

*Usefulness and limitations of evaluation scales in the care of elderly people**

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ABSTRACT. Evaluation scales are used in the care of elderly people. They are useful for estimating the workload, the necessary resources, the care cost, the patient's dependency or autonomy in daily life, and/or the patient's needs. The large number of grids already indicates their insufficiency. This article explores the stakes implied by the evaluations, which use concepts more or less clearly defined as autonomy, dependency, deficiency, incapacity. It also questions our understanding of interdependence, vulnerability, and responsibility, and their implications in the care relations with elderly people.

KEYWORDS. Elderly people, evaluation scales, autonomy, dependency, narrative ethics

INTRODUCTION

Different evaluation scales are used in the care of elderly people. In Belgium, the Katz scale is currently being used by assisted living facilities and nursing homes to evaluate the residents' degree of dependency, and therefore to justify the financing of these structures. In other countries, evaluation scales are being used to similar ends in home care as well as in institutions. Without dwelling on the matter, it should be pointed out that European countries can greatly differ in the way they organize their care systems, making it difficult to compare the resulting practices – including scale use. There is currently a political impulse in Belgium to replace the Katz scale with the MDS-RAI¹ scale. The desire to see this new scale used on the front line (primary care structures) is being

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met with reticence from doctors and other actors in the care system because of the complexity of its application.

Why the use of scales? Their main purpose is to refine the diagnostic provided by the caregivers' observation. The use of a scale allows them to include in their analysis as many pertinent elements as possible, without forgetting or overestimating any of them. The scales increase the objectivity's level during the evaluation of a patient, which is not therefore based only on intuitions and feelings. This added objectivity also means that comparisons are possible between one visit and the next (for example in the study of a spontaneous evolution or after medical intervention or cue event) or between one caregiver and another. The Katz scale actually proposed in many institutions studies the capacities of the elderly in the following areas: getting cleaned, getting dressed, going to the bathroom, eating alone, mobility, continence, and orientation in time and space. Each item is marked from 1 (no problem) to 4 (total dependency or disorientation). The sum reflects the degree of care's needs for each patient. The actual tendency to replace the Katz scale by the RAI scale can be explained by various factors. To begin, the RAI scale is much more exhaustive and takes into consideration more items² than the Katz scale. It is also intended to be filled by different evaluating profiles (nurse, physiotherapist, doctor, social worker, the patient, and the family). By using a specific computer program to manage the data thus obtained, the user can quickly receive a table of alarms, together with the relevant intervention domains. Starting from there, a care protocol can be agreed upon by the care team. Many other evaluation scales are used in the world, but these two have been chosen for discussion here because the first one is largely relied upon today in many Belgian institutions, and the second one is currently being tested.

In addition to discussing the type of scale to be used, I will explore the stakes implied by such evaluations and the concepts more or less clearly being applied. The notions of autonomy, capacity, dependence, vulnerability and such are used in many different situations, without always

I. DAGNEAUX—USEFULNESS AND LIMITATIONS OF EVALUATION
SCALES IN THE CARE OF ELDERLY PEOPLE

being clearly defined. These definitions are the purpose of my analysis, even if a complete philosophical approach is not intended. The objective is to induce a reflection on the clinical and ethical part of the evaluation process. We will not spend time on a scales' critical (on their contents) but focus on the use the caregivers can make of it.

AUTONOMY AND DEPENDENCY: TWO SIDES OF THE SAME COIN?

Let us first turn to the definitions provided on the Belgian institutions' Web sites. While the Socialist Insurance Companies define the Katz scale as an "evaluation scale used in the sector of institutions for the elderly to measure the patient's degree of autonomy,"³ an article published on the site of the Independent Health Insurance Funds in January 2004 is entitled "Dependency: put an end to the Katz scale?"⁴ It begins with the following epigraph: "The economic issues in health care are considerable. It is therefore essential to allocate resources fairly, using transparent and verifiable tools. As far as dependency is concerned, the Katz scale only partially fulfils this criterion. The government must select a new tool that can be used to evaluate the quality of care while also assuring that resources are allocated fairly. Such an instrument must also make it possible to more accurately measure the workload of carers and the health care resources required for at-home care and in nursing homes." These few lines touch upon numerous elements: such tools must serve not only to fairly allocate financial resources, but also to measure nursing workload and to control the quality of care, while their initial goal is to measure the physical and mental dependency of the individual concerned⁵! The degree to which these different elements are directly linked is variable. Though it may be possible to imagine "transparent and verifiable" tools from an economic point of view, is it not dangerous or limiting to demand the same of a tool for evaluating the dependency and/or autonomy of a human being? First of all, as Gommers and Dargent show, evaluation

scales can serve three types of objectives⁶: epidemiological research at the population level; to gain “knowledge about the condition of a given individual in order to ensure follow-up care and establish an intervention programme”; and to gather data for management purposes. They rightly call into question the possibility of finding a common tool for such a wide variety of objectives: “the existence of a considerable number of grids (almost 500) seems to indicate that it is illusory to hope to find an ideal instrument, adapted to all situations.”⁷ But one may also wonder about the terms used. Do the notions of autonomy and dependency counterbalance each other exactly, in both positive and negative terms? Is evaluating dependency the same as evaluating the loss of autonomy, or positively, the remaining autonomy? Beyond the semantic conflicts we can feel approaching, and beyond the polysemy of the term “autonomy” – which is probably given too little attention – we can wonder if this notion (alone) is sufficient for grasping what is at stake at this stage of life. Let us start by reviewing several of the terms in more or less frequent usage, so as to specify their relationships, contributions, and implications.

DEPENDENCY, DEFICIENCY, INCAPACITY, HANDICAP

Choosing a term is not the result of happenstance and is not without consequence. In recent years, old age has been increasingly equated with “dependency”, and it is appropriate to wonder what this term implies. Though it can connote a positive sense of exchange, to the extent that life is made up of interdependencies, the term is more often heard in a pejorative sense of submission and loss of autonomy.⁸ We must first distinguish “dependency” from “deficiency,” which is defined by the WHO as “a loss or abnormality of a structure or of an anatomical, physiological or psychological function”⁹ and which can be resolved by the individual suffering from it. “Incapacity,” which indicates “difficulty or impossibility in carrying out an activity considered to be normal in human functioning,”¹⁰

does not necessarily lead to dependency either, as, like a deficiency, it can be compensated. However, this term involves a normative aspect for which the elderly could pay the price: the elderly stop performing certain activities considered as normal for adults because, for them, those activities have lost their essential character. Only the incapacity to carry out a task essential to survival requires the assistance of others. When not in reference to the elderly, this situation is called a “handicap”: why is this term no longer used for old people? There is a great risk that the term “dependency” will be reserved for the elderly, and will even be automatically associated with old age: as evidence of this shift, consider the surprise most people experience when meeting octogenarians who are “fit as a fiddle,” or their astonishment at hearing that two thirds of them live at home! The issue is not only semantic, though it is important to keep in mind how these terms partially overlap, especially when it comes to completing an evaluation grid in which the different notions are often mixed. According to P. Meire, the confusion in the use of these terms leads to the exclusion of elderly people from systems of protection reserved for other age groups, and also leads to the creation of new products such as “dependency insurance.” This boils down to favoring market principles over a system of exchange and giving, and to a particular interpretation of autonomy, which I will come back to below while exploring the links between individuality and socialization. “Words are not innocent: attributing the idea of dependency to old age is risking a new tear in the social fabric.”¹¹

FRAILITY

In recent years, there have been a series of attempts to approach the elderly from the perspective of vulnerability or frailty. “The expression ‘frail elderly’ is regularly used in geriatrics, but this term is reserved for a certain type of patient, and not for elderly people in general.”¹² The notion of resilience – which can be seen as the opposite of vulnerability – is

often forgotten in discussions about elderly people, even though many of them display a surprising capacity to continue to “take control of their lives” and be “autonomous.” We must therefore remember that the adjectives used, i.e., frailty and vulnerability, merely express a possibility, the susceptibility to being damaged or hurt (without this necessarily being the case), whereas their use often seems to result in an individual being definitively categorized in a particular state.

P. Meire distinguishes four possible dimensions of frailty in the elderly: somatic, mental, social, and ethical. Loss of autonomy in one dimension does not imply a similar loss in another: while it is easy to understand that “a patient with a loss of functional autonomy can remain very autonomous in his choices and decisions,” we often forget or are unaware that “even in these cases [of dementia], a certain mental autonomy seems to be preserved.”¹³ As far as the first dimension is concerned, the existing scales assess the continuation – or lack – of complete autonomy in activities of daily living. The goal is to obtain an indirect measure of the deficiency in physiological function, but the evaluation scales used up to now have proven to be limited in their ability to actually represent such a measure. And this is only in reference to somatic vulnerability. “Numerous factors modulate and complicate the notion of frailty: individual factors (self-esteem, resilience, education, adaptive abilities, etc.); community factors (living environment, social support, etc.); factors linked to the health care system (quality and continuity of services, etc.).”¹⁴

Reminding us that each human being is frail and dependent, P. Meire points out that the terms too quickly attributed to elderly people imprison them in a ghetto of condescension with no regard for their rights, which is tantamount to denying their dignity as human beings¹⁵. In his article, the use of the term “autonomy” seems to reflect the current double meaning of this term and the tension linked to its polysemy: on the one hand its “socio-medical” sense, on the other hand its “philosophical” sense (in our own terms). The former has to do with evaluating the capacity of autonomy, that is, the ability to carry out minimal activities of daily living

without exterior help, and to do so while oriented in space and time. This is the vision of the Katz scale. The other scales are more complex, but are based on the same simplistic vision. The second sense of the term “autonomy” refers to “the ethical dimension of the premise of autonomy upon which humanity is based.”¹⁶ Let us take the time to examine this in further detail.

AUTONOMY

P. Meire’s closing remark – or injunction – invites us to come back to the notion of autonomy: “We cannot evaluate the value or dignity of a human life by measuring its vulnerability or autonomy.”¹⁷ In its “philosophical” sense, autonomy is in fact understood to be one of the classical foundations of human dignity: but which kind of autonomy is it?

Respect for autonomy is one of the four principles of bioethics established by Beauchamp and Childress in 1979. Kant regarded autonomy as man’s rational capability to define his own moral law, rather than receive it from an external source. As such, moral life is based on respect for the principles and laws that human reason assigns itself. Engelhardt helps translate this notion into the context of the twentieth century, particularly in the field of bioethics, by relating it to the consent of the autonomous individual: “The principle of autonomy expresses the fact that the authority for resolving moral disputes in a secular, pluralist society can be derived only from an agreement of the participants in the disputes, since it cannot be derived from rational argument or common belief. Therefore, consent is the origin of authority, and respect of the right of participants to consent is the necessary condition for the possibility of a moral community. The principle of autonomy provides the minimum grammar for moral language ... [the] maxim: do not do to others that which they would not have done unto them, and do for them that which one has contracted to do.”¹⁸

Generally understood today to be the ability to make one's own decisions after having been reasonably informed and without excessive influence from external factors, autonomy tends to be equated with individual self-sufficiency and personal self-determination. In view of this tendency, we can see that it is not possible to think of autonomy without also thinking of its opposite, dependence or heteronomy, nor without tension: "Autonomy feeds on multiple dependencies. The autonomy of a human being is fed not only by dependencies upon the biological world, but also on social and cultural dependencies. It is clear that in the modern world, our autonomies are founded on a very tight network of dependencies."¹⁹

To take just one example, the Belgian law on patients' rights,²⁰ if it were to realize its full potential, highly praises a notion of autonomy which, while already problematic for healthy people, is all the more problematic for patients whose illness and need to wait for care inevitably renders them dependent and weakened. Patients who are capable of exercising their autonomy as it is expressed in the law are exceptions to the rule.²¹ Furthermore, cross-cultural situations sometimes highlight the fragility and limitations of our theories and principles.²²

I will not go into detail here on the inadequacy of the classical conception of autonomy – or rather the conception of autonomy as it is classically accepted in Western philosophy. Calls are being made to attempt to view autonomy differently; for example, in a way that could take into account the specificity of existence as it relates to human existence. Without questioning traditional ethical principles, A. Donchin calls for a reconfiguration of those principles in view of autonomy from a relational perspective. She begins her argument by pointing out the inadequacies of the dominant conception of autonomy, including how "the identity of the individual deemed a free and rational chooser of her own ends is severed from the social context that constructs and facilitates those choices."²³ Thus, by placing too much emphasis upon autonomy as a norm (to the extent of sanctifying it), it is put in direct opposition with interpersonal

I. DAGNEAUX—USEFULNESS AND LIMITATIONS OF EVALUATION
SCALES IN THE CARE OF ELDERLY PEOPLE

relationships. This consequence, though already harmful to healthy subjects, reveals the full extent of its unsuitability in reference to sick, elderly, and dependent individuals. “Coming to see autonomy as relational in this way brings into central focus a dimension of provider/patient relationships relegated to the periphery by conceptual schemes that regard individuality in abstraction from particular contexts of social interaction.”²⁴

An article published in *Médecine* (October, 2006)²⁵ could be seen as laughable from a clinical point of view, but it does tie up with one of the aspects of this conception of relational autonomy. The article describes a doctor who allowed an elderly woman to be assisted by her spouse while taking an MMS test to evaluate her cognitive abilities: even though such a test might not sound very “academic,” it is nevertheless much more representative of the reality of a couple’s daily life in which they use their capacities in a complementary fashion, not only in performing activities of daily living but also to aspire to a certain quality of life.

AUTONOMY, VULNERABILITY AND RESPONSIBILITY

The difficulties experienced in applying the concept of autonomy in a clinical setting have proven it to be insufficient, and have shown the need to link the concept to the reality of vulnerable patients who, for cognitive, economic, family, or other reasons are no longer in a situation that allows them to defend or achieve this autonomy. Certain clinical situations have even shown the damage that can result from demanding such autonomy from patients who are not capable of it, and how it can eat away at the sense of responsibility felt by medical staff. Though Emmanuel Lévinas may not have intended to go into the field of bioethics, the way he sees the relationship with the Other, responsibility and affection for the Other is of great interest for overcoming the inadequacies of a hegemonic notion of autonomy. “To consider medical ethics is to set out ‘in spite of oneself’ to link people’s autonomy with the injunction to protect their

vulnerability; it is the very essence of the democratic project.”²⁶ To Lévinas, the need to consider suffering and death goes back to the finite quality of human life, which in the end is quite removed from an ethics based on the autonomy characteristic of the healthy subject and of a view of medicine that is based on the promise of health. We cannot consider autonomy alone, without its opposite, heteronomy, in the same way that freedom without its opposite or without obstacle would be meaningless. “It is [nevertheless] the fluctuation in one’s existence between periods of autonomy and periods of vulnerability which makes intersubjectivity possible. The vulnerability of the child, of the sick person, of the old man, is an appeal to the responsibility of the autonomous individual, and a reminder or memory of his past or future heteronomy.”²⁷ The subject is never a subject on his own; he is a subject in face of the Other, awakened to himself by the sudden appearance of the Other’s face, which affects him and appeals to his sense of responsibility. As such, the subject’s autonomy does not emerge in the absence of a counterpart, but rather through dependency or interdependency. Thus, “Lévinas suggests an ethic where heteronomy, in a mental framework that is diachronic to the principle of non-contradiction, is not the opposite of autonomy, but its condition. He makes it possible for ethics to be the arena in which we consider this complexity.”²⁸

Let us go back for a moment to P. Meire’s comment on the link between the medical evaluation of autonomy and the dignity of the individual. Bruno Cadoré’s Levinasian view of medical responsibility helps us understand this link by making a connection between subjectivity and objectivity, rationality and affection. “The effort of bioethical reflection is indicative of the demands people make of themselves in attempting to fulfill their capacity for theoretical knowledge while leading a daily existence that attests to human dignity (...) It is therefore the task of biomedical reason to prove this dignity, which constitutes its primary challenge. That challenge can take any of at least three forms: the confrontation with suffering, the ambition of health production, the ability to master the body.”²⁹

I. DAGNEAUX—USEFULNESS AND LIMITATIONS OF EVALUATION
SCALES IN THE CARE OF ELDERLY PEOPLE

The challenge facing bioethical reason is particularly evident in the context of suffering because it leads to a connection between knowing and helping others. This results in a powerful paradox in which the strength of rationality is confronted with concern for the most vulnerable. Consequently, the choice is made to follow the path of humanity. In response to this, it is necessary to develop a theory that combines scientific and ethical rationality and promotes them as a joint, elemental human capacity. “The care relationship is particularly evocative of this human task,”³⁰ both in terms of the solicitude involved in close community relationships and a broader sense of solidarity, and in the exercise of reason being confronted with the boundaries of finiteness.

TALKING AND LISTENING TO RESPECT AND PROMOTE AUTONOMY

B. Cadore’s interpretation of medical responsibility when faced with the challenge of suffering shows the extent to which the rationale generally and predominantly applied in the medical profession is not capable of serving the patient in how he experiences his illness, his dependency, or his “fragilization.” There is good reason to develop a new medical competence that will accompany the patient in his experience of frailty and uniqueness, and in his search for meaning.³¹ Furthermore, through the working process, a question has arisen regarding the involvement of the individuals concerned in deciding to make the evaluation, conducting it, and its consequences. One does not frequently hear about this, which is an indicator of the objectification of the person to be evaluated. Nevertheless, “we would once again like to insist on ... the importance that must be assigned to the patient himself in his own evaluation. If the evaluation leads to a care or assistance plan, we must first start by listening to the patient, his requests and his wishes, as, after all, the care and assistance are intended for him. Not listening to him would be the same as going against his autonomy and therefore working against the desired goal.”³²

Therefore, I believe it is important to turn our focus back to the desires expressed by the patient. Indeed, though evaluation scales can be useful in relation to a well-defined objective and though they help attain a fresh perspective on the patient's situation to be able to provide better care, they obviously remain limited in painting a complete picture of an individual's uniqueness and complexity. It is in this respect that I see the ethical value of a narrative contribution. "In order to allow the patient to be and to remain a unique human being, the master of his own destiny, we must be able to refer to his history, to what makes it unique, to what makes him individual."³³ C. Bolly shows that narrative ethics promotes the recognition of important elements such as patient competency, the patient's request – upon which the care relationship and intersubjectivity are founded and which makes it possible to recognize the Other as a subject – the search for meaning, the plurality of values, and the universal quality of humanity as experienced in the concrete reality of uniqueness.³⁴ I will focus – somewhat arbitrarily – on the first two elements. In reference to evaluation scales, a request from the patient is an evanescent reality. Rather, the request tends to be political, institutional, administrative, or scientific. In light of the discussion above, the gap between what I have described as the two meanings of the notion of autonomy seems even more flagrant, to the point where we become aware of the following paradox: we allow ourselves to talk about the autonomy of a patient without any request from his part, and without asking his opinion! This brings us back to patient competency: subject in a body, the patient is the one whom our efforts should serve. This is far from being an obvious fact in real-life experience, where many carers of the elderly demonstrate the balance of power inherent to a normative medical practice and health policy.³⁵ As the first person affected by the care provided and the decisions taken, the patient must have a say in these decisions, even if his capacities of comprehension, expression, etc., are impaired: such impairment can sometimes be an easy excuse for making a decision on the patient's

behalf. As such, it seems essential to take his story as he tells it into consideration. I also believe that it is crucially important to pay attention to the way in which he describes his experiences, even if doing so requires time, competence, and sometimes creativity. If the request does not come from the patient, if the care proposal arises from an evaluation and applies elements that are exterior to the patient, how can the doctor integrate this into the patient's history? Will the diagnosis presented to the patient remain objective, scientific, and exterior to the patient, or can it also become an account by the doctor that takes the story of the patient into consideration to help him integrate the two?

Without a doubt, genuine dialogue is a reflection of true respect and not a failure to take responsibility or indifference when faced with a patient who, for instance, refuses care. The title of one article is striking in this sense: "Persuasion as Respect for Persons: An Alternative View of Autonomy and of the Limits of Discourse." At the start of the article, the author asks if we have ever spent as much time trying to convince a patient as discussing among colleagues his right to refuse treatment. More precisely, "the same length of time talking to that patient with ardor and passion, understanding his situation, and convincing him to accept what we professionally believe is the best for him."³⁶ The author shows that respect for autonomy is acquired through meaningful conversation that takes into account the patient's subjective experiences, values, and preferences. Taking a patient's experiences and personal account seriously is tantamount to promoting his autonomy as the subject of his own history and of the decisions that affect him. Nevertheless, we must not overlook the conditions necessary to prevent this powerful conviction from becoming paternalistic or an abuse of power: "the litmus test of this respect is a sincere and non-coercive attitude of interpersonal discourse about personal issues in which **one is willing to be persuaded while trying to persuade**"³⁷ ... which is not possible without evoking the argumentation ethics!

CONCLUSION

The present reality of a variety of care structures taking responsibility for elderly people makes it necessary to evaluate needs on an individual level as well as a collective level. Consequently, evaluation scales are necessary. It is important to define the objectives of their use and to be aware of the limits of each scale, as is true for any evaluation with an objectivizing goal. There is cause to continue research and reflection on the subject, as too many grids have failed to show inter-observer reliability and temporal reliability. In addition to the knowledge gained through analysis by evaluation scales, which offers a partial view of the elderly individual, it is important to develop other care approaches which recognize his account, the story of his life, his experience as an elderly person, his perception of his needs, what he is or is not willing to accept in what is proposed to him, and his judgment. Paying attention to the patient's account can make way for these elements. There is no need to choose between one approach and the other; we have to be able to use both – and more – for what they offer as a means to accompany a patient in what he experiences in his life as he goes through the aging process, by allowing him to remain master of his own destiny. The stakes are particularly high with regard to the elderly because the excessive use of the notions of dependency and loss of autonomy often gives rise to condescending attitudes.

The reflection that we hoped to induce on the use of various linguistic terms can lead to various practical uses clinically. The uses and limitations of the evaluation scales have been recognized, which allows now for other complementary approaches. This paper is not intent on listing them all, but a few leads can be proposed. First of all, the care team can be informed about the importance of the terms they use and their clinical meanings. A team can therefore spend some time discussing the presuppositions and the consequences of its use of the term “autonomy,” for example: whenever they say that a patient is not autonomous, it can in fact represent different realities and thus needs to be defined clearly for every-

one. It can relate to the patient's walking autonomy, or autonomy in instrumental activities, but this doesn't mean that the patient is not able to participate in discussions about his/her future or his/her quality of life. Such team meetings on the meanings of words can open new ways to improve the patient autonomy in any domains in which he can still participate, make decisions, initiate new process or go on with existing ones, alone or with the help of others. More specifically, cases of dementia need new ideas to implicate the patient in the decision process. Another path to follow is this: to optimize objectivity, the evaluation scales are used by the entourage of the patient and not the patient himself. To avoid the coldness of the process, it is essential to propose a complementary approach that gives center stage to the patient in terms of decision-making, and a subject of his own history. Practically, it means that the care team should think of any possible way to implicate the patient as much as possible in the evaluation process and in any related decision. This should probably start by giving the patient and its family all the necessary information, as well as time enough to digest and discuss it. The fact that the entourage of the patient is implicated is part of his autonomy in his relationships with the others. The example of Luc Périno giving a MMS test to a couple is a good example of creativity in the use of evaluation tools. The patient needs time to give his account, to include in his experience anything that happens to him in relation to his sickness. The care team also needs time to listen to that account and to adapt proposals for that particular patient.

Though general medicine has a natural inclination toward the narrative approach, my aim here is to pass on the questions that emerged from B. Cadore's interpretation of the two rationalities, scientific and ethical, at work in reference to the suffering – and I would add vulnerable – subject. It is important for doctors to learn to develop both types of rationality in their dialogues and to leave room for creativity, so that the patient may remain at the center of the care process: in this way, scientific knowledge will continue to serve the needs of the ill and the elderly.

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NOTES

1. Minimal Data Set - Résident Assessment Instrument. Several versions exist, each adapted to its special environment : « Home Care » at home and « Long Term Care » in institutions. (As written in a working document by Mme N. Grauwels)
2. 350 items classified in 80 headings and 17 sections (Idem).
3. From the Web site of the socialist insurance companies, consulted on 14/12/2006: <http://www.mutsoc.be/e-Mut/MutSoc/300/Help/Lexicon/E/echelle-katz.htm>
4. On the Web site of the Independent Health Insurance Funds, consulted on 14/12/2006: <http://www.mloz.be/jsp/internal.jsp?id=179&idDoc=308&language=Fr&origin=Mloz>
5. See the document "Annexe 41 : échelle d'évaluation justifiant la demande d'intervention dans une institution de soins", which can be consulted on the INAMI Web site: <http://inami.fgov.be/care/fr/residential-care/pdf/ANNEXE%2041%20au%201-1-07.pdf>.

I. DAGNEAUX—USEFULNESS AND LIMITATIONS OF EVALUATION
SCALES IN THE CARE OF ELDERLY PEOPLE

6. Gommers and Dargent 1997, 64.
7. Gommers and Dargent 1997, 65.
8. Meire 1997, 125.
9. Quoted by Gommers and Dargent 1997, 59.
10. Gommers and Dargent 1997, 61.
11. Meire 1997, 142.
12. Meire 2000, 82.
13. Meire 2000, 83.
14. Meire 2000, 84.
15. Meire 2000, 82.
16. Meire 2000, 85.
17. Meire 2000, 88.
18. Engelhardt 1986, 86.
19. Gommers and Dargent 1997, 63.
20. Law relating to the rights of the patient, August 22, 2002, published on August 26, 2002.
21. I was working in a Neurological Rehabilitation Centre when the content of this law was explained to us, and we tried to find patients who fit the picture that had been presented: it did not apply to the children, nor the elderly, nor the patients with head injuries resulting in cognitive disorders, nor the mentally handicapped.
22. A colleague helped us to understand that the notion of autonomy is also very cultural by recounting the story of a late-stage cancer discovered in a Turkish woman. This resulted in her family circle assuming total responsibility for her care, which led the patient to understand the nature of her condition, even though it had not been explained to her using objective medical terms. It was impossible for the oncologist to obtain her consent for palliative chemotherapeutic treatment, as the family thought it out of the question that she would be informed of the diagnosis and because she did not speak French. We discussed the “shifting” of the concept of consent and of the related concept of autonomy, principles subject to actual reality (“Ethical Commission” of the General Medicine Chair, November 2006).
23. Donchin 2001, 374.
24. Donchin 2001, 378.
25. Perino 2006, 384.
26. Baum 1998, 390.
27. Baum 1998, 390.
28. Baum 1998, 391.
29. Cadore 1994, 46.
30. Cadore 1994, 57.
31. Cadore 1994, 54.
32. Gommers and Dargent 1997, 79.
33. Bolly 2002, 8.
34. Bolly 2002, 12-19.
35. Ennuyer 2001.
36. Barilan 2001, 13.
37. Barilan 2001, 20.