Agency, Autonomy and Euthanasia

George L. Mendz and David W. Kissane

Introduction

An important reason given in support of euthanasia or assisted suicide is respect for the autonomy of individuals. "Respect for persons demands respect for their autonomous choices as long as those choices do not result in harm to others."[1]

In several countries, this respect for the autonomy of individuals who request euthanasia or assisted suicide is determined broadly by establishing informed consent and preventing abuses, although the subjects to which the various laws apply, and the actual legal requirements and their implementation vary from country to country. For example, on April 10, 2001, the Dutch Parliament legalized euthanasia and assisted suicide, and on May 28, 2002, the Belgian Parliament approved a law on euthanasia. In both countries, the patient involved in such decisions was to be an adult and mentally competent at the time of requesting euthanasia. Nonetheless, the Dutch law contains special provisions for dealing with requests from individuals aged 12 to 18 years, and on February 13, 2014, Belgium legalized euthanasia by lethal injection for children. In both countries euthanasia and assisted suicide have been allowed for persons with psychiatric disorders. The Parliament of Canada in June 2016 legalized both physician-administered euthanasia and physician-assisted suicide, which became known as Medical Aid in Dying, and the legislation that governs access to both procedures, which were limited to terminally ill adults, and excluded the mentally ill and children.

In Belgium, a second doctor must be consulted if the patient is unlikely to die naturally within a short period, that is, a procedure exists for non-terminally ill patients. In the Benelux countries, medically assisted dying is no longer restricted to the terminally ill, but can be used by those who decide that their sickness is intolerable. Thus, a steady rise in the mentally ill (patients with depression, autism, anorexia nervosa, etc.) accessing such legislation has been evident in their respective reporting periods.[2] In Canada, there is no longer need to have a fatal or terminal condition to be eligible for euthanasia, and experiencing an unbearable mental suffering that cannot be relieved under conditions the patient considers acceptable is one of the criteria to be considered.[3]

In the United States the requirements for assisted suicide vary between jurisdictions. The oldest legislation is that of the State of Oregon, and in its "Official Report for Year 22" (2019), terminal diseases that qualified some patients for the lethal overdose included diabetes, arthritis, arteritis, blood disease, complications from a fall, etc. Bills were introduced last year explicitly to expand the definition of "terminal disease" that will make thousands of Oregonian residents eligible for doctor-prescribed suicide.[4] Currently Oregon's Death with Dignity Act stipulates that either of the two physicians involved in the petition for assisted suicide shall refer the patient for counselling if in their opinon a patient may be suffering from a psychiatric or psychological disorder or depres-

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sion.[5] The Year 22 Report indicates that out of the 188 patients who received the lethal drug prescriptions in 2019 only one was referred for psychiatric evaluation.[6] Prescribing doctors have to report whether there were any complications when a patient took the lethal overdose, but those doctors were not present at the vast majority of deaths, and in 68% of deaths the number of complications is listed as "unknown."[7]

In Switzerland there is no requirement for the illness to be terminal, nor for any life expectancy limit. The Swiss Academy of Medical Science Guidelines indicate that the capacity of the patient must be carefully assessed for mental disorders but the assessment refers to the individual's decision-making capacity. In 2014, 742 cases of assisted suicide were recorded in Switzerland, 26% more than in the previous year, and two and a half times more than in 2009, whereas the number of suicides without euthanasia remain stable in the country.[8]

This study reviews the concepts of agency and decisional capacity, and examines the idea of autonomy from the perspective of agency. It reviews three psychological conditions and a life circumstance with focus on their potential to diminish agency, and thus affect a person's autonomous capacity to make life and death decisions. Currently, the exercise of personal autonomy envisaged by the laws of various countries is reduced to verification of the expression of a desire and of the capacity of the individual to make decisions, without proper assessment of her/his capacity as an agent. This work draws attention to the need to assess the agency of individuals, particularly in life or death circumstances, in order to respect properly their personal autonomy.

An aim of these laws is to protect individual autonomy, but autonomy is founded on personal agency. An agent is the ultimate source of actions, which are free, intentional, and uncompelled.[9] This study reviews the concepts of agency and decisional capacity, and examines the idea of autonomy from the perspective of agency. It reviews three psychological conditions and a life circumstance with focus on their potential to diminish agency, and thus affect a person's autonomous capacity to make life and death decisions. Currently, the exercise of personal autonomy envisaged by the laws of various countries is reduced to verification of the expression of a desire and of the capacity of the individual to make decisions, without proper assessment of her/his capacity as an agent. This work draws attention to the need to assess the agency of individuals, particularly in life or death circumstances, in order to respect properly their personal autonomy.

Agency, Decisional Capacity and Autonomy

Agency

A distinctive human characteristic is the capacity to exercise control over one's own thought processes, motivations, and actions.[10] Agency is the internal capability of persons to exercise self-governance in the competent control of their life and with the freedom to exercise personal choice. From the perspective of agency, autonomous agents are those who initiate their actions exercising their power to do so; they act by self-governing. Social cognitive theory proposed a model of emerging interactive agency based on a triadic system of reciprocal causation involving cognitive, behavioural and environmental factors.[11] An agent's mental states and events determine the intentionality and initiation of his/her actions.[12] Thus, an account of human action should include self-generated, interacting and circumstantial influences. Internal factors of personal agency include self-belief of efficacy, goal representations, and anticipated outcomes.[13] External factors that impact upon agency include collective intentionality, where mutual consensus needs to operate at a practical level.[14] In the psychiatrist's assessment, agency is examined by exploring judgement, insight, and cognition, while excluding altered perceptions and delusions that mar reality.

Several accounts have been given of the conditions between an autonomous agent and her/his own motives that are required to preserve personal autonomy. These accounts propose understandings of the various roles that agents can play in their own actions by considering the effects of internal and external

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elements and emphasising the role of freedom from external causes, the capacity for self-transformation, the response to reasons, or the mental states.[15] Having an intact capacity to exercise reasonable judgment, together with insight into the self's relationship with the true reality of the predicament, form part of a clinician's regular mental status examination. However, these approaches "do not spell out the minimal conditions under which a person's exercise of authority over how she behaves reflects her own power to determine how she exercises this authority."[16]

It is recognized that agents could be deprived of their autonomy by various conditions under which they do not govern themselves, even if they act thinking that they have sufficient reason to do so, even if they have (thoroughly) considered the pros and cons of various options, and have endorsed their behaviour on this basis, and even if they would have acted differently if there had been stronger reason to do so. Most agents who are capable of acting with the characteristics just described are confident that they are the authors of most of their actions, and are thus accountable for most of what they do.

Decisional Capacity

The functional term "decisional capacity" refers to the mental or cognitive ability to understand the nature and effects of one's acts.[17] To give consent to medical treatment or to participate in clinical research, individuals need to have decisional capacity that "can be defined as the ability of health care subjects to make their own health care decisions."[18] Decision-making capacity is assessed by clarifying understanding of the illness, appreciation of its impact on the person, reasoning about the risks and benefits of any treatment, and election of a choice consistent with the person's values. Decisional capacity is decision-specific and understood as a threshold concept. It is "assessed relative to a specific decision, at a particular time, in a particular context."[19] Also, capacity judgments are of a bivalent type, determining whether a person can or cannot make a particular decision.[20] Moreover, the idea of autonomy as a justificatory alternative to moral and prudential reasons often underpins current legal thinking about decisional capacity and any judicial decision about competence.[21]

Decisional capacity is examined by physicians' assessments[22] in five component areas: understanding, appreciation, reasoning, choice, and values.[23] To complement these there are multiple psychometric tools to assess decisional capacity; e.g. Colorado Childhood Temporal Inventory.[24] MacArthur Competence Assessment Tool-Treatment,[25] Hopemont Capacity Assessment Interview,[26] and University of California, San Diego Brief Assessment of Capacity to Consent.[27]

Autonomy

Autonomy is the personal exercise of self-governance, choices and control over aspects of human life that the laws of society permit the individual to govern.[28] Autonomy is a trait exercized by a person endowed with agency and decisional capacity which are requirements but not dimensions of the former. This study does not establish a hierarchy amongst these capacities, it argues that both are necessary for the exercise of autonomy.

The capacity of a person to make her/his own decisions is fundamental to the ethical principle of respect for autonomy; it is a key component of informed consent to medical treatment.[29] Respect for the autonomy of individuals requires health practitioners to establish the patient's decision-making capacity to give informed consent to specific treatments offered. The legal term "competence" is defined as having sufficient capacity, ability or authority to be in control of one's self;[30] judicial declarations of incompetence might be limited (e.g. to finances) or be global, and include loss of both decisional capacity and agency.

Notwithstanding the inalienable nature of their authority over themselves, it is possible for agents to fail to govern themselves in spite of demonstrating decisional capacity. Simply, because the forces moving an agent to act may not owe their power to the capacity of the agent to decide what to do; in which case, they undermine the autonomy of the agent.[31] Examples of undermining influences that threaten personal autonomy are addiction, brainwashing, trauma, fatigue, etc. But there are less obvious ways in which the autonomy of an agent can be undermined: four well-studied states that can affect agency deeply are depression, demoralization, existential distress, and family dysfunction. This work investigates how these life situations pose a challenge to personal autonomy.

Internal Influences on Agency: Demoralization, Depression, and Existential Distress

Demoralization is "A clinical state of low morale and poor coping, characterized by feelings of hopelessness and helplessness, triggered by a predicament in which the person feels trapped and stuck, and leading to loss of meaning or purpose in life."[32] There are clinical features and diagnostic criteria for demoralization;[33] instruments to appraise it, e.g. the Demoralization Scale (DS) and the Beck Hopelessness Scale (BHS);[34] and treatments with various cognitive and meaning-centred therapies.[35] Demoralization may be present

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in 30%-50% of the terminally ill,[36] and 13%-18% of the elderly.[37] The intervals of percentages quoted (that is, their precision) are broad because they have been measured for different cohorts, cultures and conditions; they are given here to provide an indication of the extent of the problem.

"Depressive disorders are characterised by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness, and poor concentration."[38] Depression has been studied extensively and its risk factors, symptoms, and diagnosis are well established.[39] Validated specialized tools are used to screen for depression,[40] and treatments include medications, cognitive behavioural therapies and counselling.[41] A report by the UN World Health Organisation identified depression as a leading cause of disability worldwide. It estimated that more than 300 million people worldwide are affected, the majority of them women, young people and the elderly.[42] Several factors increase the risk of becoming depressed including life events such as the death of a loved person, physical illness, and problems caused by alcohol and drug abuse.[43] Between 15%-50% of terminally ill patients suffer medium or severe depression,[44] and a significant proportion, 8%-15%, of major depressive disorder is found in the elderly.[45]

Death anxiety, fundamental aloneness and fear of loss of control are examples of the existential distress that is a given of our humanity.[46] The end of one's existence is characterised by a decline in health and loss of normal roles, and it can be accompanied by withdrawal from social networks and loneliness.[47] Loneliness has been defined as "an intolerable emptiness, sadness, and longing that results from the awareness of one's fundamental separateness as a human being."[48] Population studies in cancer patients have identified a variety of experiences in which their physical and mental conditions lead to an existential distress[49] that is marked by "hopelessness, burden to others, loss of sense of dignity, desire for death or loss of will to live,"[50] and even threats to self-identity.[51] A number of validated tools are employed to assess this disorder, e.g. questionnaires such as EDS[52] and Profile of Mood States, of Diabetes-related Distress Scale.[53] Reviews of existential distress data indicate a high prevalence (30%-50%) in cancer patients.[54] Older persons can expect to live longer, and in many countries the proportion of older people living alone has increased dramatically. In some European countries over 40% of women aged 65 and older live alone, and even in countries with strong traditions of multigenerational living arrangements such as Japan or India there is a trend for older persons to live by themselves.[55] Older people living alone have an increased risk of isolation and suicide.[56] Various group therapies[57] and more recently meaning-centered therapies[58] have been employed in the treatment of existential distress.

These three disorders share characteristics that refer to the individual's perspective on the personal future. Examples taken from statements of depressed persons such as "loss of meaning or purpose in life," "a bleak pessimistic outlook on the future," "perception of a limited prognosis," "desire for death or loss of will to live" indicate experiences that can impact their agency. In the sections to follow, a more detailed discussion will examine ways in which these disorders may compromise agency.

External Influences on Agency: Family Dysfunction

Family life seeks optimally to respect and nurture the personhood of each individual member to creative accomplishments. In families operating dysfunctionally, higher rates of mental illness occur, including relapse of serious mental disorders when family members express criticism of one another with resultant hostilities.[59] Family therapy has long been a key therapeutic modality used in the treatment of mental illness and in the care of the medically ill, including palliative care.[60] Shame, blame, and contamination can exist subtly amongst family and cultural beliefs, while the burden of care and competing needs of members exist in and often unspoken but realised tension.[61] Family dysfunction is defined clinically by difficulties in family members communicating openly with one another, working cohesively and collaboratively as a team, and tolerating differences without conflict occurring.[62]

Systemic theory has long recognised the reciprocal influence of the interpersonal processes seen in family networks.[63] An underlying interdependence of family members contributes to the reverberating emotional shockwaves that illness can bring. Rather than achieve the shared agency of a collective undertaking found in the therapeutic group process, contralateral commitments can disrupt the group mind,[64] and evoke negative consequences for individual members.[65] Thus anti-family events can result from existential uncertainty, ambivalence and stress, exemplified when envy and conflict break out, the family fractures, and expulsions, withdrawals or separations occur, with profound unconscious impacts on the behaviours and choices of some members. Suicide in a family can invoke deep trauma, a questioning guilt, loss of trust, a struggle to repair relationships, and frozen narratives that can fail to comprehend the agency and intentions of the deceased. Shortly, the way in which the family environment can have a powerful impact on the agency of its members will be examined in more detail.

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The following more detailed discussions will serve to elucidate ways in which agency can be compromised by these internal and external influences.

Agency and Demoralization

The loss of morale can present across a spectrum of mental states. This range spans disheartenment (a mild loss of confidence), to despondency (the beginning of losing hope and purpose), to despair (a state where all hope is lost), through to severe demoralization where meaning and purpose are lost.[66]

The BHS questionnaire to ascertain demoralization measures three major aspects concerned with feelings about the future, loss of motivation and expectations. The DS instrument measures five dimensions of demoralization: loss of meaning, helplessness, disheartenment, dysphoria, and sense of failure. According to these scales, central diagnostic criteria of demoralization are: hopelessness and a negative view of the future that lead to a considerable feeling of being trapped and loss of purpose in life.[67]

The demoralization syndrome typically involves mental states of hopelessness and helplessness that lead to a lack of meaning in life. In demoralization a conflict arises between the reality of existence and the inability of a person to cope with it.[68] Its importance as a psychiatric syndrome is its association with a desire for hastened death that raises the issue of agency in demoralized persons.[69] Hopelessness has long been recognized as a key predictor of suicidal behavior and a predictor of suicide stronger than depression.[70] Recent studies have also confirmed demoralization to be a stronger mediator of suicidal thinking than depression.[71]

Competence to consent to treatment is ordinarily assessed by the expression of choice, understanding of medical information, appreciation of the personal relevance of this information, and logical reasoning. However, when persons frame their prognosis pessimistically and out of proportion to the perception of their health providers, this disordered relationship to their future could impair their appreciation of the personal relevance of their medical information. Moreover, demoralization may disrupt the coherence of personal preferences by changing them, in the process diminishing the agency of the person.[72]

Thus, respect for the autonomy of persons who present a form of psychological distress that features hopelessness and an inability to cope with life requires an assessment for demoralization. If the presence of this psychiatric syndrome is established, it should be treated by a meaning-based intervention that has the potential to improve the quality of life of the patient,[73] instead of assenting to suicidal desires that may arise from an absence of proper agency.

Agency and Depression

A sense of the ability and capacity of individuals to act fully in control of themselves is related to agency. A characteristic of depression is a profound sense of inability and incapacity, based on the loss of experiential access to both the person's surroundings in general, and to other people in particular. The failure to connect and marked decoupling from others is considered a core dimension of depression. This disconnectedness manifests an impaired agency, which is required in the normal active exercise of an individual's communicative and interpersonal capacities. Depression challenges the very foundation of a person's experiential view of the world. Sometimes depression leaves the individual entirely unable to act by paralyzing or eroding her/his agency.[74]

The exercise of autonomy is attributed substantially to self-regarding initiatives based on the agency of a subject; thus, it becomes an independent source of justification for action. Autonomous agents are the source of free, intentional, and uncompelled actions; these actions imply a robust, albeit not always direct, link between motivation and evaluation.[75] The process of assessing the true exercise of autonomy can integrate the intuition that there is a close link between autonomy and self-respect by focusing on the person's relationship to her/his motives.[76]

Identification is understood as the relationship of an individual to her/his motives; it conveys autonomy to an agent's initiatives. Depression typically involves mental states where the underlying connection between motivation and evaluation is impaired or apparently severed, such that a depressed person may feel less and less motivated to seek what is good.[77] The relationship of a depressed individual to her/his motives is ambivalent, with inner conflict such that depressive identification is self-alienating, with a loss of self-esteem based on a perception of the self as an inadequate source of actions. An initiative to act based on a conflicting relationship to one's motives cannot be regarded as autonomous, because the lack of control over one's motives makes the action not truly determined by the individual, who simply goes along with it, independently of the person endorsing the action post factum.[78] The person may appear to consider a course of action worthwhile, but she/he is no longer motivated to act one way or the other because of a perception of the self as an inadequate source of actions. This paradox of depression is that the desirable is not desired; thus, it challenges the classical conception that in agency, a subject engages in a pursuit because it is regarded as valuable in some respect.

Depression poses a problem for the agency and personal autonomy of an individual, and questions the

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ability to distinguish reliably between autonomous and non-autonomous decisions in depressed persons. For instance, the refusal of treatment by people who suffer from depression is motivated in many cases by low self-esteem and suicidality. These decisions are cases of non-autonomous initiatives, since these symptoms exercise undue influence on the agent through a plausible causal link to the motives for action. A depressed person could not only reach a refusal decision, but also endorse it on reflection; that is, to conclude that his life is not worth living even when knowing that this kind of decision is often a sign of a mental disorder.[79]

A quantitative investigation of relations of agency with depression and suicidal ideation was conducted with older men (n=69) and women (n=150), the majority of whom (93%) lived in their own homes. For both men and women, higher levels of depression were associated with higher levels of suicidal ideation. The study recommended that "Interventions that aim to improve the mental health of older adults may benefit from focusing on increasing agency. Offering older people greater opportunities to foster mastery, independence, confidence, and competition may achieve this end."[80]

Agency and Existential Distress

Death anxiety can have a profound impact on a person's view of their future, which is intricately related to his clinician's estimate of her/his prognosis. The coping style of some individuals creates an optimistic hearing of this prognosis, while for others a pessimistic perception predominates. Levels of prognostic awareness vary across cultures and coping styles. High levels of death anxiety become associated with demoralized states of mind that potentially impact agency,[81] especially when a negative view of the future is adopted. For example, interventions to reduce fear of cancer recurrence or progression have proved worthwhile to allay death anxiety and its deleterious social and personal effects.[82]Aloneness is another form of existential distress, including that found despite supportive families. Where alienation or isolation exist, socioeconomic deprivation or poverty can deepen the depth of social isolation, accentuating desperation and despair in coping with illness. Few states of existential aloneness have been identified, requiring more clinical research of this very real predicament. Powerlessness can lead to abandonment of any sense of personal agency as fundamental aloneness casts an individual adrift, victim to the environmental forces that appear to control his or her fate.

A well-developed sense of control to run one's life, to make personal choices and to build a life of one's own making are the essence of existential freedom. So strongly does this operate as the expression of autonomy that a deep-seated fear exists against any perception of loss of control. Yet illness challenges the societal distortion involved in people holding a perception of absolute control. Nobody exerts that much control over her/his life, accepting as one does laws and communal courtesies that regulate traffic and driving, behaviour associated with consumption of alcohol, limits about smoking, and even respect for property and people. Fear of loss of control to illness can lead some individuals to dread what might lie ahead such that they would consider forfeiting agency over the quality of the life that remains. In this sense, a profound fear can diminish agency and paradoxically reduce the very autonomy driving their choices.

Hence, forms of existential distress existing as deep anxieties that distort human perceptions have the potential to diminish agency and thus limit true autonomy. This is one reason why screening for distress has been recognised as equally important as screening for pain.[83] Specifically, there is significant relationship between a cancer patient's distress and the distress of his or her carer — they experience similar levels of distress.[84] Existential distress reverberates reciprocally through families, carers, and communities, contagiously yet unconsciously diminishing agency and the autonomous exercise of control over life.

Agency and Family Dysfunction

One of the curious patterns of the contribution of the environment in complementing the genetic imprint that exists over life is the transmission from generation to generation of deleterious behaviours that harm communal and family life. It has been described as a dramatic script that family members follow unwittingly as if the dice were strongly cast and disempowered their individual agency to live life differently.[85] Such family influences can operate as sources of resilience as much as sources of deficit. It is the latter that diminishes the agency of individuals, well exemplified by patterns of alcohol abuse, domestic violence, sexual addiction, infidelity, and gambling. Adolescent struggles to achieve individuation in anorexia nervosa exemplify another vulnerable phase of life.

Alcohol is one example of a potentially destructive factor in family relationships, where heavy drinking can be modelled, and circuitous ways of relating cause arguments that are soothed by alcohol abuse and lead to a carefree attitude, disinhibition, poor judgement, and loss of insight.[86] In essence, this sequence steadily diminishes agency in affected family members.[87] In severe and chronic states, alcohol dependence impairs cognitive function, with classic syndromes such as Wernicke's encephalopathy and Korsakoff's psychosis contributing to alcoholic dementia.[88] In milder states,

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family dysfunction coincides with alcohol abuse, with deficits in communication, cohesion, and conflict resolution in relationships contributing to poor judgments and eventually to the limited insight that impedes agency.

Autonomous Agency and Euthanasia or Assisted Suicide

In this study, three mental conditions and a life situation were reviewed which may compromise personal autonomy through loss of agency owing to factors that could escape the understanding of affected individuals, their carers and treating health professionals. It is not an exhaustive investigation of psychological conditions and the life circumstances that may result in deterioration of individual agency by nullifying a person's autonomous capacity to make life and death decisions, but it brings to light the potential role of such mental states and life situations to compromise agency and thus autonomy.

The greatly improved knowledge of mental states and circumstances that affect individuals, particularly towards the end of life, achieved in the last 20 or so years, calls for a significant revision of the criteria and ways of assessing the agency of persons, and consequently their capacity to make autonomous decisions.

Minimal conditions of personal autonomy are those that establish agents as no more nor less than the power behind whatever reasoning directly gives rise to their behaviour. It is proposed that the identification of the minimal conditions of autonomy requires distinguishing between autonomy-*conferring* reasoning and autonomy-*undermining* reasoning, without implicitly appealing to the very phenomenon one is trying to explain.[89] Acting "out of character," weakness of will, defying accepted normative rules, abandoning well-constructed value-based plans, etc. can be evidence of impediments to agency. Amongst other reasons, this is because "the human capacity for self-reflection enables human agents to distance themselves in thought from every aspect of their own psyches — even their rational reflections."[90] Thus, attempts to establish the minimal conditions of personal autonomy based on the requirement that people are responsible for securing identification with their own motives leads to endless regressions of the type: what conditions must agents satisfy in order to identify with the motives that move them to identify with some of their motives and not others?[91]

A way to escape from this regression would be to identify an attitude from which a true agent cannot possibly be alienated. Such an attitude could be the desire to be a self-governing agent; that is, the desire to have sufficient power to determine one's own motives.[92] Importantly, this desire is ordinarily absent from persons who request euthanasia. They find themselves in a situation in which they regard death as their only escape; this is an autonomy-*undermining* reasoning. Although the request for death may be expressed freely, their circumstances disempower them from determining their own motives. The motivation to act can be forced upon them by their impaired perception of their own situation. Not being able to appreciate their own motives, they are not self-governing agents.

The authors acknowledge that they do not agree with euthanasia or assisted suicide as a solution for the problems faced by patients at the end of life or in difficult life circumstances. However, independently of their personal views, it is clear that the application of these procedures without appropriate assessment of the agency of individuals would be a failure to respect their personal autonomy. Moreover, the legal frameworks designed to protect this autonomy should establish not only adequate decisional capacity but also prove positively the person's ability to act with unaffected and undamaged agency. Without true agency, there can be no genuine autonomy.

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Note

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