that is based on values and that concerns "good care" in its entirety. We will thus endeavour to realise the integral character of the model and address the first two stages of the procedure. We will then apply the model to the ethical dilemmas derived from the research project. In this way we will make an initial attempt to realise the operational character of the model and to address the third stage of the procedure.

b. A value based ethical model

We propose an ethical model based on values.^{5 8} We prefer the concept of values to that of principles. A value represents the importance or significance that a person attaches to an action or situation as good, worthwhile, or desirable. The term "value" places greater emphasis on the ethical interpretation of an object, action, or situation that has to be valued by a subject, a human person. This valuation is not objective, but intersubjective. Values have to be weighed or balanced against each other. The term "principle" suggests more of an objective bias.

In our proposed model we selected and identified eight fundamental values: autonomy, privacy, support, safety, trust, participation, solidarity, and justice. We call them fundamental because they serve as the foundational pillars of mental health care. Each of these fundamental values encompasses various subsidiary values related to or deduced from the fundamental value. These values are related to all the stakeholders involved in community care. Nevertheless, some values are more related to one stakeholder than to another. Although autonomy, privacy, and participation represent outstanding examples of values related to clients, they can also be very important for family and professional carers and for neighbourhood residents.

We start with the value of *autonomy*. This value entails the freedom to choose from a variety of options. Autonomy presupposes an external possibility to choose. This requires a real variety of options and an absence of impediments or any form of coercion in relation to the individual concerned.

Autonomy, however, also presupposes the inner capacity to choose. At certain times and for certain activities this capacity can be affected by a psychiatric disorder. Those involved in mental health care must endeavour to the best of their ability to restore this capacity to choose so that the person concerned can make free choices. They must likewise respect these free choices to the greatest possible extent by requiring an individual's informed consent.

From autonomy we derive the value of *privacy*. This means the personal life or intimacy of a person. Physical privacy refers to the intimacy of one's own body. Psychological privacy concerns one's emotions and life story. It is important, therefore, to distinguish between desirable and undesirable psychological and physical contact. Informational privacy consists of all oral, written, electronic, or visual data on the person and is protected by confidentiality laws.

Respecting and promoting autonomy and privacy presupposes *support*. This includes all of the efforts and activities aimed at promoting the health or wellbeing of the person in care, in order to rehabilitate him into society and to improve his quality of life. Support represents the response of the community to another's ethical appeal. It takes the person's demand for help as its point of departure and endeavours to take into account and respond to his wishes as far as possible. Those directly involved are expected to offer the highest possible quality of care, and must be ready to question their care continually. They must offer an adequate quantity of care, tailored to the client, neither too little nor too much. Finally, they must guarantee the continuity of care.

The other side of support is represented by *safety*. This implies the protection of the person in care from any form of harm and ultimately concerns all stakeholders. Safety has three levels: the protection of life itself, the protection of physical and psychological integrity, and the protection of the physical and psychological health of a person. The physical and psychological aspects of human persons are interwoven. People experience such protection and the absence of threat as safety.

The fundamental value underpinning any form of relationship is *trust*. This represents a belief in the capabilities and loyalty of others. Good care will succeed only if people commit themselves to cooperation. Trust is the basis of cooperation. Since a relationship of confidence is neither obvious nor certain it has to be given the opportunity to grow through mutual respect. People can work on trust by being close enough to the other without intruding on his intimacy. This presupposes a balanced attitude between distance and closeness.

Trust is a precondition of true *participation*. This value is the core value of community care: people have to stay in the community as long as possible before being hospitalised and they must be returned to the community as soon as possible thereafter. Participation implies a genuine desire on the part of the person in care to integrate with other citizens in the community. At the same time it also implies a genuine desire on the part of other citizens to actively include the person in care within the community.

This participation presupposes *solidarity*. This value represents the encouragement and help of one individual or group for another, rooted in shared aims, opinions or feelings. It presupposes that individuals are not only concerned for their own individual interests, but that they can also give priority to another's interests and to the general interest.

Finally there is the value of *justice*. Justice amounts to the right distribution of goods and services in society. The general rule whereby everyone is given his due ultimately applies in this regard. Given the fact that individuals are unequal in their mental health, they can be treated "unequally" for a

period of time in order to afford them equal opportunities to function in the future. In other words, means ought to be provided according to real needs. At the same time, however, the available resources and services have to be distributed in a fair way. It is at this juncture that we encounter the principles of effectiveness and efficiency used by the policy makers.

In the practice of community mental health care, those involved are not always able to act in accordance with all the aforementioned values at the same time. In such instances, therefore, they are often confronted with an ethical problem or dilemma. They want to respect or promote certain values, but in doing so they inevitably threaten or violate other values. They are thus forced to make a choice. It is impossible to rank these values in an objective order of importance or priority. No value is fundamentally superior to any of the others. The assessment of values has to be made in each particular case.

The primary criterion for the assessment of values is *proportionality*. We can define proportionality as a judicious and balanced ratio between various different values in a particular situation. A choice is ethically justified when the values endangered and violated are in proportion to the values respected and promoted. There must thus be a proportionate or commensurate reason to justify a choice whenever any value is endangered or violated.

If we now look back at the consequentialist and utilitarian ethics, which typified the approach of the policy makers, from the perspective of a value based ethics, we can observe one striking difference: the approach of value based ethics is much more integral. The combination of the eight values outlined above has the capacity to cover the various perspectives of all the stakeholders involved. It will be evident that the value of justice—together with the principles of effectiveness and efficiency—does not stand alone, but requires the presence of the seven other fundamental values. When the eight values are taken together, the perspective of the policy makers is respected in equal measure to that of the clients, the informal and professional carers, and the neighbourhood residents.

In the remainder of the present contribution we will endeavour to determine whether our value based ethical model works in practice. To this end we will employ the said model as the basis of our critical reflection on the results of the European empirical research outlined above. We will address the ethical dilemmas derived from the data that emerged from the meetings referred to in the opening paragraphs, to which representatives of each stakeholder group were invited.

ETHICAL DILEMMAS CONFRONTING THE STAKEHOLDERS

a. The clients

The most significant dilemma facing the client is best expressed thus: *care in the community* versus *continued care in a psychiatric hospital*. This is the central question in the entire process of socialisation in the context of mental health care. The acid test is, nevertheless, the extent to which socialisation contributes to an improvement in the day to day life of the client. Several values have a role to play at this juncture: support and safety, autonomy and privacy, participation and solidarity.

A period of residency in a psychiatric hospital can be worthwhile in terms of the safe environment it provides. A hospital can represent a protected milieu in which the client is enabled to feel at home and enjoy a sense of safety. Moreover, the professionals in the hospital context endeavour to take into account the boundaries of the client's personal autonomy. Psychiatric problems, however, can

sometimes deprive the client of the necessary competence to make considered choices. In such instances, therefore, support is required.

The protection of the client's safety and autonomy also constitutes the negative side of a period of hospital residence. The secure environment offered by the hospital unavoidably implies a form of isolation from society and social existence in general. While it goes without saying that the client is free to take part in the life of the hospital and professionals are aware of the need to stimulate his social participation, the degree to which this is possible remains more limited than in the context of care in the community. In addition, the longer a client remains in the psychiatric hospital the more difficult his reintegration into society will be. The hospital environment is often insufficient to stimulate the client's autonomy, frequently taking over responsibilities that the client is still able to bear. The acquisition or reacquisition of a significant number of personal abilities thus becomes a quite formidable task in preparation for a return to life in the community.

The positive side of care in the community is clearly rooted in the client's participative freedom. Participation in society has become an important ideal in contemporary living: every individual is equal and each has the right to live his citizenship to the fullest. Socialisation thus implies that the client becomes less and less a patient and more and more a citizen. Such a process encourages autonomy and stimulates personal responsibility. Personal privacy likewise increases according to the client's integration into society as a full citizen.

The negative side of care in the community is that certain clients can be left without sufficient support. The support and safety of the client are thus placed under potential threat and the chance that the client might regress or even relapse becomes all the more real. While it is evident that certain clients will require more intensive support than others, one is left with the question whether they have the capacity to genuinely participate in social life, even with respect to those who are able to persevere in the community. Some clients lack sufficient communicative and self protection skills to function effectively in the community without increased support. Also a lack of solidarity on the part of other members of society is likely to confront virtually every client. Individuals with psychological and psychiatric problems are often stigmatised and their incorporation into the life of the community resisted. In order to increase the chances of genuine participation in community life it is thus necessary that we work on a change of mentality at all levels.

b. Informal carers

The socialisation of mental health care likewise confronts the informal carers of clients with an ethical dilemma: *care of the mentally sick person versus a life without the duty to provide care*. Values such as support, autonomy, privacy, participation, and solidarity are at stake here: values that can be realised on behalf of the client in the context of home care.

Home care implies a number of restrictions with respect to the personal lifestyles of the carers. At first sight, such an option represents something of a violation of their own self support, autonomy, and privacy. It goes without saying that home care can be enormously taxing and unavoidably implies that many other meaningful options are no longer available to the various members of the family. Certain families are confronted with greater burdens than others. Informal carers who support a person with a low degree of social function tend themselves to exhibit a high degree of avoidance behaviour, to lack openness toward others, to have few social contacts, and to maintain that important elements in the support of the client are not being realised.

On closer inspection, however, it would seem that support for a family member need not necessarily imply an infringement of the self support, autonomy, and privacy of the remaining family members. Where the latter freely opt for home care and experience their option as meaningful, this can represent a valuable enhancement of their sense of autonomy. As a matter of fact, informal carers can experience the support process in a highly positive manner through the development of solidarity between parents and children, brothers and sisters, the experience of the concern and sympathy of friends, and the acquisition of a more positive attitude with respect to individuals with mental health problems.

c. Professionals

Professionals tend to be confronted with a variety of different dilemmas. In the first instance they themselves have to deal with the choices of clients and family members. In their relationship with the client they are faced with the following dilemma: *stimulation of the client toward increased responsibility versus protection against increased responsibility*. Values such as support and safety, autonomy and participation, and trust and solidarity are at stake here. It goes without saying that one of the tasks of the professional is to offer the client new perspectives and to encourage his endeavours to live in the community, thereby promoting a significant number of values on behalf of the client. At the same time, however, professionals often find it difficult to determine whether it is in the client's best interest to stimulate his enthusiasm or to moderate it.

On the one hand, professionals and clients alike should not overestimate the potential benefits of community participation otherwise they will be likely to pay insufficient attention to the client's limited autonomy and thereby jeopardise his safety and overall support. Such dangers are particularly evident in the context of job rehabilitation. In such circumstances clients frequently exhibit unrealistic expectations and a mistaken evaluation of their capacity to function in the work environment. If professionals are nonetheless inclined to stimulate such unrealistic goals, they run the risk of exposing the client to probable future failure and disappointment. The acceptance of limitations as well as the stimulation of new steps in the process of recovery constitutes essential elements in every rehabilitation process. Professionals are always involved in the complex processes required to achieve a balanced and paced implementation, just as they are similarly involved determining the most opportune moment to carry out the various steps.

On the other hand, one of the duties of the professional is clearly to stimulate and encourage the client. Some clients opt to remain in the hospital environment on account of the sense of safety and refuge it can offer. Professionals have the duty to encourage the client's sense of autonomy and to support their social network in order to make a greater participation in community life possible. They thus respect the client's autonomous option without further compulsion. Within the relationship of trust they have established with the client, however, professionals can enter into dialogue, introduce, and address potential aversion to socialisation, work with latent feelings of anxiety, and set up a gradual process of rehabilitation.

d. Policy makers

Policy makers are similarly faced with a significant dilemma: *setting aside budgetary resources versus the provision of further financial incentives for community care*. It is a widely known fact that economic considerations have played a primary role in the socialisation of health care: the Belgian government has been obliged to reduce its spending or at least endeavour to maintain a balance in its health care budget. New theories

with respect to client rehabilitation and the development of new forms of mental health care have thus been forced into second place.

Values such as justice and solidarity are at stake when one is confronted with this dilemma. Distributive justice insists that people be treated equally when they are equal and unequally when they are unequal for one reason or another, or when they find themselves in a situation of inequality. The latter certainly applies to those in mental health care whose situation is clearly not equal to that of the average citizen in terms of their support requirements. These persons require quality support appropriate to their individual needs.

It remains a fact, however, that good quality care and support must be accessible and affordable for all. Health care is such a valuable commodity that society is not at liberty to submit it to the laws of the market. Its best option is thus to include it as an essential element of the solidarity exercised by society as a whole. It would thus be irresponsible for society to attach a different price tag to the necessary forms of health care and thereby force the client to absorb extra costs in line with the extent of the required support. In such circumstances, the increased socialisation of particular forms of support would inevitably lead to an increase in the personal contribution of the individual client. It should be evident that the toleration of such inequality would have a counterproductive effect on the socialisation of health care and would represent a contradiction in government policy.

e. Neighbourhood residents

When clients receiving mental health care live in the community they inevitably come into direct contact with their local social environment or neighbourhood. Other neighbourhood residents are thus likewise confronted with a dilemma: *respect for the client's particularity* versus *respect for their own particular needs*. It will be evident that values such as autonomy and privacy, support and security are at stake here, but the additional values of solidarity and participation also have an important role to play. We have already described how the stigmatisation of mental health problems can represent a significant hurdle for the participation of clients in social life. The goal of participation, however, cannot be achieved when neighbourhood residents are unable to muster sufficient solidarity with the mental health clients in their midst. This implies acceptance and appreciation on the part of other neighbourhood residents for the uniqueness of the client, respect for his autonomy and privacy, and promotion of his support. It also implies that neighbourhood residents be prepared to relativise a number of their own interests because the secondary effects of living with others are not always positive and desirable.

Mustering the necessary respect for the privacy and safety of other neighbourhood residents also calls for a learning process on the part of certain clients, and here they should be able to fall back on the support of the professionals. Indeed, support from the social networks in which clients live represents a central point of interest in the socialisation process. Support for the relationships in which clients are involved, the establishment of ongoing dialogue, and the

maintenance of mutual respect are thus of essential importance.

CONCLUSION

Our goal in the present contribution was to offer a reflection on the results of the European qualitative research project outlined in the opening paragraphs. To this end we have drafted a value based ethical model that offers a more integral approach to "good care" than that provided by the consequentialist or utilitarian model. The latter tends to appeal in the first instance to the principles of effectiveness and efficiency seen from the perspective of the policy makers. Our value based model takes eight fundamental values as its point of departure. Taken together, these values have the capacity to represent the perspectives of all of the stakeholders.

The challenge is therefore that the stakeholders are enabled to arrive at a responsible choice when confronted with one or other dilemma by explicitly addressing the underlying values involved and engaging in the process of proportional evaluation. The determination and proportional evaluation of conflicting thus reveals that our value based ethical model can work. All choices are based on fundamental values that ultimately have an effect on all the stakeholders involved. The stakeholders are invited to make their underlying values more explicit, so that opposing views, hidden assumptions, different assessments, and unintended consequences are brought into the public domain. Professionals and policy makers should create a culture of consultation and deliberation in which all persons concerned are enabled to discuss their respective values and evaluate their options.

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