

# **Balancing Autonomy with Paternalism for Psychiatric Patients? Ambiguities in Personal Choice and Advance Directives**

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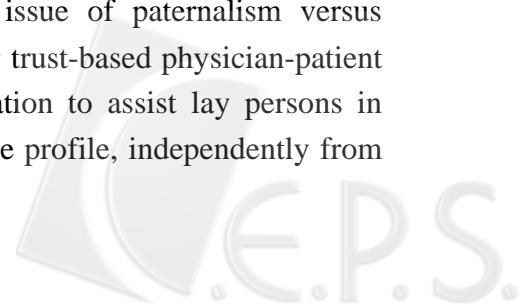
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Cultural attitudes towards mentally and physically challenged and handicapped fellow-humans have changed from culture to culture and from century to century. But all cultures seem to have visible or hidden recognition of the dignity and uniqueness and sometimes divine characteristics of the handicapped. From bodily and mentally challenged acrobats and artists in the Chinese Imperial Court and the residences of European feudals to the divination of certain psychiatric persons in Eastern and Western cultures to limited legal rights of self-determination for the incompetent in many contemporary democracies, there is a wide range of acceptance and refusal of the 'other' who is different to most of us. In this paper I will discuss more specifically some selected aspects of the genuine competence of those who have been declared legally incompetent in accordance with certain cultural preconceptions or neurological or psychiatric criteria for tests.

## **Cultural and Individual Preferences in Paternalism and Autonomy**

Modern bioethics has been described as a late reflex in the medical culture of the age-of-reason model of personal autonomy and the right to individual choice free from governmental and professional tutelage. Major conceptual work in bioethics has been devoted to support and to applause the transition from previous paternalistic physician's ethics to the new patient's autonomy based medical ethics. However, given global cultural diversity, changing modes of cultural and moral preferences, and in particular individual preferences towards self-determination and being advised, guided and cared for, those historic differences mark also personal differences and cultural differences in the preference between paternalism and autonomy, between mutual solidarity and self-responsibility, between the 'good of the patient' and the 'will of the patient'. [4;9;21;26]

While different countries have different cultural traditions and attitudes, the same is true for individuals and the balancing of paternalism and autonomy. Also, autonomy and self-determination can be influenced, even compromised by social and cultural influences and intellectual disabilities. It seems to be crucial, to view the issue of paternalism versus autonomy in the wider framework [a] of the quest for improving trust-based physician-patient interrelationship and [b] of physicians recognizing their obligation to assist lay persons in making medical choices based on their individual wish-and-value profile, independently from



the individual patient's physical or mental abilities or disabilities.

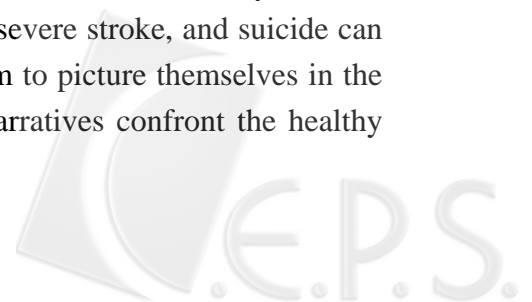
If patients suggest or advice in advance specific medical treatment or the withholding of treatment, those suggestions have to be clear and applicable. A recent cross-cultural study on physician's attitudes to communicate with patients of early signs of dementia truthfully, found that 64% of US American physicians would do so, but only 14% of German and 9% of Japanese physicians. Asked whether they would provide for a feeding tube, if the patient had stated earlier in an Advance Directive that in the case of severe dementia 'no heroic' treatment should be administered, 9% of US American and 43% of German and 85% of Japanese physicians would provide for tube feeding; the responses for antibiotics were 45%, 86%, and 85%; for hospitalization 22%, 43% and 75%; for re-animation 0%, 14%, 8%. However, if the Advance Directive would have stated precisely 'no antibiotics, ventilator, or CPR' the responses would honor such a specific request 100%, 85% and 62% [10:281f].

### **Narrative Methods to Establish Patient's Value-and-Wish Profiles**

Stories have played an important role in the history of philosophy and ethics; Plato and Aesop use story rather than theoretical argumentation to identify ethical issues and to formulate moral judgments, principles, and virtues. According to Paul Ricoeur 'the interpretation of a text is a proposal of a world in which I would like to live and develop my possibilities' and that there is 'a correlation between the telling of a story and the temporal character of human experience' [17:121;87]. Margaret Walker has described the role of narratives in medical ethics consultation; she understands moral as 'points in continuing histories of attempted mutual adjustments and understandings among people' as compared to bioethical principles resembling 'lawlike directives of high generality, like those giving autonomy, sanctity of life, or beneficence absolute or relative priority' [28:35].

Physician-patient interaction is based on communicating in the hermeneutics of the patient's narrative of her or his stories surrounding his well-being, well-feeling, pain, scare, distress, anxiety, quest for help. Communication-in-trust and cooperation-in-trust defines the success in predictive and preventive medicine and in acute intervention. The methodological approach to use narratives methods for the preparation and validation of advance medical care documents for competent patients or future patients builds on the hermeneutical insight into the superior role of narratives for dealing with specific topics in human communication and on the tradition and experience of medical practice.[3;9;19]

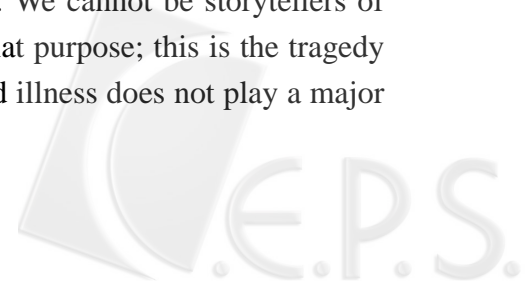
Over the last decade the use of narrative methods to assess competent patient's values and wishes and to establish preferences for medical and nursing care in advance has been well established. [7;8;20;21, also the contribution of Kielstein in this issue]. As Kielstein describes, the narrative method uses stories to confront competent prospective patients or patients with typical future situations of surrogate decision making, they might encounter. Carefully selected and tested stories of dementia, multimorbidity, prolonged coma, severe stroke, and suicide can be employed in order to invoke patient reactions and enable them to picture themselves in the situation and determine their preferences of treatment. Those narratives confront the healthy



and competent person with 'real' situations or scenarios and allow for differentiated responses, for actual self-understanding and self-value-anamnesis and for future self-determination and for voicing in advance wishes and values for medical treatment care. Experience tells us, that not more than four or five well chosen stories are necessary to cover the most basic clinical situation where the will of the patient or the presumed will of the patient has to play an essential role in guiding medical decisions, to provide, to modify, to withhold or to terminate certain medical interventions [8]. For specific diseases, in particular degenerative chronic diseases, where patients and physicians should communicate about the probable future course of degeneration, specific narratives could be developed, in particular for assessing attitudes of adaptability, loss of zest, and increase in frustration or depression; the same is true for intellectually or emotionally compromised persons. In particular, when hospice care is preferred or when withholding of clinically available life-prolonging technology is contemplated, decision must always be based on the individual's value-and-wish profile, thus integrating value status, clinical status, blood status, and other information into a truly differential diagnosis and prognosis.

Using narrative methods in the care of the mentally disturbed and demented patient will provide similar benefits and will prepare and assist caregivers in making good and patient-oriented choices in the care and treatment of those patients. Nursing care and medical care of patients with intellectual disabilities needs to be individualized care the same way, competent patients are given individualized care. As Meininger points out, narrative methods can and will change attitudes of nurses and physicians and result in better care: 'A new approach to personalized care and support should therefore be based upon a narrative and hermeneutical model of interpretation and support as opposed to an empiristic model of diagnosis and treatment.' He points out: 'Life stories, and the knowledge they convey, can be used for several purposes. The purpose may depend on the occasion on which the story is told, written, read, or listened to... Persons with intellectual disabilities themselves should be seen as prime authors of their own life stories. However, in the construction of their written life stories, family, friends, care workers or researchers may play an important part. Sometimes they serve as assistants or ghost-writers; more often they are readers and interpreters.' [13:2]

Well chosen narratives containing issues of health and disease, pain and suffering, shame and dependency, death and dying seem to be an excellent way to gain access to problems which in societies primarily build on principles of success and power, self-determination and self-rewarding, good life and quality of life have been pushed out of the prevailing culture, put under taboo and into those institutions we have created precisely for the purpose of collectively and individually not being bothered with: hospitals, psychiatric institutions, geriatric wards and old age homes. Mordacci and Sobel have pointed out: 'The possibility for us to tell a story about our illness rests on the availability of communicable meanings that can give an acceptable sense to our frailty, to which we can give out assent. We cannot be storytellers of our illness if our culture is deprived of any useful contents for that purpose; this is the tragedy of an exclusively technological culture.' [14:36] As far as pain and illness does not play a major

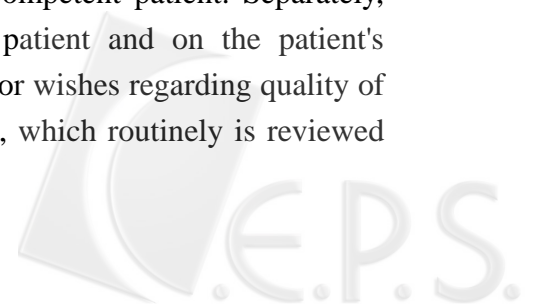


role in the life of most of us, these issues have by means of story-telling and story-listening and -discussing be webbed into our own life narratives before we are capable of making as prudent, informed and experienced advance decision and directives as possible. In a related empirical study, we have found, that lay people, previously not confronted with narratives of pain, severe illness and death and dying situations, are quite competent to understand those scenarios and to give directives in advance for future situations based on but different from their actual self-evaluation.[20]

### **Extraordinary Methods for Diagnosing Value-and-Wish Profiles of Patients with Intellectual and Psychiatric Disabilities**

Loss and distortion of memory and of social contact are an integral part of the most challenging disease of the new century, dementia.[15;16;19;24] Therefore extraordinary means have to be explored so that caregivers can adequately communicate and cooperate with demented fellow citizens, i.e. 'act in such a way so as to support the evident selfhood and semiotic nature of the afflicted by recognizing his or her personhood, intentionality, and semiotic nature through the veil of symptoms that the disease produces. .. In working to preserve the selfhood of the afflicted we act in accordance with Kant's dictum that we should treat others as ends in itself.'[18:47] A severely demented patient might 'through the veil of symptoms' communicate that he or she does not suffer from feelings of hunger and thirst any more, is no longer able to swallow, and does reject feeding tubes, then respect for human dignity and autonomy has to treat the patient as an 'end in itself' and accept that 'the patient's inability to swallow is one clear marker of Alzheimer's disease severe stage. Artificial nutrition and hydration are generally not a solution, because patients almost invariably perceive such intrusions as unwelcome. Physical discomfort and iatrogenic complications are equally serious considerations. No wonder that persons with Alzheimer's disease repeatedly pull out feeding tubes. The ADRDA guidelines for the treatment of severe dementia are clear: 'Severely and irreversibly demented patients need only care given to make them comfortable. If such a patient is unable to receive food and water by mouth, it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube. Spoon feeding should be continued if needed for comfort.'[1;16:75]

As the basic narrative approach cannot be employed to many demented patients, a special form of a narrative value history, called value diary, has been developed by Grundstein-Amato [5]. Through a series of repeated interviews and statements of previously recorded interviews with patients, the caregiver records a 'Value Diary' and establishes a systematic index to the patient's preferences, wishes and values. For multimorbid dialysis patients Kielstein has utilizes a model based on an 'Individual Care Group' (Betreuungsgruppe) of two or three nurses and physicians, supported by friends or family members of the incompetent patient. Separately, they write private reports on their communication with the patient and on the patient's preferences in treatment and his or her pronouncement of values or wishes regarding quality of life. They then compare notes and device a long term care plan, which routinely is reviewed



[see Kielstein, in this issue].

Clearly, the Grundstein-Amato and the Kielstein approach are paternalistic methods to gain access to value-and-wish information and directives, which otherwise would be expressed autonomously by the patient with or without communication and advice by a health care expert. But their approaches seem to be the most adequate ones to indirectly base nursing and clinical decisions on the patient's life narrative and value profile, even though only through the veil of the patient's symptoms and shortcomings. While developed for persons suffering from various degrees of dementia, such a communication-narrative approach could be used for different groups of psychiatric patients in different and disorder-specific ways.

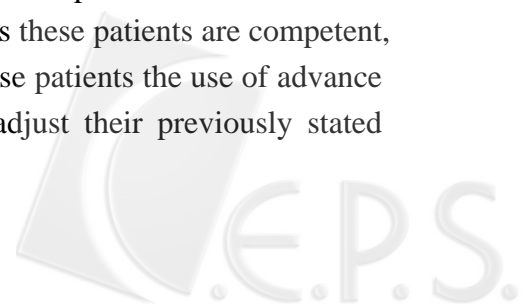
### **Patient's Values and Wishes: the 'Old' and the 'New' Person**

There is an extended debate whether or not previous directives should be honored or whether the 'presumed actual will' of the patient at the time of intervention should guide intervention decisions. The normative conflict can best be illustrated by the German legal situation where all medical interventions have to be based on the 'patient's will' and in the absence of a patient's will based on the 'presumed will of the patient'; an advance directive is not understood as representing the will of the patient, rather only as an instrument to assess her or his 'presumed will' at the actual moment. Supreme Court decisions in many countries, including Germany and Austria [11:162] hold that previous directives are binding, if the person giving those directives was competent at the time of making those decisions, and that so-called objective criteria of futility may only be used as a default position in the clear absence of the expression of individual preference. A possible conflict between the previous and the actual person is real, but the controversy seems to be somewhat artificial and will have to be discussed in different scenarios. [9:20;12:189-191]

(a) As long as competent persons have not changed oral or written statements and directives those statements should be taken as their true position and others should act accordingly in respect for persons; it is the right and obligation of competent persons who change their views and preferences to let others know, and if they do not do so they carry the risk of being misunderstood and mistreated.

(b) If someone falls in a state of wishlessness such as deep and prolonged coma, this person will have no new experience on which a change of values and wishes could be based and therefore should be treated according to wishes and values expressed.

(c) Patients suffering from chronic and progressive illnesses and persons suddenly confronted with physical disabilities will or will not adapt to new and quite different parameters of quality of life. Clinicians are very aware that many chronically ill patients and also those suddenly in a situation, which they might have thought previously would be worth living in, indeed, do adjust to new challenges over and over again. This phenomenon of human adaptability has been widely described in the literature. As long as these patients are competent, they have ample opportunity to accept or reject treatment; for those patients the use of advance directives is not indicated, and they, if they choose so, may adjust their previously stated



preferences according to their new experiences and visions for life.

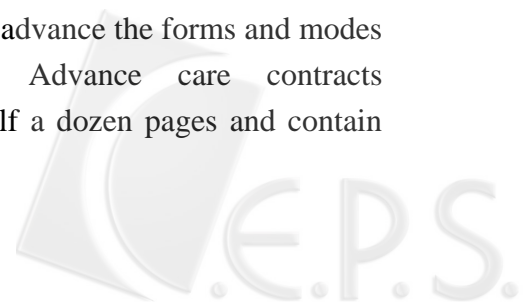
(d) Severely demented patient, not knowing who they are, where they are, and unable to recognize friends and loved ones, who while fully competent have executed advance directives refusing or requesting certain interventions in given situations, should be honored as the persons they were when they made those decisions which they then felt would be the most appropriate expression of their visions and values. This does not exclude, to honor those actual present preferences which are based on the person's adaptability to new situations and changing understandings and experiences of quality of life issues as long as the 'grande vision' of the advance value-and-wish directive is kept as a overall guiding force.

(e) Hard cases, however, seem to be those, where patients are semi-competent, where patients are in psychiatric confusion, or where incompetent patients request forms of comfort care which would contradict previous instructions. These are situations full of ambiguity in making the most appropriate benevolent clinical decision and often the care for the 'good' as presently expressed by the patient probably should be honored over previous statements. We have to discuss this in more detail.

### **Respecting Psychiatric Patients' Values and Wishes**

It is the illness of most psychiatric patients that they sometimes or all the time are confused, contradictory, self- and others endangering, or in other ways compromised in self-understanding, self-determination and in communication and cooperation with others. We have to differentiate between these two scenarios, one in which patients are intermittently ill, and another one in which they are chronically ill. Quite number of countries seem to develop new legislative and regulatory approaches to give mentally ill patients more input into treatment and care decisions; the actual debate is not centered around whether or not, but how much decision making capacity psychiatric patients should be given, balancing the autonomy principle with the harm (to others and themselves) principle. [11;1215;23] The recently legislated German Care Law has made a huge step forward to recognize and to honor will, wishes, and values of persons with dementia and psychiatric illnesses; however, the refusal of life-saving or life-prolonging treatment and the refusal of 'necessary' (as defined by professional medical quality standard) routine psychiatric treatment is not part of the patient's right to choose.[11;12; Bernat and Koch in this issue]

(a) There are psychiatric diseases such as epileptic and schizothymic patients, where patients are only compromised some of the time, not all the time, where there are acute and non-acute stages. In non-acute situations most patients are quite capable to understand, communicate logically, judge prudently and give directives in advance for future acute situations, similar to those they had experienced before in the course of their illness. It is indispensable and, if not done, it would be a violation of professional ethics and medical standard to assist patient in establishing as detailed as possible in advance the forms and modes of care they prefer in the case of acute illness. Advance care contracts (Behandlungsvereinbarungen) for epileptic patients can have half a dozen pages and contain



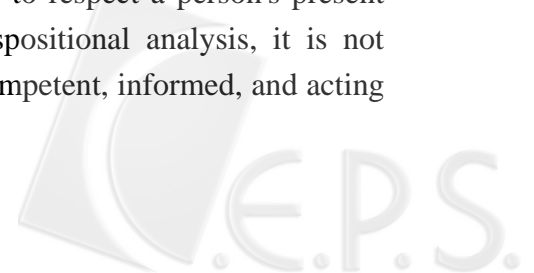
detailed clauses on physical or pharmacological restraints, names of persons requested and names of those rejected for bedside vigil in case of four-point or other physical restraint, such as the Bielefeld Advance Care Contract (Bielefelder Behandlungsvereinbarung). [2;3;11:161;27] These are not the death-and-dying scenarios addressed in other situations where overtreatment is feared and unwelcome to the person's value-and-wish profile and understanding of quality and meaning of life. These are care-contracts or care covenants (Vereinbarungen), discussed, negotiated, and signed in advance by the psychiatric patient and his or her care time and physician [11:161;3]. We are looking at directives given in advance by patients who are familiar with those situations and who have the right, the competence and the duty to make those decisions and not burden their caregivers with heteronomously choosing between intervention options in the absence of the patient's wish and will [2;5;10;14]

(b) But then there are psychiatric illnesses, where patients seem to be compromised all the time and where their wishes are either a threat to themselves or others or cannot be established coherently at all. Four models of paternalistically identifying the 'good for the patient' where the 'will of the patient' is in fact, or is presumed to be, self-destructive and dangerous, have been recommended: a community based standard, a provider based standard, and a dispositional-preference standard.[2;6;;14;19]

A community of patients standard based on a 'local patient community medical directive' originated from shared preferences and values within a small community as compared to another community. Patients have morally significant preferences and attitudes. The benefits of community based directives over expert consensus include the indirect recognition of the autonomy of the constituents, the experience of patient's preferences, and the interactions among local providers such as the German Sickness Funds. These funds are locally based and administered, and incorporate local values, cultures and preferences. Community based preference lists for good clinical practice reflect preferences, attitudes, and expectations of a particular community.

Within larger communities of diverse preferences, a provider based standard might be more efficient and justifiable. In communities of culturally diverse populations, various approaches compete to define the best clinical care and support a dignified process of dying, according to the provider's corporate ethics as chosen by the patient [6]. The provider defined standard of good clinical practice and dying in dignity serves a multicultural community only when a multitude of options are offered. In regard to complex psychiatric illnesses characterized by severity, iatrogenic influence, undeterminable competence of the patient, the provider-based standard and peer review of caregivers including nursing specialists might be better for determining and reviewing the good of the patient.

Savulescu and Dickenson have proposed a dispositional-preference standard, allowing psychiatric patients to express present preferences relevant for care and treatment, including the refusal of medically beneficial intervention. 'The imperative to respect a person's present preferences in a liberal society is great. According to the dispositional analysis, it is not necessary for clinicians to show that a mentally ill person was competent, informed, and acting



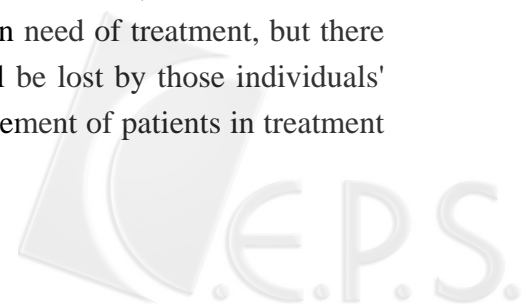
freely at the time he expressed his preference in an advance directive, but only that the person has a present dispositional preference similar to that expressed in the advance directive, and he was free, competent, and fully informed at some point during the time he had the preference. We distinguish this dispositional analysis of advance directives from an analysis in terms of substituted judgment' [23:224]. To prove their human-right and civil-right point of respecting autonomy, they 'suggest that the mentally ill should be able not only to consent to treatment in advance, but also to refuse it, and indeed to refuse life-saving medical treatment or psychiatric treatment when they are a risk to themselves' [23:226]. The dispositional preference standard thereby imports into the theory and ethics of psychiatry again the century-old debate on how to best respect and to honor human dignity and individual choice, when self-determination might be confused or compromised and harmful the person herself or himself [13:19]. However, the basic philosophical and cultural issue of how far the state or professional rules may paternalize individuals and their rights and obligations to choose, will not be solved within the circles of psychiatrists or bioethicists, but by the modes of changing cultural value preference over time and within different cultures.

There is a fourth form of paternalistic decision making. It is the proxy model widely used, where legally accepted, in designating a friend or family member as legal representative to make medical decisions by requesting, accepting or refusing treatment; I have not discuss this model in detail. But, given the complex nature of decisions to be made, proxies or family members might not be well informed or act under distress or conflict of interest. Therefore this model should be reserved for the few well analyzed cases where it might be appropriate and in the patient's best interest.

## **Conclusion**

All four models proposed for optimizing and individualizing treatment of psychiatric patients are based on the 'good-for-the-patient' principle. The dispositional-preference model gives priority to the recognition of personal liberty and free choice, even though the free will of patients suffering from psychiatric disorders might be questioned and the choice might be self-destructive. The peer-group standard and the community-based standard also orient themselves on the principle of the 'patient's good' as they stress a professional or neighborly obligation to prevent harm and to provide support, care and human solidarity. But all three models are paternalistic as far as they have made a basic philosophical decision regarding what standard is best for 'others': psychiatric patients.

Under a least-restrictive standard 'only intervention directed at the patient's harmful behavior is allowed; intervention is never justified because the provider prefers goals other than those expressed by the patient'; such an approach might lead to undertreatment and can be interpreted as unethical refusal of professional. A most-therapeutic standard, on the other hand 'promises a broader range of treatment to more people who are in need of treatment, but there is a risk that the heart of liberty, the right to self-definition, will be lost by those individuals' [15:245]. Theory and practice of psychiatry and the active involvement of patients in treatment





decisions and making advance directives and having their present preferences been honored will always have to oscillate between these two poles. These academic and social debates, also the rewriting of political and organizational rules and regulations, will not come to an end soon, as the positions taken are classical options in how to deal with fellow humans, suffering from specific mental disorders.

As far as I see, neither position has empirically proven to be superior yet, nor has any one of these models be given overwhelming cultural or political support over the others. For an academic philosopher and bioethicist, this is an uncomfortable situation in the transfer of reasoning and values into the complex every-day work of psychiatric wards and old-age homes. Therefore the most prudent common-sense consequence would be to understand the different models as theoretical default models, to be used as guiding visions only, not prescriptions or instruments to be followed strictly.

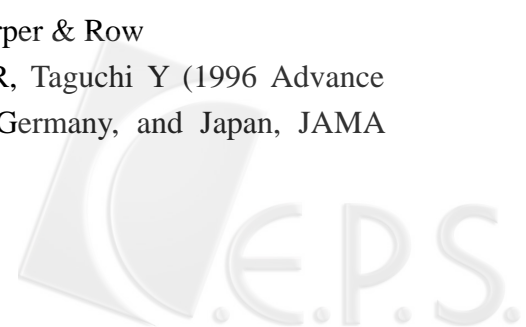
Whatever model is preferred in guiding geriatric or psychiatric care decision making, narrative methods seem to be the superior choice for individualized care, or in the words of Meiningen: 'A new approach to personalized care and support should therefore be based upon a narrative and hermeneutical model of interpretation and support as opposed to an empiricist model of diagnosis and treatment. Consistent with the latter model is an interventionist character of professional practice. Conversely, processes of (re)constructing and interpreting stories demand a professional commitment in which "presence" and "engagement", as distinct from "intervention" and "distancing" are central characteristics'[11:3]. Given human frailty and incompetence in many areas, not just among the demented and not only in psychiatric wards, our intellectual capacity might be competent and strong enough to solely determine all and every form of human-human interaction, thus pointing at other human capacities such as care, love, solidarity, without which no society and no human communication and cooperation ever will work, - or in the words of the French philosopher Pascal 'le coeur a ses raisons que le raison ne connait pas', the heart has its rationalities which rationality does not understand.

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