Beyond disability. Assessing participation and autonomy in medical rehabilitation
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CHAPTER I

On autonomy and participation
in rehabilitation

Abstract

Objective: to explore the concept of autonomy as a basis for social participation, with particular reference to rehabilitation.

Methods: a study of relevant literature from the field of rehabilitation, building on theory developed in other fields (ethics, social sciences), and deriving important concepts and strategies for rehabilitation practice.

Results: conceptions of autonomy vary among individuals and cultures, but a crucial distinction can be made between decisional autonomy (the ability to make decisions without external restraint) and executional autonomy (the ability to act as one wishes). The liberal-individualist account of autonomy over-emphasises physical independence and does not sufficiently recognise the inter-dependency of all people, including those with disabilities. An ethic of care, complementary to the principle of respect for autonomy, should guide the development of rehabilitation strategies to enhance individual autonomy and participation in daily living. For rehabilitation, this entails an attentive attitude, maximising opportunities for informed choices, taking full account of each person’s preferences, needs and social context.

Conclusion: autonomy is central to client-centred rehabilitation since it is a prerequisite for effective participation. We suggest that autonomy, conceived as a basis for participation, is the ultimate aim of rehabilitation.

Introduction

"From the time my [disease] was first diagnosed through my entry into wheelchair life, I had an increasing apprehension that I had lost much more than the full use of my legs." ¹

Until recently, medicine has been more interested in disease than in the person behind the disease. Responding to social and political pressure, health care practitioners have started to move from a predominantly medical approach to one in which the individual takes centre stage. Understanding the effect of illness on a person’s life has become as important as consideration of disease itself.² The aim of this paper is to explore the concept of autonomy in relation to the participation of
people with a disabling condition in society and to discuss its relevance for rehabilitation. We suggest that autonomy, as the fundamental pre-requisite for participation, is a key concept for client-centred rehabilitation.

The publication of the ICIDH (International Classification of Impairments, Disabilities, and Handicaps) in 1980 signalled an important advance in conceptualising the mechanisms of components of disablement. Measures of function (e.g. strength, range of motion) were supplemented by measures of functional ability (e.g. tasks such as walking) and social functioning.

In rehabilitation, evaluations of functions or (dis)abilities are of frequent occurrence, whereas handicap, defined as the social consequences of disease, is seldom evaluated either in treatment or in outcome assessment. This is surprising and regrettable, given that the ultimate aim of rehabilitation is to maximise a person's participation in society. In the revised classification, the ICIDH-2 (International Classification of Functioning and Disability), 'handicap' has been termed 'participation', which is defined as 'the involvement of an individual in life situations in relation to health conditions, body functions and structures, activities, and contextual factors'. Participation is closely allied to the concept of disadvantage. As such, it depends on normative criteria. In the ICIDH-2, an individual's participation is compared with that of a person without disability. Participation, like handicap in the original classification, is therefore evaluated from a societal point of view. This approach exposes a conceptual contradiction inherent in the WHO scheme. While the terms handicap and participation purport to recognise the impact of illness as lived experience, they are assessed in terms of externally imposed norms which may be totally at variance with an individual's perspective.

The concept of autonomy adds a personal perspective to the assessment of participation. A person's participation can be demonstrated through life roles such as the worker's role, but the extent of personal choice often remains unknown. Similarly, lack of activity need not imply lack of participation, and if it does, it has many possible explanations. Some individuals actively choose to lead solitary lives, but many lack opportunities to participate. And even when a person declines opportunities for participation, the possibility of free choice may have been diminished by psychological and sociological pressures such as those experienced by residents of 'total institutions'. Thus, objective factors are not the only cause of disadvantages. In the domain of participation the main question to be answered should not be 'how does this indi-
individual’s social activity differ from that of others?’ but rather ‘how does this person experience her social existence?’ Quality of life instruments go someway towards addressing this question. However, they fail to give an adequate account of life as perceived by the individual, even though they address a variety of indicators regarding behaviour and perceptions. And they leave a further question unanswered: how much autonomy - how much scope for social action and for interpersonal relationships - does an individual have? Quality of life measures cannot be accepted as global indicators of the impact of disease unless they assess participation in relation to autonomy. In this paper we argue that a person-centred understanding of participation requires autonomy to be taken into account alongside the ICIDH-2 framework and quality of life, as currently understood.

**Concepts of autonomy in the context of disability**

The principle of respect for autonomy (literally: self-rule) is based on the notion of respect for the thoughts, will, decisions and actions of other persons. The most influential model of autonomy in Western countries is the liberal-individualist view, which stresses freedom of choice and action. The liberal view has provided an important foundation for rights, such as the right to self-determination and privacy, informed consent and protection from interference by others, but it has important limitations. Liberal individualism tends to equate autonomy with physical independence. As a result, dependency measures are widely used as markers of quality of life. However, there is abundant evidence that physical disability is a poor predictor of quality of life and that external perceptions of disability are misleading. The liberal view does not sufficiently recognise that individuals are social beings. Interdependence is a characteristic of human life, not an aberration associated solely with illness or disability. The liberal view is especially inadequate in relation to the rehabilitation of people living with the daily reality of disability. In chronic conditions dilemmas regarding autonomy may be less obvious, more complex and more far-reaching than in acute care. Decisions concern a person’s way of life, not just choice of treatment. Differences between the values of patients and of rehabilitation workers are frequent sources of confusion or conflict. There may be disagreements and misunderstandings about what abilities or capacities are needed for participation, about what counts as an acceptable quality of life, and about ultimate goals in treatment. Conceptions of autonomy derive from a cluster of value-laden ideas which differ between persons, social groups and cultures. In Western cultures, autonomy is strongly associated with normative states such as
health' and 'adulthood' which allow maximal independence and freedom of choice. Different culturally-determined conceptions of adulthood, illness, independence and social roles are encountered among other communities, including minorities living within western states. Communities which value inter-dependence within and between families may not perceive individual autonomy as the pre- eminent goal of rehabilitation. Such cultural variations have profound implications for the contents of rehabilitation treatment.20,21

The liberal conception of autonomy has been extended by proponents of an 'ethic of care'. In some contexts, 'care' can appear to be inimical to personal freedom, but the ethic of care endorses the idea of autonomy as self-governance, while placing greater emphasis on the social context. According to Tronto care can be understood in four inter-connected senses.22 Care can be described as an exchange: care is thus a process of directly meeting practical needs (care-giving), and also something received (care-receiving). Two further aspects of care, describe attitudes which can also be exchanged or shared: care as concern for another person (caring about, attentiveness), and care as responsibility (taking care of). An ethic of care views each person's individual needs within the context of their life's narrative11,22-24, where all four aspects of care are likely to be expressed in reciprocal relationships. The liberal view of autonomy is focused largely on maximising a person's scope for independent action. The care perspective is more ambitious. It aims to maximise a person's opportunity to act authentically within a social framework which does not deny the reality of inter-dependence.

**Decisional autonomy**

To understand the meaning of autonomy in relation to a disabling condition it is important to distinguish decisional autonomy from executional autonomy.8,25,26 Executional autonomy is defined as the ability and freedom to act on the basis of decisions, e.g. actually dressing oneself as one wishes. Physical disability may diminish autonomy of action without necessarily diminishing autonomy of decision making. Decisional autonomy is the ability to make decisions without external restraint or coercion, e.g. deciding when and how to get dressed. The first requirement for decisional autonomy is physical conditions which allow chosen actions to be carried out. Such conditions are difficult for people with a disability to achieve, even where care systems are well resourced. For example, reliance on wheeled transport inevitably reduces a person's ability to respond flexibly to the environment. Even the simplest projects have to be planned in advance, and it is difficult to
make ‘spur of the moment’ decisions. All too often, physical restrictions cause expectations to be lowered so that decisional autonomy is undermined. The second requirement for decisional autonomy is psychological conditions which allow choices to be made freely. Ignorance restricts decisional autonomy just as information facilitates it; a choice of two alternatives may be offered, while other options are not disclosed. Other psychological barriers to decisional autonomy are too complex to be discussed fully here, but one everyday example is the restriction of an individual’s autonomy by a rehabilitation worker who controls the choice or timing of daily activities. Psycho-dynamic mechanisms can be important, for example the dominance of a person with a disability by a powerful partner (the reverse also occurs). Sociological factors cause personal horizons to be narrowed by institutional life, so that decisional autonomy is diminished. An important product of decisional autonomy is self-realisation: the ability not only to make choices freely and independently, but also to shape one’s life into a meaningful existence which expresses individuality. A person requires psychological rather than physical independence in order to take control of one’s life, and to choose among options what life to live and what risks to take.

**Autonomy and participation in rehabilitation**

Autonomy is not a state of being, but rather something individuals develop in the course of their lives. Autonomy can be viewed as a continuous and personally unique variable which exists in different degrees, depending on a person’s circumstances. Thus, autonomy may be restricted by changes in the physical or social environment, just as it can be affected by impairments, for example following trauma. Reduced autonomy in some aspects of life, however, is compatible with full autonomy in other aspects. Furthermore, the actual and desired degree of decisional and executional autonomy will vary among different roles and activities. In rehabilitation, therefore, we should not strive for some ideal state of autonomy. People should be enabled to choose which decisions should be made by themselves and which should be left to others to make. As Komrad stressed, the health professional must respect the person’s potential for autonomy at all stages of treatment.

Chronic or progressive disability necessitates a renewed reflection on one’s goals and values in order to find a new way of living life as desired. In this process all aspects of autonomy should be taken in consideration: decisional, executional autonomy and self-realisation. Rehabilitation workers can guide the individual in deter-
mining options and strategies. They can provide meaningful information, allowing time and creating an environment in which autonomy is respected and encouraged to the extent of the individual’s abilities or wishes.\textsuperscript{35,36} Meaningful information gives people a sense of control over their situations, even when they hand over decisions to others, and can help people to accommodate themselves emotionally and practically to illness and disability.\textsuperscript{18} Individuals have different methods of adjustment, and each phase of rehabilitation generates choices and strategies for maximising autonomy and participation.\textsuperscript{37} At the outset, a comforting and directive approach may take priority over enablement. Later, or in a different person, these strategies could severely restrict autonomy.

The basic concerns of a person with a disability are the same as those of a person without a disability: to live a good or meaningful life and to participate in the social and occupational activities of one’s choice. When disability restricts the range or quality of activities, respect for autonomy will be an especially important issue in the domains and activities that contribute to the identity, self-esteem and roles which the individual values.\textsuperscript{30,31} The more important an activity is to the individual, the more important it may be to ‘be in charge’, especially when one is not able to perform the activity oneself. Accordingly, in the light of autonomy, participation should be understood primarily in terms of individual preferences, rather than in terms of general competencies.\textsuperscript{9,29-31,38} Relearning to write or to play with a grand-child might be far more important for an individual than learning how to dress independently.

When advising on services, rehabilitation workers must be aware that the terms on which a service is provided has a bearing on how far it is an aid to autonomy. Money is the single most important means of enhancing autonomy for people with a disability, as for others.\textsuperscript{39} A person who pays for services such as house-cleaning or personal care may perceive these as equivalent to paying for a taxi when one is not able to drive a car, but unpaid help may be perceived as humiliating dependency.\textsuperscript{39} Unfortunately, those who most need care are the least likely to be able to reciprocate.\textsuperscript{39} However they are provided, services must be designed to maximise autonomy. In the Netherlands and in the United Kingdom, services for people with a disability often restrict autonomy rather than promote it. For example purchasing the help one needs with governmental funds [persoonsgebonden budget in the Netherlands, or direct payments in the UK] is still not easy because of long waiting lists or unclear procedures.

In conclusion, we suggest that the patient-professional encounter should be a dialogue through which an individual’s values and prefer-
ences are discovered. For the professional, respect for autonomy requires a client-centred rather than a biomedical perspective. An ethic of care complementary to the liberal view on autonomy can guide the development of treatment strategies to enhance autonomy and participation in daily living. An understanding of the uniqueness of people is paramount. For the client, an equally radical shift from a personal to an interpersonal perspective is required. Respect for autonomy does not license a person to do or say as he pleases. It entails responsibilities as well as rights, and demands negotiation which takes account of the views of others, including the therapist. Understanding interdependence can be a crucial first step in regaining autonomy. In recognition of the above mentioned aspects, we suggest that respect for autonomy, and the process of enabling it, should be built into the definition of rehabilitation. The ultimate aim of rehabilitation is to regain and retain the highest possible level of autonomy, in order to maximise participation.

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References


