

**HUMAN AUTONOMY AND HEALTH SYSTEM
RESPONSIVENES IN DEVELOPING COUNTRIES: THE
POSITION OF THE ELDERLY DECSIION MAKING
INHEALTH CARE IN KENYA.**

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Abstract

Observance of autonomy in health care delivery to the elderly isvariably compromised globally following the demographic transition of the 21st century that got many nations unprepared to meet health care needs of this group. As an element of health systems responsiveness, the review examined the implementation of autonomy in caring for the elderly with focus to Kenya. The hypothesis is that the observance of autonomy in health care delivery is compromised.The paper analytically reviewed the global to regional perspectives of the implementation.Findings are that both the health care providers, the elderly and the community contribute significantly to compromise autonomy in health care delivery. Key features include negative verbal utterances and negative attitudes that negates conducive participatory decision making environments. However, there are also good practices that promotes and enhance observance of autonomy when caring for the elderly. Theories that anchor promotion of autonomy include economic efficiency and psychological theories. Elderly persons who get the opportunity to participate in their care experiences good physical and mental wellbeing which translate to optimal aging.Improvement in observing autonomy in caring for the elderly can be achieved through health promotion, specialized training in gerontology and community sensitization.

Key Words: *Beneficence, Competent individual, Elderly, Informed consent, Optimal aging.*

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I. Introduction

The term autonomy refers to one of the universal fundamental ethical principles of freedom which is also reflected in most health related professional codes. The term has its origin in the Greek word “*autonomia*” from *autonomos* literally” having its own law: *autos* for self and *nomos* for law (Eileen et al. 2014; Andresen et al. 2008, Stiggelbout et al. 2004). It is a principle that expresses the idea that persons should direct their own actions and be free from coercion or undue influences in doing so. Deeper insight which incorporate concepts of critical reflections and negotiation expands its meaning and application to include informed decision making (Agich 2002; Dworkin 1988). The emergence of patient autonomy is traced back to the years 1960s and 1970s in the great social movement that created diverse range of civil rights of which some including the expanded individual rights in health care such as access to abortion, end-of-life decision making, privacy and informed consent were constitutionally protected. Autonomy touches almost all areas of social life but has profound effects on medical ethics and practice where it is expressed in the doctrine of informed consent.

This review is part of an ongoing study that seek to evaluate health systems responsiveness to the health care needs of the elderly in Kenya in light of the World Health Organization’s elements of health systems responsiveness. The aim is to rejuvenate and encourage the Kenya health system to incorporate the elderly as active participants in the decision making process in order to gain their compliance in health care delivery. The impact of the demographic transition of the 21st century got many countries unprepared to adequately meet health care needs of the elderly. This results in poor and compromised observance of the elements of health systems responsiveness of which autonomy is (Pew 2014; Falk, 2013; Seychell et al., 2013; Dwele, 2012; Mubila, 2012; Pearson et, al. 2012; Ameneh et al. 2011; Abordein, 2010; Matt 2009; Velkoff et al 2007, WHO 2000). The Kenya health system adopts the Medical model which is however silent on the implementation of the elements of health systems responsiveness. Experiencing autonomy promotes both physical health and mental well-being of persons therefore health promotion strategies are of prime concern for the elderly. Proposed strategies include training health care staff in the field of gerontology and sensitizing the population to the course of the elderly. This paper intends to inform the Kenya health policy for the purpose of improving care to the elderly and also contribute knowledge to the care of the often chronic, complex and far reaching

conditions of the elderly, a state which requires the clients to actively participate in decision making on the management of their health conditions. The hypothesis is that the elderly persons would experience autonomy, enhanced mobility, independence, well-being participation and optimal aging. Further research is imperative in the area of training health care providers in field of gerontology. Two theories that underpins the principle of autonomy according to Rice (2001) are Economic

II. Theories underpinning Autonomy

Efficiency theory and Psychological satisfaction theory. The Economic Efficiency theory posit that consumers will be best off if they are allowed to make their own choices about the goods and services they consume. This is further exemplified by the theory of “Revealed Preference” which advance that allowing people to make their own economic choices will make them reveal themselves by bundle the bundle they choose to buy over the other. The theory relies on individuals’ abilities to make utility-maximizing choices and can be concluded that allowing consumers to make their own choices will lead to the highest possible outcome of the process. When the elderly person make health care choice the associated implementations are therefore subscribed to, welcomed and owned. The Psychological satisfaction theory postulate that individuals are likely to get more satisfaction out of the goods and services they purchase if they choose them. It is plausible that individuals would prefer the particular goods that they picked out of a set of alternatives, rather than having had these goods assigned to them by someone else. This would be true in health care, where consumer decisions (such as what doctor to see) are very personal, individualistic, and can be of considerable import. Enhancing patient autonomy therefore means helping patients to make their own decisions (Stiggelbout et al. 2004).

III. Methodology

Data for this review was obtained by literature search in line with the study objective: the observance and application of the principle of autonomy in caring for the elderly persons by the Kenya health care systems. Data was obtained by reviewing literature taking the global, regional and the Kenyan perspectives. The review was organized to cover the introduction, findings and the conclusion, summary and recommendations. The contentious points were discussed by the two authors to bring meaningful understandings. Literature was thematically approached to

bring out relevant elements of interest. The collected data was analyzed and interpreted thematically in line with study objective

IV. Results and Discussions

Literature points that observance and application of autonomy in health care for the elderly persons is variably compromised globally and that there are indications of widespread insensitiveness of health care providers to the application of autonomy when delivering care. Alvarez et al (2015) quote an article as reporting “As a society, we have ignored the material and social conditions that are required for autonomy to flourish. We have allowed autonomy thwarting institutions to dominate the care of the infirm and the sick old. Rather than building autonomy-sustaining institutions, long-term care of elders has accepted a medical paradigm of the delivery of services rather than a paradigm of providing an environment suitable for sustaining a compromised autonomy”. Health care providers often dominate decision making and planning processes thus negate client’s power for participatory ownership of care.

Descriptive studies in health care are reported to have assessed the prevalence of patient preferences for the liberal individualist interpretation instead of assessing patient’s ideals (Stiggelbout et al 2004). This has significantly contributed to the dismal ethos in practice implementation. On the positive side, autonomy support criticisms of ageism, social attitudes and practices that limit the freedom of or relegate elders to a secondary social status. It also support the elimination or modification of age-based discrimination. It has also highlighted an understanding of the autonomous individual as one who has the capacities for self-directed and independent action, deliberation, and decision-making. By making these values preeminent, the assumptions demarcate standard views of autonomy that have implications for optimal aging.

3.1 Concept of autonomy.

From the normative perspectives, there are six moral concepts which defines the relational aspects of patient autonomy. These include the liberal legal concept; liberal individualist concept; autonomy as critical reflection; actual autonomy as identification; Socratic autonomy and autonomy as a negotiated consent. The liberal legal concept stresses “freedom from” interference by others and demand respect for a patient’s integrity. It is directed towards those

who treat or care for the patient and not to the patient himself. The liberal individualist concept assumes that patients are rational and reasonable agents and thus define autonomous patients as choosers who act intentionally with understanding and without external controlling influences for their actions. As a critical reflection, autonomy gives room for conscious submission to some form of external authority (physician, religion, leader, etc.). Central to this concept is that patients may choose to let the physician decide which treatment is best. Actual autonomy as identification refers to the process of association with one's actions in the light of value orientations. It is a phenomenological approach where patient identify with the decision made, not so much to make the decision by him or herself. This context accommodates dependenceso that one can identify with the source upon which he/she depends on. Socratic autonomy stresses the importance of caring, and thus links the concept of autonomy with existential fragility and patients' vulnerability. The core point is an ethics of care and of interdependence which emphasizes the give and take principle. As negotiated consent, autonomy refers to interpersonal and social communication which is understood as a process of negotiation in which people try to define the meaning of the situation in which they are involved. Patients and physicians get into an intention to mutual understanding, explicit and just communication. All these perspectives touches on the various facets of the elderly conscious decision makings.

3.2 Features of autonomy

According to Agich (2002) autonomy has four significant features which creates a range of problems in the context of elderly care. First, the autonomous person is regarded outside a developmental framework and is therefore assumed to possess all autonomy-related faculties. Standard view of autonomy does not accommodate states of incapacity and since decision making is a cognitive process, any manifestation of cognitive impairment therefore exonerates the elderly from solely making decision. Second, autonomy implies independence and self-direction. States of dependence which are likely in the elderly are therefore regarded as incapacity. Third, autonomy focuses on the individual in abstraction from social structures like the family. The aged individual in this context is seen as possessing value, purpose, and rights that are separate from the social and personal relationships that provide everyday support and assistance. Fourth, the standard view of autonomy incorporates an assumption that freedom of choice or decision-making is a most important dimension of being autonomous.

3.3 Autonomy in Health care situation.

In order for autonomy to be meaningful, a competent individual decisions should be respected even when those decisions conflict with what others believe to be reasonable. Over the last few decades, respect for autonomy has come to be recognized as a fundamental principle in bioethics (Andersen 2008). In health care contexts, it requires that a competent individual should be able to decide which medically indicated procedures are appropriate for them. This morally obligates health care professionals to provide patients with accurate and complete information to be able to make informed decision. In the context of valid consent (informed consent) which defines a set of patient rights and reciprocal obligations for health professionals, autonomy implies that patients make informed choices/decisions about their health care based on their understanding of the information on health condition, treatment alternatives, and the burdens and benefits associated with the recommended treatment and alternatives. Consent is a concept that bridges law and ethics and when infringed constitute malpractice. It is based on three fundamental criteria: competence, truthful information and voluntarism. Competence allows patient to make rational decision. Factors that constitute competence as criteria for determining individual's competence include one's ability to communicate choices, being adequately informed about health status and procedures surrounding it, and an ability to appreciate the consequences of a decision. Communicating choices indicate patient's preferences for the desired ideal environment. A study by Furman (2014) indicates that even if the parent may not have competency to make financial decisions or make health care decisions for themselves, they are still able to clearly communicate their wants and desires. Being adequately informed about the health status and the procedures surrounding it includes but is not limited to being informed of the benefits and risks of a given procedure and the alternative options. Truth telling (veracity) is an obligation which the society cherishes most. The interpersonal interaction between patient and health care provider is based on the assumption that they are being told the truth (Eileen et al. 2014; Beauchamp et al. 2008; Boyle et al. 2001). Truth must however be told cautiously bearing that the way truth is delivered is equally as important as the content delivered. Appreciating the consequences of a decision is manifested in voluntarism or the absence of coercion into making a health care decision. Determining whether a person is being coerced is not always easy because coercion can be done in elusive ways therefore if any of the three above are not met, then the patient's

“consent” should be re-examined. Recognizing that patients sometimes lack the ability to make their own medical decisions, legislatures in the United States of America created advance directives (Patient Self-Determination Act) and enacted by Congress in 1991 which empower patients to direct their future medical care even when they shall have lost the ability to make decisions. It also ensure that advanced directives are followed in accordance with a patient’s wishes (Gamroth 1995). In the Kenyan context apart from the use of significant other or the application of the minor, this advance directives may be in the form of as a written “will”

With regard to elderly populations, there is concern about whether age, physical and mental illnesses associated with aging erodes the power to autonomous decision making. Literature indicates that old age alone does not preclude a patient from ability to give consent. . However, since a large number of elderly patients suffer from debilitating mental illnesses, obtaining consent can become a challenge. Prolonged debates have ensued in health care communities about whether elderly patients with conditions such as dementia are capable of making rational decisions. “Dementia” is an ailment generally characterized by the progressive impairment of various cognitive abilities. It typically impairs, memory interferes with judgment and abstract thinking and may cause personality changes as well. A demented person’s appreciation and awareness of own condition can also fluctuate during the course of the illness. As a result, physicians disagree about when patients suffering from dementia lose the capacity to make decisions. There is no definitive marker indicating when a patient suffering from Alzheimer’s disease loses the ability to make health care decisions. The health care team might therefore need to frequently check patient’s ability to recall information. In such case it would be rational to take the beneficence way where the physician plays a more “paternalistic” role in deciding for the patient (Dymek et al. 2001; Auerswald 1997). The other factor to consider is whether age and illness makes elderly patients vulnerable to coercion by health care teams and/or family members into making decisions. Since a significant percentage of elderly patients is vulnerable due to poverty, inadequate education about technical medical matters, physical and mental impairment, conditions of ill-health and old-age can contribute to helplessness which can in turn make elderly be open to undue influence by others. It is important that health care providers and families listen to and respect the wishes of the patient instead of assuming that their own values match what the patient wants (Anderson 2008).

Decision-making in older patients is a complex process that should be based on a comprehensive assessment of the patient as a tool to weigh the risks and benefits of treatment. In many cases comorbidity, functional capacity and cognitive status are more determinant of patient survival and quality of life than the actual process to be treated. Together with patient's wishes, these should form the framework supporting the development of therapeutic decisions (Alvarez et al. 2015).

In some cases, courts usually demand for sufficient evidence that the person in question is unable to manage life decisions before a guardian is appointed. In Florida for example, the guidelines for selecting a guardian, and the duties associated with being a guardian, are outlined in Florida Statute Chapter 744. The state guidelines for selecting a guardian for health care related issues are outlined in Florida Statute Chapter 765-Part II. Appointment of a guardian can help ensure that the patient's best interests are pursued. Increasingly, however, guardians are being appointed in situations where an incompetent patient does not have an advanced directive and there is no identifiable family member or friend available to assist in decision-making. Guardians are charged with making medical decisions (Andersen 2008). In a situation where family members argue about the best course of action for their elderly relative then the health care provider may be in a tempting position to resolve the dispute. To guard against weaknesses and draw backs associated with surrogacy and guardianship, periodic report to local court as determined on the status of the client may be among the checkpoints. Similarly provided the individual in question is competent, then family members do not have the ability to override the decision of the patient. Although family members might believe that their relative's decision is misguided, the patient's choices are to be respected so long as the steps for obtaining valid informed consent have been followed properly.

In Western Australia, Saras Henderson found that nurses considered patient involvement in their own care as an interference in the nurse's duties, and that the majority of nurses were unwilling to share their decision-making powers with patients. This creates a sense of exclusion, resulting in little input by patients. In South Africa, findings of a study by Peltzer et al. (2012) indicated that autonomy ranked lowest among the elements of health systems responsiveness and is

identified as priority area for actions to improve healthcare services. A similar result was obtained in China by Kowal et al (2011). In North America and Europe, informative model sees patients as a consumer who is in the best position to judge what is in his/her own interest, and thus views the health care staff mainly as providers of information. In contrast, the service provider in Kenya is regarded as an authoritarian benefactor while the patient is considered vulnerable and expected to be subservient. Authoritarianism may curtail the claim to rights despite growing international consensus that all patients have a fundamental right to autonomy among other elements of care services. A human rights approach calls for an accommodative provider-patient relationship which would ideally guarantee the patient the right to autonomy, free expression, self-determination, information, personalized attention, and non-discrimination (Ojwang et al. 2013). The greater percentage of workforce in the Kenyan health facilities is the nurse whose shortage contribute to the negative authoritarian attitude occasionally manifested.

Among the unsatisfactory communication strategies cited include withholding information and failure to explain requirements to patients. The most recurrent complaints by patients indicated that nurses do not bother to explain procedures but are quick to blame any deviant acts on the uninformed patients. This violated the patient's right to be informed unconditionally as per the Kenyan charter of patients' rights. Another unsatisfactory strategy is forcefulness and over-determination, not caring whether patient is ready for a process of a procedure (i.e. dressing) or not. Similarly, another patient reported a direct accusation by a nurse who quarreled and said that the patient lacked respect, instead of clarifying the procedures. Poor communication is also cited in a case where nurse carelessly told the patient's relatives that his condition (tuberculosis) was contagious, hence it was up to them to approach patient's isolation room. This ignored the patients' right to preserve self-esteem. Here, the patient's experience illustrates the violation known as objectification, in which an actor is treated like a thing and not a person. It exemplifies abjection, which entails forcing an actor to humble oneself by compromising closely held beliefs or by forced association with material or practices considered unclean. Ignoring and dismissing patients' concerns is yet another reported unsatisfactory strategy. Patients reported nurses' dominance and control of interactions. The report indicated that nurses were harsh and did not want to listen to patient's explanation. All they wanted was a "yes" or "no." The act of dismissing, ignoring, or discounting the patients' perceptions, concerns, needs, and feelings

violated the right to express opinions freely on matters related to the course of their treatment. This is also specified in the Kenyan charter of patients' rights. A host of undignified cases cited in a study by Ojwang et al (2013) points the degree to which patient's autonomous participation in care planning and service delivery is unlikely. Similar negative comments of older service users and their carers reported in England include the following sentiments: "She was left to lie in her excrement and urine"; "An old boy about 90 had wet himself. On changing him, they left him lying on the bed (naked), curtains all open" "I was both shocked and appalled at the callous attitude of the nursing staff on the ward"; "I found my mum's dignity was non-existent in their eyes". "There were problems with preserving dignity and individuality when meeting patients' essential needs"; "The GP just says 'confused.' She's never explained it". Although patients find themselves in confinement due to their health conditions, acts that humiliate them and limit their fundamental rights are undesirable. The same study however also highlights acts of good practice that may enhance patient participatory contribution for self-care services. A Kenyan study by Nzinga et al. (2013) highlights the need for training for senior and mid-level hospital managers in two key areas that may have impacts on patient's autonomy. As mentors/coach and as strategists/negotiator. The former encompasses goal setter, therapist and motivator. The latter encompasses information managers, communicator, decision maker and problem solver. Literature points that for hospital managers to be effective, they should be empathetic, emotionally intelligent, and approachable and have the ability to put people at ease with a rapport that invites people to come to them with problems, questions and suggestions. In assessing the health services for the elderly in England, Lothian et al (2001) point that maintaining high standards of autonomy in health care may be a global problem but the key to tackling poor attitudes by staff towards older people is through extensive and continued training. One study reported that more positive attitudes towards older people were found among nurses working in elderly care than among those working in acute care (which covers all ages) and attributed this to a more specialized training in gerontology. Such would open doors for the elderly to autonomously participate in their care planning and delivery. Swedish researchers reported that after a year of special education, medical trainees came to view older people with dementia as "unique human beings" rather than "a homogeneous group." Another study reported more favorable attitudes towards the care of older people among students attached to a geriatric ward than among those attached to a general ward. It seems, then, that training in geriatrics has a

positive effect on the attitudes of staff. In fact, the evidence shows that mere exposure to certain groups of older people is beneficial. Older students and those with grandparents as role models have been found to have better attitudes towards older people. Indeed, several authors have written about the importance of healthcare staff being exposed to older people who are healthy as well as to those who are patients. Increased and improved training and exposure to older people is also likely to do much to raise the status of geriatrics. Improved status is likely to have a positive impact on attitudes and encourage more individuals into the field. Positive impact on attitudes and encourage more individuals into the field, which in turn will benefit older patients. Relational understandings of patient autonomy facilitate recognition of potentially oppressive aspects of health care regimens, and support the development of respectful, bilateral relationships that enable patients to develop and exercise self-governance skills, both within and beyond health care encounters.

V. Conclusion

Anecdotal evidence suggests that older people's autonomy is being undermined and compromised in the health care setting globally though at various degrees despite the existence of national standard benchmarks.

Experiencing autonomy is recognised to promote health and well-being for all age groups but perceived lack of control has been found to be detrimental to physical and mental health therefore health promotion strategies in the elderly group are of prime concern for optimal aging. Autonomy does not mean only the making of informed decision, it is also concerned with elements of attitude, and how individuals are viewed and treated within the health care system. Giving older people and their care's adequate information for them to make informed choices about care increases their autonomy.

Many healthcare professionals hold stereotypical, negative attitudes towards older people. Tackling negative attitudes through exposure and education can help to preserve older persons' autonomy. In Kenya senior and midlevel hospital managers need adequate preparation as mentors, strategists and negotiators so as to provide high-quality services.

The policy measure by Kenya's Ministry of Health in 2006, intended to make health service provision humane, compassionate, and dignified, still faces implementation challenges which have both health care workers, the patients and the community as contributors.

VI. Recommendations

Kenya should start special education in gerontology for health care providers and social workers
Further research is necessary in the field of health care for the elderly

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