Autonomy and rehabilitation

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ABSTRACT

In minority world countries, autonomy is central to client focused rehabilitation, as it represents a prerequisite for effective participation in the process of rehabilitation. The diverse and dynamic paradoxes within the "autonomy paradigm" will ensure its safe application and survival in such communities. However, the strong family relationships and different cultural backgrounds of majority world countries motivate us to conclude that a "patient-family interactive deliberative process" based on accommodation and negotiation is more acceptable, reliable and implementable in these communities. Our suggested model of decision making is more convenient, particularly in cases where competency is compromised by cognitive dysfunction, political or religious restrictions. The insistence on absolute autonomy beyond such borders could be counter productive for both patients and health care personnel. Clearly, the need for further research is paramount, as a deeper understanding of the various cultures and subcultures is essential for developing a more useful structural framework for rehabilitation.

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The nature of medicine has changed dramatically in the last few decades. It has been more interested in specific diseases than in the persons behind these diseases. During the past 3 decades and probably as a relatively young field, rehabilitation medicine has concentrated on acquiring recognition and acceptance by the medical community.[1] Unlike traditional medicine, it is not oriented towards the process of healing, rather it attempts to ameliorate handicap by restoring skills and capabilities through functional retraining and environmental adaptations.[1,2] Although, minor formal attention was originally directed to the ethical aspects of rehabilitation care, ethical issues have become an unavoidable part of rehabilitation theory and practice. As a response to extensive social and political pressure, health care personnel started to move from a primarily medical approach to one in which the key person is focused upon. However, ethical dilemmas inherent to the rehabilitation process have appeared in the literature,[2-4] and the deep understanding of the effects of illness on the individual's life has become as crucial as the disease itself.[5] Among the fundamental ethical principles pertinent to rehabilitation practice is autonomy and the social role of people with disabilities. The definition of these disabilities has evolved during the past 3 decades to difficulty in conducting daily activities resulting from specific health conditions interacting with the social and physical environment.[6,7]

According to generally accepted opinion in the Western medical communities, autonomy is a prerequisite for reaching high quality of life and it is considered to be the primary goal of rehabilitation programs. The principles of autonomy involve respect for the values and beliefs of other people. Individuals possess the rights to self-determination and making decisions about their personal life. Decisions should be respected even if they appear to be unwise.[3] The quality of life encompasses different aspects of a human being's existence. These aspects range from purely physiological and ability to return to work, to a complex series of social activities and psychological problems.[8-11] No doubt that quality of life is a subject of numerous

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biological and social influences. It has personal instead of general particulars. If we accept quality of life as a primary goal of rehabilitation and autonomy as a prerequisite for reaching this goal, then we have to create a rehabilitation model, which incorporates high respect for clients' autonomy. Maybe, more compelling to clinicians is the evidence that patients who are satisfied with the client-centered aspect of care are more likely to have better clinical outcomes.[9]

The liberal concept of autonomy that is widely accepted in Western societies is strongly associated with the health status of each person. According to that concept both, decisional and executional autonomy will be negatively affected in people with physical and mental impairments. Such people suffer from a lack of participation in rehabilitation, this automatically means that their freedom on choice and action is severely affected.[12,13] This model of "sick role" has existed as a universally accepted model through history. That means that "when sick individuals cannot perform their normal roles and must follow directions of doctors."[14,15] This attitude will create loss of autonomy for individuals. Socially imposed stereotypes which equates autonomy with physical independence reduce the person with disability to "no choice" child in front of authoritative parents. The opinion that emphasizes that the cure is the only significant solution has a devastating effect on the self-esteem of persons with disabilities. Unfortunately, researchers focusing on creating tools that enhance dignity and self-determination are still very rare. The maxim "nothing about me without me" should be the first step in provoking dialogue between clients and professionals.

In 1980, the publication of ICIDH-1 (International Classification of Impairments, Disabilities and Handicaps) revealed an important step in the understanding of components of disablement and handicap. The revised version of ICIDH-2 introduced the term participation. There is a regrettable inability to evaluate handicap as a social consequence of disease, either in the treatment or outcome assessment in ICIDH-1. This is truly inherent to the conceptual definition of the term. The same paradox is clear in ICIDH-2 when participation of a person with disability in rehabilitation is compared with that of a person without disability and therefore, equally evaluated from a societal point of view. So, both handicap and participation are assessed in terms of externally imposed norms that may be totally at variance with the individual's perspective.[4,16,17]

The concept of autonomy adds a personal perspective to the assessment of participation in rehabilitation. However, there are intrinsic and extrinsic factors that affect autonomy. A certain degree of blurring is noticed when these factors are discussed in the Western communities. This blurring includes points other than the extent of personal choice, lack of opportunities for participation in rehabilitation, psychological and sociological pressures, interpersonal relationships and quality of life. Ironically and paradoxically, in such communities, the consideration that autonomy, as a fundamental prerequisite for participation in rehabilitation, is the key concept for client-centered rehabilitation means that there is a clear exclusion of the cultural issues in the developing or majority world countries. The concept of autonomy originated from the highly developed or minority world countries. This interesting and stimulating model provide an exciting example in that these countries provide a lead to the less developed or majority world countries. Longevity, education and income are the 3 indices used by the United Nations as more sensitive indicators of wealth or poverty of nations. Collectively, these form the human suffering index which is an alternative measurement of economic and social progress. The aim of this article is to review the origin and development of autonomy and participation of disabled people in rehabilitation. Drawing on the work described by various authors during the last two decades,[2,3,6,8-10,12,14,16,18-21] it is argued that the challenges to professionals and patients are paramount. With all the discrepancies between the 2 world groups, is it justified to consider patient-centered decision-making as universally or globally appropriate?

Concept of autonomy. Any study of autonomy requires a conceptual definition that is broadly applicable and amenable to validation. Personal autonomy remained a widely used but loosely defined concept in the literature, until it was suggested that it is 'the exercise of self determined, goal oriented behavior that is or can be potentially threatened or inhibited by a variety of circumstances, real or symbolic, intrinsic or extrinsic to the person.'[22] However, the autonomous individual must be capable of rational thought and self-governance. This led Hertz to suggest 3 defining attributes to autonomy: voluntariness, individuality, and self-direction.[23] The most influential model of autonomy in Western communities is the individualist-liberal view that tends to equate autonomy with physical independence and is considered by certain authors to be quite correct.[4] Moreover, the need to balance the promotion of autonomy and independence with the need to minimize risk constitutes an important dilemma. In this sense, independence must be viewed appropriately as one dimension or a contributing factor to personal autonomy. This is because it is most frequently associated with an individual's level of physical functioning and ability to perform activities of daily living unaided.[24] Our understanding of independence may be advanced by considering dependency as the opposite pole of a continuum. Arguably, an elderly person can be physically, economically or psychologically dependent. Yet, this does not imply that he or she cannot totally make autonomous decisions. Although the liberal view does not sufficiently recognize that individuals are social beings, autonomy and interdependence are characteristic features of human life that were deeply rooted in the human history long before the individualistic liberal view was formed and adopted by the Western countries.[25] This means that autonomy is not essentially a new concept. Of course what is perhaps new, is the idea that autonomy might be a useful framework for the development of rehabilitation services of minority world countries although it does not seem to be appropriate to consider autonomy per se as the magic solution for development of rehabilitation services in the majority world countries.

The intrinsic and extrinsic factors that affect positively or negatively the 'autonomy paradigm', were discussed in an ambiguous and less clear way, although it was admitted that the dilemmas regarding autonomy may be less obvious, more complex and far reaching.[4] The complementary effect of the 'ethic of care' to the principle of respect of autonomy is paramount, as it places greater emphasis on the social context of personal autonomy. We totally agree with viewing each person's individual needs within the context of their life narrative. Certainly, this will maximize the patients' opportunity to act confidently within a social network that is not ignoring the characteristic human interdependence. The presence of strong and competent family support can be positively used for the benefit of the disabled patient and will help in negotiating the discharge of the patient to the community.[26] This will endorse our opinion that a different framework is more suitable for the majority world countries. The complexity of life and diversity of human being attitudes are strongly opposed to the ready-made definition of autonomy. This autonomy, as well as other aspects of the life of the human being, is subject to biological and social influences, which should be taken into account. Any decision on this issue should be considered only as a framework, not as a permanent ready made solution for all peoples and communities. For some patients, autonomy, which means freedom of choice and actions,[14,20] plays only a limited role in reaching high quality of life. The question that should be addressed is which aspect of autonomy we are striving for? Autonomy in some areas of life is already restricted by cultural, social, political or religious norms over which physical abilities or inabilities do not have much influence. However, if people without physical disabilities are used as a standard to assess participation in rehabilitation and its meaningful role, we will neglect the complexity of the human being.

In this part of the world wherein we live, people with different physical and mental restrictions are placed in family settings rather than institutions.[26] Traditional relationships within the family are very strong and the role of each member has been defined in advance. In such settings, even the people with full physical and mental capacities are restricted in obtaining full executional and decisional autonomy. If one follows a liberal account, we would expect a very low quality of life in patients with chronic illnesses. But on the contrary, many times it is found that the feeling of protection and security in a family setting is a quality of life by itself. Thus the observation that one person cannot walk as others is merely a statement of fact which claims nothing about quality of life. Opposite statements cause normative implications that are not only inappropriate between cultures but also are inadmissible within cultures. To imply that physically disabled or elderly persons have poorer quality of life than younger or able-bodied individuals is nothing but reinforcement of stereotypes that underline discriminatory practices.

Decisional autonomy. Autonomy is not a simple and straightforward concept, but involves several closely interwoven ideas. The meanings acquired by autonomy were as diverse as self-governance, liberty right, privacy, individual choice, freedom of will, causing one's behavior and being one's own person. Typically, it refers to what makes a life one's own. Collopy,[27] distinguished between 6 polarities within autonomy: decisional (making decisions) versus execution (implementing decisions); direct versus delegated; competent versus incapacitated; authentic versus inauthentic; immediate versus long range; and negative versus positive autonomy. This means that autonomy is more complex in clinical practice than previously suggested.[4] The patient centered decision making that in some European countries and the United States of American (USA) is typically considered to be appropriate, may not be universally endorsed, thereby harboring the potential to complicate the care of patients from different cultural backgrounds in potentially unrecognized ways. Western bioethics now focuses on ethical decisions that are based on individual autonomy whilst the social framework of decision making has significantly diminished. The individualistic model of medical decision making the so called 'autonomy paradigm' has achieved dominance in the USA over the 'social framework paradigm'. The later, plays a greater role in other countries and some cultural groups in the USA. The family and physician opinion appear to play a larger role in medical decision making for

Japanese physicians and patients than for their counterparts in the USA who places greater emphasis on patient autonomy.[28] This means that technical development is not the whole story. The same attitudes with variable intensity were noticed in the less developed nations.[26-28] However, the reliance of the USA community on patient centered decision making, serving as the corner stone of informed consent has been referred to as 'cultural artifact', in that reliance on this concept is not universal and maybe somewhat anomalous.[28] This is because 'culture' is defined as that set of values, beliefs, customs and behaviors that are shared by a group of interacting individuals.[15] This means that culture and nationality are not identical and physicians and patients within a given national culture like the USA could be said to belong to different subcultures. So, factors that influence decisional autonomy are much more than the physical and psychological conditions, ignorance and education and sociological factors that were proposed.[4]

Contemporary life offers many opportunities to people with physical limitations to complete their expectations. The ways of communication are being changed dramatically. The possibilities of getting information and education are enormous. The person who has lost the use of his legs might view a new world, more creative and challenging than the previous one. That's why some philosophers from the Frankfurt School of thought have counseled against imposing a unique system of values on an entire population, arguing that this might prevent autonomous individual development.[15] The universal applicability of social norms may be one of possible reasons for poor compliance and adherence of patients to rehabilitation treatment. Studies to compare clinicians and patients' perceptions and assessments of disability in multiple sclerosis revealed disagreement on which domains of health status were most important. Clinicians emphasized the importance of physical disability, contrary to patients who underlined the meanings of mental health, vitality and general health.[14]

Apparently, a preconceived idea of what is right and what is wrong contradicts essential features of the human being, and his or her freedom. However, it is felt that any comprehensive rehabilitation program should take into consideration the beliefs and attitudes of patients as part of their dignity. Nonetheless, it has to be kept in mind that medical decisions bear the risk. Dignity with risk means the ability of persons with disabilities to assume the risk for themselves. Balancing the risks and right to autonomy is very important in creating right decisions. This actually includes all fields of medicine. Patients with amyotrophic lateral sclerosis (ALS) should be encouraged to participate actively in the decision making process whenever possible, particularly in determining which diagnostic and treatment approaches they found most acceptable.[29] This is of crucial importance when we know that cognitive function in ALS remains clear until the very end of life. So, in accordance with the principle of patient autonomy, physicians should respect the right of the patient with ALS to refuse or withdraw any treatment modality including mechanical ventilation.[30] This is well understood and accepted in the USA, United Kingdom and some European countries. However, it is not ethical or acceptable and considered suicidal and contradicts religious beliefs in almost all Muslim communities. In the Western communities, physicians are ethically obligated to abide by the patient's decision to refuse treatment, no matter how strongly they disagree with the decision.[25] Personal autonomy also has special roles in cardiopulmonary medicines, anesthesiology, traumatology and gerontology. It has a central role in the construction of a prediction model for functional recovery in stroke.[31] This means that it touches the borders of all areas of modern medicine.

Autonomy and participation in rehabilitation. During the past decade, there has been an increasing emphasis on patient involvement in care. The rationale is found in a growing body of research evidence to suggest that active participation leads to improvements in patient outcome and adjustment.[32] Like autonomy, participation in rehabilitation includes collaboration, partnership and involvement. In this issue, the important contribution of informed consent, patient teaching and provision of relevant information should be highlighted. More often an individualized approach instead of systemic adherence to a rigid policy must be adopted. Participation in setting goals of rehabilitation seems to have a positive impact on patient's motivation. The degree of motivation will influence the outcome in stroke rehabilitation although being in the hospital by itself demotivates patients.[33] The World Health Organization defines motivation as a global mental function, conscious or unconscious that produces the incentive to act. Motivation may be influenced by both personal factors (age, gender, personality, educational and social background, experience, coping capacity, health status and life style) and environmental factors (the manner in which health care professionals communicated information, over protection by family members and nurses, comparison with other patient's performance and the unstimulating hospital milieu).

These environmental factors can be enormous and devastating in certain countries such as South Africa and the Gaza strip.[34] In the latter, the health infrastructure is crumbling, even the basic health programs are functioning poorly if at all. The water and sewerage infrastructure had not been attended to properly, and the situation has reached crisis proportion with salinity levels in drinking water up to 5 times the recommended maximum. The common thread is that people are being granted self-determination and governance including the right to determine their own health priorities. If equity, access and respect to human rights are maintained, other priorities will flow naturally. Even, drug misuse as an environmental factor may stem from a person's autonomy to choose.[35] The challenge therefore is to develop research strategies that probe the effects of various intrinsic and extrinsic factors on autonomy and participation in rehabilitation sittings in the majority world countries.

Regarding autonomy and its relation to participation in rehabilitation, we should not strive for an ideal state of autonomy.[4] This is due to its invariable restriction by changes in the physical and social environment. In that sense, autonomy can be likened to a thermometer that keeps on rising and declining at variable stages of rehabilitation. However, the common thread should be the respect of the health professional to the person's potential for autonomy at all stages of management. This will allow self-realization to be practiced by the patients as a means of action on his own choice and independency. Important information should always be given to the patients to help to control their situation in collaboration with health care professionals and members of the family. The input produced by the various members of this team will depend on the stage of rehabilitation. At the outset, a comforting and directive approach takes priority and precedence over enablement. Accordingly, in the light of autonomy, participation in rehabilitation should be understood primarily in terms of individual preferences, instead of in terms of general competencies.[4] So, common concerns such as employment, owning house, investments, getting married, having children are the same for those with and without chronic illnesses. Giving an equal chance to all people regardless of their physical conditions to reach such goals presents a big step in achieving autonomy. Strong family support and understanding are achieved through reasonable and active negotiation.[26]

The relationship between attitudes towards patient autonomy and demographic factors (ethnicity, age, religion, level of education and income) has been studied.[36] The Korean-American and Mexican-American subjects were more likely to hold a family centered model of decision making rather than the patient autonomy model favored by most of the African-American and European-American subjects. Within the Korean and Mexican-American group, older subjects and those with lower socioeconomic states tended to be opposed to truth telling and patient decision making, even more strongly than their younger, wealthier and more highly educated counterparts. On the other hand, religion was related to differences in attitudes towards some of the autonomy indices in the European-American and Korean-American groups. However, further analysis of religious differences between various groups should be conducted. This is very clear and highly indicated in the Middle East countries.[26]

The principal changes in health care delivery should center on patient's needs and on designing an environment to humanize patient care. This total person concept attempts to address factors that contribute to health and well being by nurturing a patient's mind, body and soul through education, active patient participation, family involvement, nutrition, art and even music.[37] Patient focussed care resulted in long term benefits, such as decreased lengths of stay, increased personal and physician satisfaction, decreased turn around time for ancillary services and better use of personnel.[38] The conclusion of the various leaders in health care have opined 'no right is more important to a person's dignity and well being than the right to make health care decisions.'[40] We agree that client-professional encounter should be a dialogue through which individual's values and preferences are discovered. Stigmatizing the people based on prejudiced social standards will have the greatest negative effect on autonomy and participation in rehabilitation. Handicaps as a social consequence of disease have to be treated by social remedies. We believe that education of 'healthy' population regarding abilities-inabilities presents the best way to improve quality of life. That's why the future projects should promote the same ideas to teach society how to accept physically restricted people as counterpart members. This is the best way of promotion of autonomy based on personal choice rather than generalized definitions.

The central theme of long term care decisions is that the prevailing bioethical model of decision making, with its emphasis on individual autonomy and life sustaining medical care at the very end of life, is inadequate.[40] It is inadequate because the chronically ill person who depends on multiple supports for survival in a nursing home or at home, cannot function as an isolated person in making decisions anymore than in the rest of daily life: that person's intimate involvement with family and professional care givers necessitates their participation in the decision making process. The autonomy model of medical decision making in acute care is also insufficient because the decisions that may be of most importance to the person needing long term care are often those involving seemingly mundane aspects of life, not the crisis of acute care medicine. So, we should formulate a new way of thinking about making decisions, for those who need long term care. Collopy[27] makes his argument clearly: 'the highly medicalized, protectionist, risk-wary model of care' tends to protect people from injury, poor nutrition and poor hygiene. But, the way to maintain personhood despite diminished physical or mental competence is by 'charting one way through the minute and mundane realities of daily life', even if the chosen path jeopardizes physical safety. Such autonomy, means more than the more commonly discussed rights to make decisions about issues such as resuscitation and chemotherapy. However, McCullough and Wilson[41] and Saadah[42] argue that to make truly ethical decisions in long-term care, we need to move beyond the patient centered framework to a 'family centered deliberative process'. In clinical practice and even in the Muslim communities, this is almost always not possible without involvement of the patient himself. The strong family ties and the high respect that the individual patient displays to his elder family members and social leaders will not deny him a special position in the process of decision making. As a matter of fact, he remains and should remain the corner stone of the process. So, we believe that such framework should include the patient himself, simply because he is the most concerned. This means that we should move another step forward to modify and apply the aforementioned framework as a patient-family centered interactive deliberative process 'based on such notions as accommodation and negotiation'.

In conclusion, there are few that would argue against autonomy, conceived as a basis for participation, to be the ultimate aim of rehabilitation. However, with the strong family relationships and different cultural backgrounds of the less developed countries, a 'patient-family centered interactive deliberative process' based on accommodation and negotiation, is more acceptable, reliable and implementable in these communities. The health care professionals need to identify which part of their knowledge base is necessary for this process and how they can express this knowledge and associated skills, but simultaneously facilitate and encourage patient participation in the decision making process. Their competence should also involve an understanding of both medical and social models in a well-integrated and comprehensive manner. This educating and accommodating attitude will ultimately meet the needs of disabled people and lessen friction and paternalistic behavior of various members of the family of the index patient. It may offer a step towards a more convenient structure that respects and appreciates all interacting participants and contribute to the future change of attitude that is being recommended in the developed nations.[4]

Personal autonomy cannot be implemented to all people without limitations. It is justified as long as decision making does not interfere with the other person's benefit and the generally accepted social and cultural backgrounds. Our suggested model of decision making 'the patient-family centered interactive deliberative process' is more convenient in cases where competency is compromised by cognitive dysfunction, political or religious restrictions. Insisting on absolute autonomy beyond such borders could be counterproductive for both patients and health care personnel. Autonomy in rehabilitation must be based on individual rather than general approach. The dialogue between professionals and client should try to discover the individual's values and preferences to assure the best and optimal solution.

The need for research is paramount. A deeper understanding of the various cultures and subcultures is essential for developing a more useful structural framework for rehabilitation. There is also a need to develop new indicators to measure the efficacy of such frameworks in the various communities. Such indicators should incorporate quality of service, satisfaction, individual well being and social changes. This requires participation of health workers, disabled and able bodied people in the community. This means that researchers should consider disability as a social construct and not just as a medical impairment. Such research has to measure not only the functional limitations but also the socio-cultural barriers inherent to the index community or nation. Finally, the majority world countries need more attention to the development of rehabilitation services. Those services lack even the elementary infrastructure. As previously mentioned if we encourage self determination and governance, access and respect to human rights in such countries, optimal structural frameworks will develop naturally. However, the diverse and dynamic paradoxes within the autonomy framework will certainly ensure its safe application and survival in the minority world countries.

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