# ETHICAL ASPECTS IN THE DEVELOPMENT OF COGNITIVE TECHNICAL SYSTEMS FOR PROVIDING SUPPORT IN CASES OF DEMENTIAL DISEASES

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#### ABSTRACT

By integration of cognitive properties into technical systems, chances are opening up for developing systems that are able to act as appropriate to the situation. These systems are characterized by not just reacting purely reactively, but by generating actions according to the objective of the technical system and its capabilities. Sensor-actor chains are no longer rigidly coupled, but modifiable. The feasibility of modification results from the learning aptitude. In the focus is the application of cognitive technical systems in the medical sector for supporting the medical treatment and care of dementia-diseased patients. In the course of disease, such persons lose their own cognitive abilities. The objective of product development is, to compensate that lose by means of respective technical systems to extend that the patients' quality of life improves significantly.

Because of the abovementioned properties the systems, a number of ethical problems such as the restrictions in arranging ones life and in the patients' self-determination need to be taken into consideration. So results from the high degree of autonomy also the risk of total surveillance of patients. This is in deed desired on the one hand, as the patient's room for manoeuvre can thereby be significantly extended, but on the other hand, a deep cut in the patient's personal rights is coming along with it. Other critical questions result with regard to the safety and reliability provided by such devices. When technical systems are actuated, who is responsible for it, who is bearing responsibility in case of a system failure?

*Keywords: mechatronics, cognitive abilities, DfX, techniques consequences* 

#### **1** INTRODUCTION

The development of new technologies and techniques was in the past and will be in the future always ambivalent. Today every novel technology development occurs for a certain purpose, which is already connected with risks for the user as well as the environment that the technical devices are used. Besides, the acceptance of the risk is already to see in relation to the purpose of the development of a system. Before one uses a new kind of technology he has to investigate, which potentials however, also which risks are associated with an application. Ethical questions become more urgent if new product innovations should find an application in the context of medical technology and should be used by patients.

Under the term ethics one understand generally that based on rationality rules whether action-guiding conceptions accord to a criteria "good". In order to that ethics one understand concrete action-guiding which tend to the nature of "good". For the effectiveness of morality it needs principle integration in the everyday occurrences. From the definition follows that on the one hand sophisticated criteria's are required for the estimation of that what is "good". On the other hand it is a matter to specifying additional action-guiding aspects. Ethic-considerations appear therefore as a variance comparison between possibilities (by the technical developments) and necessities (resultant form the clinical picture).

Due to the demographic development in Germany and in Europe, their nursing care will pose a great challenge to society in the near future. Here, methods of resolution can be offered by the sector of engineering science. Besides, in the focus stand cognitive technical systems, which compensate the lost abilities of the patients with dementia to a certain level. Thereby the patients get the chance to live as long as possible in a close domestic sphere. In this case on the hand side it is necessary to consider the disease pattern in the deliberation of product development. Otherwise useful criteria's must be found to acquire volitional enhancement. Just the application of technical systems for persons with dementia and for old persons put for the question, to what extent technical support is really helpful. Will be a technical help accepted by the patient or is there merely the interest of the engineer behind the application to find out the technically possible and feasible ones.

Such questions to signification benefit and risks of technical systems special use cases specifically for applications in medical context are posing Questions for the ethical legitimacy. These are typical questions from the field of applied ethics. To answer such questions and to consider the results for the product development it is necessary to describe the disease pattern and the characteristic of cognitive technical systems, to confront both and to compare risks and benefit. Such a comparison is only finally meaningful, if social and individual aspects will be regarded.

# 2 BASIC ETHICAL CONSIDERATIONS IN CONNECTION WITH THE UTILIZATION OF TECHNICS

Technical acting is always ambivalent, which primarily means that particularly the implementation of technical systems is always coupled to feelings, thoughts and wishes of different stakeholders. These are in the case of technical systems for medical questions the designer, the subsequent user, thus the patient, but also the nursing staff respectively the physician. In such an area of conflict, the subtle implementation of technics absolutely promises a great benefit, individually for the nursing person or the patient as well as also from a sociopolitical point of view, as the nursing effort by the community can be reduced. The same technics however that helps one patient and presents itself to that patient's well-being may rather cause damage for another one due to that person's own personality. So in addition to potential chances of the implementation of technics, checking for potential risks is also always to be undertaken. Self-interest needs to be put in relation to the common public interest of the implementation of technics. Finally the engineer has to answer the question, whether the implementation of technics in a certain situation (here clinical picture) of a defined user group is right and safe or not. [10]

To obtain a basis for the assessment of technical systems by ethical aspects, a specific risk-benefit estimation is needed. For a comprehensive contemplation however, not only possible problems should be considered. Also a number of benefits arise for the user / patient that contribute to considerably improving the quality of life of a dement person. How strong or in which direction this is pronounced however depends on the respective application. So can cognitive technical systems help to give a patient's mobility back and to enable a noticeable extension of life in the familiar living environment. On the other hand is to be feared that privacy is restricted by excessive data collection about the patient. For a most objective conclusion it is necessary to clarify, which criteria finally characterize the benefits respectively the risks of a cognitive technical system in the application in connection with persons with demential syndromes. For that purpose firstly the cognitive technical system and the clinical picture of dementia shall be described more closely in the following in order to find appropriate details for product development.

#### **3 DESCRIPTION OF COGNITIVE TECHNICAL SYSTEMS**

A logical further development of intelligent multidisciplinary systems results in the consideration of other disciplines such as cognition sciences and artificial intelligence. The integration of cognitive abilities into a technical system allows that one to act autonomously and therewith as appropriate according to the situation. To understand the relevance of ethical questions in connection with the utilization of cognitive technical systems, it is necessary to describe what cognition means.

We speak of cognitive properties if a system is able to recognize its environment as well as its own system conditions, to adjust gathered data against a knowledge basis in order to then generate actions

as appropriate to the situation deriving from a comparison. A technical system that acts cognitive must in any case have the following six properties: to perceive and recognize its environment and itself, to encode data, to store information and to remember those, to think and to solve problems, to realize a motor function control and to use an appropriate type of communication in doing so [1]. The individual properties may exist in different prominences, characterizing different degrees of cognition. However all of the six properties must be existent somehow in order to speak of cognitive abilities.

A number of specific properties result from those cognitive abilities, which such a system is provided with [2]:

- A high degree of autonomy and resulting thereof the feasibility of acting as appropriate to the situation
- Active involvement in the environment, along with the ability to exchange information with that environment
- Learning and anticipating aptitude

This implies on the one hand that cognitive technical systems operate with great data volumes that need to be stored and released where required. In this way in case of application by patients, a multitude of partly very personal data is collected and processed. To a certain degree the system itself decides by it's learning and anticipating aptitude which conclusions should be drawn respectively which actions should be activated. The technical system develops an own target system, but shows no emotions. The designer however only defines an initial condition of the technical system by the feasibility for the system itself to define targets and to distinguish situations. Therefore it is ultimately not determinable anymore how the system will act in a certain occurring situation. The independent solving of problems is based on recognizing the environment and on the inner reflection of the gathered information.

From this description of properties [3] it becomes obvious what area of conflict is to be expected in the application, primarily in the context of implementation for patients with demential syndromes:

- Storing and processing of great data volumes, which on the one hand reveal very much about the personality of a sick person and on the other hand are comparatively easily accessible.
- The cognitive technical system possibly interferes with the user's / patient's autonomy of action.
- The patient gives off a not irrelevant part of his or her freedom of decision to the technical system.

From those mentioned points, elementary questions regarding the ethical acceptance of such systems result.

# 4 DESCRIPTION OF THE CLINICAL PICTURE OF DEMENTIA

Under the generic term of dementia, generally a broad spectrum of diseases is embraced that come along with dramatic losses in the mnemonic function. This causes constraints in everyday life functions and in the independence of patient up to the total dependence and need of high-maintenance care. According to [4], the term dementia comprises an atiologic, thus regarding its causes a nonspecific syndrome, which is characterized by mnemonic debility, disorders of the higher-cortial functions, disorders of speech and orientation as well as by progressing failure in everyday life performances.

Dementias in principle can be divided into three large groups: Alzheimer dementia, vascular dementia, and demential in cases of elsewhere classified diseases. One chance for a differentiated diagnosis is provided by the criteria according to ICD 10 by the World Health Organization [5]. According to that, the "existence of multiple cognitive deficits" and a "derogation of the social and occupational performance capability" due to such deficits as well as a deterioration compared to a former performance level as significant criteria. A patient has memory deficits that influence the short-term memory as well as the long-term memory [6]. Additionally at least one more of those criteria are fulfilled:

- Aphasia (disorder of speech)
- Apraxia (inability to exercise activities, even though the motor function is intact)
- Agnosia (inability to recognize persons or objects, even though the sensory functions are intact)
- Derogation of executive functions such as planning, organizing, abstract thinking, etc.

A dementia patient is no longer capable of transferring information from the short-term memory to the long-term memory. Such oblivion has the consequence that the learning aptitude of the patient and along with it, the adaptation to new situations or devices is very highly constricted. For transferring information to the long-term memory, structured information processing is required, many recapitulations and personal attentiveness. Also the long-term memory is decomposed in the course of the time. The dement patient at first looses the younger information and skills. Forgetting is dragging on in the course of the disease till the earliest phases of life. Dementia is characterized by its chronological sequence in which changes in condition may occur erratically. From the medical view, three stages are distinguished [4]:

- **Slight dementia:** Even though working and social activities are definitely affected, the ability to live independently with appropriate hygiene and intact judgment still remains.
- **Medium dementia:** A self-dependent life is associated with difficulties, but still feasible. A certain amount of supervision is necessary.
- Severe dementia: Everyday life activities are affected to such a degree that continuous supervision is needed, as the patient for instance is no longer able to keep up a minimum of personal hygiene, incoherence or mutism exists.

The objective of employing cognitive technical systems is to provide for a life in the own domestic environment for as long as possible. It has shown that the clinical picture deteriorates if this is not provided anymore. The need of high-maintenance care and bedfast condition of the patient in the third phase of dementia however can generally not be prevented. Therefore in the following, only the phases of slight dementia with the transition to medium dementia shall be considered. In later phases, other attendance concepts are necessary. Starting from disease-conditional memory disorders, a series of dementia-conditional behavior patterns occur with the patient. Those multiple deficits are expressed by a decrease in learning aptitude, by reduced retentiveness, by word finding and denominating disorders, by spatial and temporal disorientation and by forgetting of long-known information and behavior patterns.

A typical concomitant phenomenon of dementia is anxiety. The reasons for that are multiple. Anxiety at the one hand presents itself particularly in the early phases as natural reaction to the uncertainty, which results from the course of the disease. The patient recognizes his / her deficits and tries to hide them outwardly and to repress them. Another reason for the anxiety states primarily in the later phases results from the unknown, with which the patient is confronted more and more, as the patient is loosing his / her memories of persons and ambiences. Thereby the patent permanently finds himself / herself in unknown situations, for which he / she has no behavior patterns ready. The last-mentioned aspects are significantly of importance when deliberating about the design of cognitive technical systems for persons with demential syndromes.

# 5 TECHNICS CONSEQUENTIAL ESTIMATE

#### 5.1 Dimensions of quality of life

To enable conceiving a benefit potential for the utilization of technics at all, we need criteria for the assessment and ascertainment of quality of life. For this, the dimensions of quality of life according to Oswald/Mollendorf [11] are consulted, which shall show what influence the mentioned deficits have on the life of the dement person and his / her environment. From that, finally conclusions can be drawn about how the utilization of cognitive technical systems is to be benchmarked.

The Dimensions of quality of life are:

- **Autonomy**: Autonomy in this connection means that the dement person can self-initiatively decide about his / her life and as the case may be about his / her need-of-care situation. Assistive technology may allow the patient to remain independent despite of his / her clinical picture.
- **Individuality and identity:** If the dement person can express preferences and pursue his / her own interests, we speak of individuality that provides for the retention of his or her identity. Cognitive technical systems can hereby help within the family to fill in a certain role.
- **Privacy:** Privacy is provided when the dement person is able to preserve his / her physical intimacy, when personal information can be kept secret, and when the principle feasibility to exchange oneself with others undisturbed is provided.

- **Dignity and esteem:** Dignity is provided when the dement person feels respected and appreciated respectively not devaluated, incapacitated, or domineered over.
- **Functional competence:** By functional competence we understand that a dement person is able to act self-dependently and based on ones own abilities and preferences.
- Well-being: Well-being exists when the dement person senses as little as possible physical discomfort. Discomfort is also provided when the dement person realizes that others care for his / her well-being.
- **Safety and protection:** These factors are provided when the dement person experiences his / her possession and himself or herself as protected and where necessary, knows applicable provisions and procedures concerning this matter. In this context the aspect of orientation and reduction of anxiety is particularly to be emphasized.
- **Meaningful activities and suggestions:** Such exist when the dement person is able to utilize his / her freedom of action and to participate actively involved or passively observing in actions, which are experienced as interesting, worthwhile and stimulating.
- **Enjoyment:** Enjoyment is provided when the dement person expresses experienced pleasure or joy verbally or nonverbally respectively also indisposition or experienced stresses.
- **Social contacts:** Those are provided when the dement person participates significantly in interpersonal social communication.
- **Religiosity:** The dimension of religiosity is of differently pronounced meaning to each individual. However it shall not be treated any further within the scope of this article.

The effectiveness of the criteria referred to for the risk-benefit estimation of the utilization of technics shall be demonstrated by the example of a cognitive operating orientation guide. This is described in the following chapter, before then in the next chapter thereafter the influences on the development and utilization of the product is shown.

#### 5.2 An example of a cognitive operating appliance for a dement person

The device to be introduced is a cognitive operating navigation respectively orientation guide, which is to prevent a sick person from meandering around without orientation. This is a small portable device, which the dement person carries when leaving his / her domicile. The device is provided with typical information about the patient's habits outside of home. Furthermore by utilizing GPS the device is enabled to determine the current position of the sick person and also to record and to store that person's ways. Information gained in this way is brought in relation with a calendar and a clock so that the system is self-sufficiently able to work out conclusions about the patient's habits. An integrated search for patterns respectively similarities on basis of the database described allows the system to draw conclusions about the patient's present situation and to correct the patient's behavior if necessary respectively remind the patient of objectives of the excursion.

So when the patient for instance leaves each Wednesday at 10 o'clock for seeing a doctor, the system by means of the current position and by comparing to the usual ways is able to check whether the patient is still on the right way or not. In case the evaluation shows that the patient is not at the place where expected at a certain defined time, he / she will be reminded of the actual destination by a respective voice output. In return however the patient can also obtain help by the device by asking for help for orientation. In addition to the mentioned main functions, the system is prepared to remind of typical dates (e.g. for taking tablets, doctor's appointments, etc.). Via this device however, the patient is also everywhere locatable. So with it in case of disorientation, i.e. in case of exceeding spatial and temporal limits, help can be called. In this connection however immediately the thought arises that the patient is monitored.

At the first glance it becomes clear that the device is on principle able to counteract to disorientation and at the same time to provide support in respect of how to proceed in an unknown situation.

#### 5.3 Risk-benefit valuation of the application of the orientation guide

From the system description it becomes obvious that the portable orientation guide represents an interesting facility to maintain a sick person's mobility and autonomy. Today it is often so that dement persons live in nursing homes or in facilities for assisted living and are not allowed to leave those, since aimless meandering and getting lost presents a potential hazard for them. This measure constricts

the sick person in a not irrelevant way. Beloved habits like going for a walk in the park that are often associated with social contacts and conversations suddenly have to be given up. Adding to it is that conditions of inner restlessness, which may result from fears of the future, are degraded by exercise what is prevented by a confinement to the house.

Finally this drives the sick person into a spiral that can accelerate the course of the disease. Under this aspect, a great number of talks with persons concerned and with nursing staff have shown that the mentioned orientation guide is considered as a great relief for life by the sick person as well as by the nursing staff, since with it, the patient's safety can be assured better. Well-being is significantly improved by the possibility of moving around freely.

A risk, which first of all is seen by the nursing staff and by the dement person's family members, is the permanent supervision and locatability. This is generally understood as a massive ingress into personal rights and into freedom and individuality.

Such an excessive data collection and compilation as it is made by the system suggests the fear of abuse. For this reason the designer is confronted with a scenario, which he / she never will be able to preclude completely. Here we are confronted with the challenge whether the facility of locating can be made anonymous, e.g. by reporting that a sick person has left a typical moving radius, but not remaining distinguishable which one. Some of the dement persons themselves that were interviewed to that question however had hardly any problem with this type of supervision. For those persons, the gained mobility and autonomy presented a much greater benefit. The possibility of being able to further on go to the bakery or to the hairdresser and to keep up social contacts, thus to show their functional competence, has a notably greater significance for their well-being.

Different studies about the application of technical systems in connection with dementia patients in general [7,8] have shown that the handling of comparatively autonomously acting systems was felt as a thread by many of them. Such characterization is particularly to be feared for cognitive technical systems. The dementia patient due to the loss of memory lives in the past. Since 20 to 40 years ago no comparable systems existed, the patient is unable to attribute their functionality. The orientation guide is furthermore conceived so that it communicates with the user via voice. For many dementia patients it is difficult to attribute that voice, which aggravates anxiety states. Adding to this is the risk that the patient feels leached and domineered over by the system. In order to avoid this, a certain learning process on part of the sick person is necessary through which the person is communicated that he / she finally has autonomy over the application of the system.

Another problem is to be seen in the limited or nonexistent learning aptitude of a dement person. The challenge for the designer for sure lies in the task to make handling of the device as easy as possible for such a complex system. Helpful would also be if the dementia patient would be able to deal with and getting used to the system right at the beginning at the time when the disease is recognized. The risk that the orientation guide is not applied because of the lack of understanding of its handling is rather great. In addition, user instructions have to be prepared in a form adapted to dement persons. A great need for research on this still exists [9].

Primarily in the literature about assistive technology [5, 7], issues of safety are playing a dominant role. In the focus is thereby often the question of how the patients' environment can or needs to be protected against their performance errors (e.g. stove safety devices). Vice versa, particularly with the application of cognitive technical systems the question of how to allow for the patient's safety is to be raised. By utilizing the orientation guide, the patient relies on it and with it, makes oneself dependent on that system. Therefore in case of a system failure, the consequences for the sick person could turn out much tougher than if the patient would never had used such a device at all. Aspects of reliability and considerations regarding case-of-emergency situations are therefore gaining a much stronger influence on development.

# 6 DERIVATION OF GUIDELINES FOR ACTING

The above-mentioned example not only points out important requirements made on assistive technology for demential sick persons, but also highlights the social and individual responsibility of the designer. This shall be embraced in terms of guidelines for acting in the following.

#### 6.1 Justification of utilization of technics

From the described example it becomes obvious that utilization of technics shows several facets of justification. Their exact weighting is finally decisive, whether the cognitive technical system will actually be of use to the patients, to their family members, and to the nursing staff and ultimately also to the society. Primarily in the literature about assistive technology, issues of safety are playing a dominant role. [5, 7].

Often in the focus is thereby the question of how the patients' environment can be protected against their performance errors (typical example is securing the stove). But also the patient's own safety needs to be considered in this context. The increase in the patient's safety is regarded as one of the most significant arguments for the introduction of cognitive technical systems. From the ethical viewpoint however it remains imperative to clarify what will happen in case of a system failure. As the patient finally abandons part of his / her autonomy to the cognitive technical system, the patient is not insignificantly depending on that system's functional capability.

Also important appears the aspect of acceptance. Many dement persons, particularly in the early phases, would like outwardly to keep up an undamaged façade and not to appear as being in the need of help. Here society is charged with a responsible role: a society that elevates youth, vitality, and performance capability to its ideals does not provide much room for ailment and constraints caused by old age. The dement person should be able to use technical systems for the retention of safety so that the person oneself can determine the image that others have of him / her. The utilization of supportive systems must not entail in a stigmatization of the person concerned. Any paternalism by others, e.g. by forced or concealed installation of assistive technology, is to be avoided.

In Germany and in Europe, dramatic changes in the demographic development are announced for the following years. Since life expectancy is continually increasing while birth rates in turn are rather retrogressive, nursing care of the elderly will confront us in future with material problems. To counteract to this trend, an attempt is made by the approach of enabling to stay in the own domicile for a period as long as possible. To this, preferably cognitive technical systems should contribute. Whether it is a good method to replace personal attendance by technical systems shall not be discussed here any further.

It may be assumed however that the introduction of cognitive assistive technology will be forced, also because of financial advantages. If staying long in the own domicile is promoted by appropriate assistive technology for reasons merely reduced to financial advantages for the general public, the user is running the risk of falling behind. Not the user's own needs, wishes, and ideas will then be the basis for introducing technical aids, but cost savings. Limited resources of the nursing care system are necessarily to be considered, however if possible in a form that recognizes the user as the most important part in the decision. This is much better expressed by a justification of cognitive technical systems based on the dement person's autonomy than by an argumentation based upon financial feasibility.

Actually the patient's well-being should be in first place in the justification of assistive technology instead of the thought of safety. Quality of life is first of all supported if the user agrees to the application of technics and does not feel being patronized. This in turn means that cognitive technical systems may only very carefully intervene in the personal rights of the user. Also the sustainment of functional competence as justification is to be scrutinized. Dementia caused by old age is normally associated with multi-morbidity. Other clinical pictures such as diabetes for example are often coming along, however need to be considered for the clarification of the functional competence. The premature application of cognitive technical systems for support maybe takes over "mental work" or work movements too early, which however would be important for the training of residual abilities. So this contributes to a faster decay of mental abilities and mobility. Is to be feared that a technical device accelerates the course of the disease, so it may be contemplated how these properties that support a training of functional competence can be integrated.

Considerations regarding the justification of the application of cognitive technical systems in cases of demential diseases show that the engineer will have to be more and more concerned with ethical thoughts about the application of technical devices. Only detailed deliberating about risks and the potential of utilization will finally lead to an also ethically justifiable solution for the design of cognitive technical systems. Such considerations are finally necessary to effectuate the acceptance of the systems.

#### 6.2 Perspectives for the development of cognitive technical systems

The responsibility of society for the utilization of technics in cases of demential diseases finally manifests in the responsibility of the designer. Of great importance seems that the designer deals intensively with the clinical picture to enable placing the dement person and such person's personal preferences, desires and needs in the center of attention in the development task. This however means at the same time that the designer has to subordinate his / her own ideas about how the technical system should be provided to the background. In a certain way, a conflict situation arises for the product engineer when on the one hand state-of-the art technologies in development can be employed in a most creative way, but at the same time however not necessarily high-end devices should be developed. Professional prestige must finally step back behind possibly simpler solutions, which however meet the needs of the person concerned in a better way.

Product development for demential sick persons moreover calls for very individual solutions. On the one hand, this brings along a great challenge regarding modularization, but on the other hand demands from the engineer to have permanently exchange with the dement person as the user of technics as well as with the family members and nursing staff, so in order to develop products that place the person of the user and the user's individual needs in the center of attention. This requires studies, which preprocess the clinical picture of dementia from the technical point of view and so enable a better access to the problem for the designer. Basic thoughts regarding this subject are described under chapter 5.3, as from the dimensions of quality of life in the context with the clinical picture concrete criteria for the development can be derived.

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