

A User-Centered Ethical Assessment of Welfare Technology for Elderly

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Abstract. Welfare technology (WT) is often developed with a technical perspective, and little consideration is taken regarding the involvement of important ethical considerations and different values that come up during the development and implementation of WT. Safety, security and privacy are significant, as well as the usability and overall benefit of the tool, but to date assessments often lack a holistic picture of the WT as seen by the users. This paper suggests a user-centered ethical assessment (UCEA) framework for WT to be able to evaluate ethical consequences as a part of the user-centered aspects. Building on established methodologies from research on ethical considerations, as well as the research domain of human-computer interaction, this assessment framework joins knowledge of ethical consequences with aspects affecting the "digitalization with the individual in the center", e.g. privacy, safety, well-being, dignity, empowerment and usability. The framework was applied during development of an interface for providing symptom information to Parkinson patients. The results showed that the UCEA framework directs the attention to values emphasized by the patients. Thus, functionality of the system was evaluated in the light of values and expected results of the patients, thereby facilitating follow-up of a user-centered assessment. The framework may be further developed and tested, but in this study it served as a working tool for assessing ethical consequences of WT as a part of user-centered aspects.

Keywords: Ethical evaluation · Elderly · Welfare technology Assistive technology · Ambient-assisted living · Health-enabling technology Framework · User-centered · Assessment

1 Introduction

Welfare technology (WT), defined as digital technologies aimed at maintaining or increasing safety, activity, participation and independence for a person who has, or is at, increased risk of gaining a disability, is often seen as a solution to the challenges arising with the increasing number of elderly people in the population [1].

We use the term WT in this paper, aware of the amount of synonymous or at least very close terms in this context, e.g. as listed in [1]: ambient assisted living for health

[©] Springer International Publishing AG, part of Springer Nature 2018 J. Zhou and G. Salvendy (Eds.): ITAP 2018, LNCS 10927, pp. 59–73, 2018. https://doi.org/10.1007/978-3-319-92037-5_6

care [2], ambient assistive technologies for health care [3], ambient intelligence for health care [4], health-enabling technologies [3], pervasive computing technologies for health care [5], pervasive health [6], pervasive health care [7], smart home technologies for health care [8], and ubiquitous health care (uHealth).

WT is often seen as a powerful means that, once implemented, will maintain cost efficiency and high quality health and social care, as well as create a new possibility to ensure the users' dignity and empower them to better manage their health and quality of life [9]. However, in that aspect, the WT is to a large extent still in the bud and to date values such as quality of life and dignity have fallen short due to the technical focus often applied in WT development and implementation projects. Also, current focus on resource efficiency, the strive for more efficient elderly care work processes combined with a weak knowledge in how to apply and implement ethical requests in technological solutions, create little room for important ethical considerations [10] Correspondingly, values aiming to strengthen the stakeholders in the area, e.g. effects of development and implementation of WT with regard to quality of the elderly care system as a whole, or elderly persons' quality of life, wellbeing and dignity are not yet in assessment focus of the research projects [9]. Moreover, proof of diagnostic relevance and therapeutic efficacy remains limited, and an increased focus on the individuals is called for [1].

The authors of this paper concur, and as a response to this call, we suggest that WT for elderly needs to be designed and appropriated in a manner that respects the individuals of an ageing society. This is often neglected, although studies point out that 'ambient intelligence technologies' can contribute to e.g. safety and security [11]. Safety, security and also privacy are of course significant, as well as the usability of the tool, but to date assessments often lack a holistic picture and overall benefit of the WT, as seen by the users. Therefore, it is not only needed that the technology is designed in a user-centered way, the assessments also need to be user-centered, focusing on the real benefit for all users, or stakeholders. Here, intended users are the elderly, their relatives, and/or social care personnel [12]. In a user-centered assessment with a holistic perspective, the ethics play a central role.

This paper suggests a user-centered ethical assessment (UCEA) framework for WT to be able to evaluate ethical consequences as a part of the user-centered aspects. Building on established methodologies from research on ethical considerations as well as the research domain of human-computer interaction (HCI) and human factors, the assessment framework joins knowledge of ethical consequences with aspects affecting the "digitalization with the individual in the center", e.g. privacy, safety, well-being, dignity, empowerment and usability. In this study the framework was applied in a case study with Parkinson disease (PD) patients.

2 Previous Work

2.1 Existing Methods for Ethical Evaluation of Welfare Technology

Ethical and legal aspects are important to consider in development of WT within healthcare [13], thus a number of ethical frameworks supporting ethical analyses have been suggested in the literature [14, 15]. For instance, Beauchamp and Childress [16] propose an ethical assessment framework based on four principles: (1) the principle of beneficence, (2) the principle of non-maleficence, (3) the principle of respect for autonomy, and (4) the principle of justice. However, these principles are considered to be too general to be used for evaluations of WT aiming towards the healthcare sector [17]. More adopted for this purpose are principles suggested by Collste [18]: (1) doctor–patient relationship, (2) responsibility, and (3) respect for autonomy.

However, most of the assessments of moral issues and ethical implications of health technology are not comprehensive and often ad hoc [19]. As a response to this problem, Hofmann [20] developed a 33-point checklist for assessing ethical issues emerging at implementation and use of health technologies. Sanchez et al. [19] used this checklist to review moral and ethical issues related to smart house technology. Their study showed that 28 of 33 issues in Hoffman's list are more or less discussed in the literature. The most often discussed ethical challenges are cost-effectiveness, privacy, autonomy, informal consent, dignity, safety and trust [19].

Other scholars, e.g. Kolkowska [21] and Kosta et al. [22] argue that applying existing general ethical guidelines in the context of WT implementation in elderly care may be difficult due to conflicting interests that can arise between different stakeholders, as well as the complexity of this socio-technical environment where the technology is meant to be an integrated part of home care processes and the elderly's daily life and activities [21, 22]. Therefore considering various stakeholders' interest in ethical assessments is important. Recently Nordgren [23] proposed an *ethical value matrix* to support systematic ethical assessments of WT aimed for personal health monitoring. The matrix supports identifying values that are important to various groups of stakeholders in relation to personal health monitoring. In previous work [15] we have found the matrix to be a suitable methodological tool also for ethical analyses of WT, and the intention is here to appropriate the matrix to our purpose and to include it as an integrated part in the UCEA framework.

2.2 Adopting a User-Centered Perspective

As pointed out in the previous section, many stakeholders are involved in development and use of WT and these different stakeholders often have their own, sometimes conflicting interests and values that they want to realize through the new technology [19]. Usually not all values and interests may be realized and consequently the new technology does not address all stakeholders' needs and values [24]. To address the needs of all stakeholders may not be the ultimate goal, nor a feasible way of developing new technology [25]. However, it is imperative to focus on the real end-users and the potential benefit WT can provide to them and their relatives, regardless of whether it may be cumbersome to elicit needs, demands and potential benefits.

Adopting a user-centered perspective, as proposed in the HCI literature, is a viable way and methods to support such approach have been applied in other areas since long. A user-centered perspective consists of different quality aspects, where pure functionality may be one, and usefulness or usability another. These aspects are important, and relatively easy to measure, but often the socio-technical exploration whether the new technology alters the users' lives, and how, is neglected [12]. Regarding elderly as users of WT, we consider values like wellbeing, dignity, privacy and safety in relation to use of a WT innovation important to assess. To our knowledge there is a lack of an assessment framework that comprises dignity of life, well-being of a person and usability of a WT paired with ethical consequences regarding use of the WT. An exception to this is the Norrlandicus method developed by Norrlandicus Care Lab, a living lab aiming to assess welfare innovations for elderly, together with the elderly themselves, their relatives and social care personnel [12].

The Norrlandicus method is an elderly-centered assessment method, based on quality criteria, such as well-being, dignity, value for the elderly as well as usability of the innovation (in this case WT). The Norrlandicus method builds on the recommendations by The National Board of Health and Welfare "National Values for Social Care of Elderly", here translated as "Dignity of Life" [27]. Addressing basic health and functional needs are important; a salutogenic approach to health, considering participation and independence, promoting good health and rehabilitation are core values in the assessment method. Along with salutogenic values, the assessment method strives to enlighten dignity and well-being as dimensions of Dignity of Life. To our knowledge, this assessment method is unique as it is based on concepts from Dignity of Life and relates those to a (technical) innovation in elderly care. The evaluation is further guided by a third dimension, quality criteria of the international usability standard, highlighting usage as a function of the innovation and consequently its benefit for the defined end-users (Fig. 1).

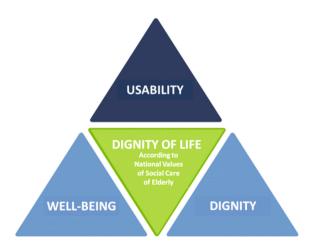


Fig. 1. Three dimensions of the Norrlandicus method with the core value Dignity of Life [12]

3 The User-Centered Ethical Assessment (UCEA) Framework

Aim of the Norrlandicus method is to support assessment of ethical, as well as practical aspects of WT from the users' point of view. This is in line with the requirements posed for the UCEA framework. The Norrlandicus method builds on a principle that each innovation (product, service or process) needs to be assessed using quality measures from the users' point of view and focuses on three dimensions: usability, well-being and dignity that together support the core value Dignity of Life (see Fig. 1). While the concept of usability is well-defined and rather easy to assess using available models and methods, well-being and dignity may have different meanings to different people. In the "National Values for Social Care of Elderly" [26], which the Norrlandicus method builds on, well-being and dignity are not clearly defined and there is no clear cut between these two concepts, making a mere translation to an assessment tool of ethical consequences regarding development and use of WT less feasible. In Norrlandicus Care Lab, a truly user-centered approach was adopted; goals of well-being and dignity of each innovation was defined for each user group, and a statistical instrument (consisting of a scale with two dimensions) was used during pre- and post-intervention interviews with each user group. It aimed to cover all mentioned aspects of well-being and dignity, for each innovation. The answers from each user group (e.g. elderly, their relatives or health and social care staff) were later triangulated, and compared to the results of the usability assessment of the particular innovation. The two dimensions of the construct dignity of life, dignity and well-being, were operationalized as numerical variables, and differences in means between post- and pre-intervention measures in any of the two dimensions would indicate that the intervention had an effect on the dignity of life of the elderly persons in the sample [12].

In "National Values for Social Care of Elderly" when well-being and dignity are discussed, values such as autonomy, safety, privacy, participation, and health are emphasized, thus focusing on these values could facilitate (operationalize) assessment of ethical aspects, as in terms of well-being and dignity. To operationalize well-being and dignity for this matter, we used the ethical value matrix [23] that suggests a checklist consisting of ethical, moral and practical values. The values in the checklist are divided into three groups (Fig. 2): (1) Practical values (Reliability, Ease of use (usability), and Affordable price); (2) Quality of life values (Health, Independence, Safety, Social contact); and (3) Moral values (Autonomy, Privacy, and Justice).

By combing the Norrlandicus method with the ethical value matrix we suggest a framework supporting evaluation of ethical consequences as a part of user-centered aspects. Moreover, by using the ethical value matrix, the hypothesis is that it is possible to notice which values are emphasized by the involved stakeholders, and thereby ensure that the following assessment is performed in line with the core values.

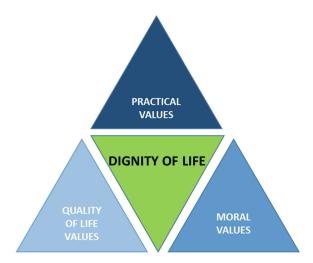


Fig. 2. User-centered ethical assessment (UCEA) framework based on the three dimensions of the Norrlandicus method with the core value Dignity of Life [12], aligned with the ethical value matrix [23].

4 Research Methods

4.1 Case Study

We applied the UCEA framework in a case study [27]. The case study was part of a currently ongoing health informatics research project, EMPARK, which aims at developing and evaluating IT-based solutions that combine registration of PD symptoms and dosage information for enabling patients to better control their symptoms by giving adequate feedback on past and current state of their disease. Main objectives of the project are to individualize the measurement of symptoms in a home environment and increase patient empowerment by strengthening patients' participation in the care and ability to control the disease. The system developed in the project will gather objective PD measures by a range of sensors and dosage information by an electronic dosing device and will present the data to patients via a tablet. The idea is to collect such data from home environments of patients. Subjective symptoms will be gathered through a smartphone, which contains a set of PD-related questions. Data collected by the mobile devices will be sent to a central server for storage, further data processing and analysis. Based on the analysis, aggregated symptom and dosage information will be fed back to the patients through an interface.

This case study reports from the first part of the EMPARK project aiming at development of an interface for providing symptom information to PD patients. In addition to creating a patient interface, usable for elderly, the plan is to also develop an interface for clinicians, who will use the same data but with more specialized and detailed views, such as the association between motor function and physical exercise and other scores, as well as analysis of physical exercise in relation to disease progression.

In line with the UCEA framework the study was conducted according to User-Centered-Design (UCD) [28] that regards system development with user participation and places users' needs in the center of the development. UCD was applied with consideration of the special needs of the elderly PD patients [29]. The user interface was developed by an iterative design and an evaluation process was based on interviews and observations with 11 (6 men and 5 women) PD patients, following the UCEA framework. Special attention was put on the practical, moral and quality of life values emphasized by the patients. The patients were all above 60 years of age and had lived with PD for more than 5 years. The patients were recruited through the PD patient organization in Örebro, Sweden.

4.2 Data Collection and Analysis with Focus on Dignity of Life Values

Data collection in the case study was qualitative. Three workshops with PD patients were organized to identify ethical as well as practical aspects related to the user interface. Firstly, a three-hour workshop with seven patients was organized. In addition, the design team, representatives from the industry as well as a PD nurse were involved. In the first part of the workshop, the patients were divided into groups of two and were interviewed by a researcher to communicate their patient profiles. Focus of the interviews was on explaining a typical day with PD, common problems/symptoms, treatments, and IT tools they often use. Patient answers were documented by the researchers for later analysis. In the second part of the workshop, patients and researchers had a group discussion where patients were asked questions with the aim of gathering information on how the interface could help them to better understand their symptoms and improve the treatment. Some of the questions posed to the patients were: "How could data from the system be of any help to you?", "Which information would you like to see?", "How would you information to be presented/visualized?", and "What could motivate you to keep measuring your status?".

The session was audio-recorded, transcribed and analyzed with focus on practical, moral and quality of life values in line with the UCEA framework. Based on the requirements collected during the first workshop a prototype of the user-interface was designed.

Secondly, a two-hour workshop was organized with the same group of patients. The main aim was to evaluate the prototype of the user-interface that was developed based on the users' requirements from the first workshop. In the beginning of the second workshop patients were introduced to the visualizations and given a walk-through of the prototype structure. This was followed by a structured task-based evaluation session where the patients were divided into groups of two and were asked to perform a set of tasks using the prototype. The 25 tasks that the patients were asked to perform focused on usability of the interface and clarity of the visualizations, but the patients were also asked if they wanted to add something else to the prototype or if something was unnecessary. The researchers observed and documented all feedback from the patients, following a think-aloud approach.

In a third validating workshop, 4 patients that were not involved in the development process during the first two workshops and 1 patient who was involved before participated. Similarly as in the previous workshops, patients were given a walkthrough of

the prototype, followed by a task-based evaluation, which was observed by the researchers. Patient feedback was documented by the researchers and analyzed with focus on practical, moral and quality of life values. In our analysis we included all the values listed in ethical value checklist [23]. Table 1 shows two examples from our analysis; one concerning the *Practical value* "ease of use" and one concerning the *Quality of life value* "health". The examples show which functionality in the system realizes the patients' values (column 2) and what are the expected results of using the system compared with a life without the system (column 3). In the most right column (4), comments regarding each value and functionality were added to ensure transparency and traceability, and that the values will be designed for in subsequent steps of the development. The examples are described in detail in Sects. 5.1 and 5.2.

	Emphasized values	Functionality in the system	Expected result	Comments for transparency
Practic	al			
Ease of use	Yes	Not too many questions	The system is easy to use, not a burden	The subjective measurements may be adjusted for each patient. Collecting different measures during different periods
Quality	of life			
Health	Yes	Collect both objective and subjective data	Clearer and more holistic picture of the symptoms	Conflict with ease of use
Moral		-		

Table 1. Practical, moral and quality of life values emphasized by the patients

5 Results of Applying the User-Centered Ethical Assessment Framework

Applying the UCEA framework allows to study and to compare values emphasized by various stakeholders, but in this first study focus was only on PD patients. Later in the project clinicians will be studied when using the care professional interface to access patient data in order to adjust medication and treatment to the individual needs of the patient.

5.1 Practical Values

Within the Practical values category patients emphasized the importance of the system to be *easy to use* and *reliable*. Besides common aspects of usability such as easy to use, easy to learn, logical flow, clear and understandable visualizations, the patients also emphasized the importance of limiting the number of registrations they have to do during one day. As one of the participants during the workshop stated:

Our life should not only be about Parkinson. We cannot take measures and answer questions about our disease too often. We also want to have a normal life.

Another concern highlighted by patients within this category was the difficulty to use the system due to tremor when touching the screen, as well as too small areas for 'clicking on the links'. This first design caused unresponsive tapping on buttons which created insecurity among the patients testing the prototype during the evaluation workshop. After the evaluation the sensitivity of the screen was adjusted to the patients' needs.

Reliability value is, according to Nordgren [23], about measurement, which means that the measurement provided by a technical device must be correct. In relation to this value the patients especially emphasized the importance of individual adjustments of the measurements. The patients stressed that the system should be able to individualize their preferences and needs. For instance, one of the patients stated:

You can only hope that this system could help you to find what the optimal solution is for yourself, since nothing works the same for all. Some people exercise a lot and that works well for them, but for others exercise just makes them feel worse. It would be nice to get reminders when you should take your medication, when you should eat and the amount of exercise and sleep that is the best for you, as an individual.

To improve the data entry design for physical exercise, one of the patients suggested that each patient should create an own profile. In their own profile, they select the types of exercises they usually do, which form an individual list that will be shown every time they register a physical exercise. Generally the patients strongly emphasized the need of individual adjustments because of their different symptom profiles and because their symptoms vary from time to time. As one of the patients stated:

It is difficult for outsiders to understand how different our symptoms and our needs are! We can only hope that it will be possible to find optimal solutions for each of us... I want to know when I am supposed to take my medication in relation to meals and how much I am supposed to exercise to sleep and feel as good as possible.

The patients stressed that lack of understanding of their different needs is a huge problem. The patients hope that by visualization of their symptoms through the interface, they will be able to show the clinicians how different their needs are. As one of the patients explained:

They often group our needs and generalize our treatment, but we have very different needs.

In the system, the interface retrieves subjective and objective symptom information from the central database where sensor and dosage data are stored. This enables individualized evaluation of symptoms and treatments by the users. So far the system does not provide possibility to individual adjustment of the subjective measurements. This needs to be realized during the clinician trial of the system when individual data about each patient will be available.

The patients did not raise any issues regarding *the price* in this early stage of the development.

5.2 Quality of Life Values

In this early stage of development the patients especially emphasized Quality of life values and *health* related issues. Regarding data that should be collected by the system

to allow patients to better understand their symptoms the patients emphasized the importance of including both objective and subjective measures. They argued that in this way they would get a clearer and more holistic picture of the symptoms. Besides objective measures collected by the system (motor fluctuations, and time in bed), the patients also wanted to include subjective well-being (how do I feel), meal time (when start eating), physical activity, medicine intake, sleep patterns and nightmares, and maybe also what the meal contained. Some of the patients also mentioned stress, depression and social activities, "Because all these factors have an impact on the day".

Although such variety of subjective measures would give the patient a rich picture of factors influencing his/her symptoms, it would at the same time lead to a larger burden on the patient, since he/she would need to register all data. The wish to collect a large number of subjective measures is in conflict with one of the practical values: *ease of use*, where the patients emphasize the importance of limiting burden and time required for data registration in the system. One way of satisfying both these values could be adjusting the collected subjective measures for each patient or collect different subjective measures during different periods of time to see which measures have the greatest impact on the PD symptoms. For instance it should be possible to collect more variables (food, physical activity, and sleep patterns) during a limited period of time, for instance 8–10 days and it could later be possible repeat such a period, but the patient does not collect all the variables all the time. This example is illustrated in Table 1 in Sect. 4.2.

Another need emphasized in relation to *health* was to see correlations between different subjective and objective measures. The patients wanted to track e.g. the routine of an ideal day, so they could repeat such behavior in the future. They argued that better understanding of correlations between objective and subjective factors would motivate them to change their behavior, to use the system and motivate them to excise, eat well, and comply with the medication schema. As one of the patients argued:

"If you clearly see for yourself [with help of the visualizations in the system] that you feel better when you exercise, it would motivate you to exercise".

Other correlations the patients wanted to see were e.g.:

- effect of meal timing on medicine effects,
- the status during a single day based on sleep, medication intake, physical exercise, motor function, and meal intake,
- effect of meal timing on medication
- effect of motor function in relation to overall day score
- effect of motor function in relation to medicine compliance
- effect of motor function in relation to physical exercise
- effect of motor function in relation to sleep
- effect of motor function in relation to meal intake timing.

The required correlations are visualized in the system. The patients stressed that by analyzing these correlations they increase their understanding of Parkinson and are able to adjust their behavior. Another benefit highlighted by the patients was the possibility to use the analysis when they consult their doctor. The patients argued that the

consultations are so rare that it is impossible to remember and retell the most important events and symptoms. Thus the consultation could be more fruitful if it could be based on actual data saved in the system. The patients pointed out that in this way it could be possible to improve and adjust the treatment to every patient's special needs. Although the system supports visualization of symptoms and correlations, at this stage it cannot be evaluated how these visualizations will support the patients during meeting with the doctor. Such requirements will be evaluated during clinical trials that are planned at the end of the EMPARK project.

To improve the sense of *safety*, the patients wanted the system to remind them when to take the medication. They stressed that it is easy to forget, especially when having a bad day. The patients also wanted to get a notice about their trending; an early warning/indication if the patterns of their symptoms deviate towards the worse, i.e. if they sleep worse than usually or if their tremors are worse than they usually are. They stressed that using trend figures they will be able to contact a physician or a nurse. Ideally, in this case the system should automatically indicate the responsible physician or nurse to take adequate measures. These wishes are partially implemented in current version of the system. The patients are warned if their symptoms are deviating, but the system does not yet send any information to the care providers. This requirement needs to be discussed and designed for in later stages of the project when developing the interface for care professionals.

The patients also discussed the possibility of using visualizations to reduce the relatives' concerns related to the Parkinson symptoms. As one of the patients explained:

I think it will be helpful for my closest relatives to see it [the visualizations] also. Usually they notice the changes, but they don't understand the reasons for the changes so they get stressed and worried. The system will help them to understand better.

However, the patients also expressed some concerns that the system can increase anxiety and stress regarding their symptoms. They explained that it could be stressful if the system indicates many "bad days" or if the system shows negative patterns. One of the patients explained:

Usually I'm not worried between the medications and I can do other things...but I think the visualization could stress me... I'm afraid that I will imagine that I feel worse than I actually do.

This concern should be taken seriously and evaluated in later stages of the project, potentially by use of demonstrators of different functionality.

Independence. Nordgren [23] argues that patients' ability to act independently may increase the ability to perform everyday activities on their own. In our study the patients stressed that better understanding of symptoms and reaction on medication could improve the ability to plan their activities during the day. For example one of the patients explained that often when he is visiting friends or relatives he has to hurry home to take the medication on time. By using the system he could learn how his body reacts on medication delays, and he would know the time span without risking to worsening his symptoms. He meant that in this way he could avoid these stressful situations. Another aspect of independence was the possibility to slightly adjust medication based on changes observed in the system's visualizations.

Social Contact. Regarding this value the patients pointed out the possibility of sharing and discussing individual observations with other PD patients. Although, as the patients emphasized, symptoms and correlations are very different between the patients, it could be of value to share and discuss individual results with others. As one patient explained:

If I can see that something has improved the health condition for another patient, I want to try it too. It would be very interesting to use the system in this way because, actually we get as much tips from each other as we get from the doctors.

5.3 Moral Values

The value *autonomy* is about having control [23]. The patients argued that the system will allow them to increase their control of the disease and the symptoms. One of the patients stated:

The knowledge gives us more power...if you know that you can take your medication in relation to your meals at the right time and you understand that it is better to exercise, it gives you the power to better control the symptoms.

The patients also argued that knowledge gained by using the system will empower them in discussion with their care providers. The patients did not discuss *value of privacy or the value of justice* in healthcare.

6 Discussion

In this section we describe lessons learned from applying the framework in a case study focusing on the development of an interface for providing symptom information to Parkinson patients.

Generally, the UCEA framework directs the attention to the values emphasized by the patients as especially important. In our study, functionality of the system was evaluated in the light of the values and expected results of the patients, thereby facilitating that both the assessment and the subsequent follow-up work were performed with a user-centered perspective. We believe that constantly seeing the functionality of the system in relation to values and expected results of the users (see Table 1) can prevent a techno-centric development as well as solutions that are not able to address needs that arise in social environments.

The framework used in all stages of the development process created a transparency and a traceability that allowed developers to keep track of which values were realized and which were not. This is important since usually not all values can be realized. We believe that being able to trace involved stakeholder values will help developers to make informed decisions with focus on the benefits of real end-users.

When applying the UCEA framework in the case study we observed that some of the values were in conflict, as illustrated in Table 1 example the *Practical value* "ease of use" and the *Quality of life value* "health". The patients emphasized the importance of collecting a variety of subjective measures that would give them a clearer and more holistic picture of symptoms necessary to increase control over the disease. However,

satisfying this requirement without reflection may result in a system placing another burden on the user, i.e. the one of reduced ease of use. Visualizing this conflict gives the developers an opportunity to find a solution satisfying both values, in our case by limiting the number of subjective measures in line with the need of the individual patient and/or collecting different measures during different periods of time.

Another benefit from applying the UCEA framework that we could observe during the analysis was the possibility to understand which values could be realized by the functionality of the system and which depended on the willingness of other stakeholders. We noticed that the patients' requirement "that the system should automatically indicate the responsible physician or nurse about the patient's impaired health condition" could not be realized without the clinicians' involvement. Even if the system would have such functionality the patient would not feel safe unless the responsible physician or nurse would react on the notification and take adequate measures.

In the case study we focused on one stakeholder group, the PD patients. Another important group of users that will be studied later in the project are clinicians. They will use the care professional interface to access patient data in order to adjust medication and treatment to the individual needs of the patient.

According to both the Norrlandicus method [12] and the ethical value matrix [23] all stakeholders need to be studied to be able to analyze important values and goals. In this project this will take place in the second work package. Results from both user groups will be triangulated and the design will be tested during a clinical trial.

7 Conclusion

By combing the Norrlandicus method [12] with the ethical value matrix [23] we suggested a framework supporting evaluation of ethical consequences as a part of user-centered aspects. Applying the UCEA framework in a case study improved transparency and traceability of the values emphasized by the involved stakeholders. The framework clearly directed the attention to values emphasized by the patients and allowed to evaluate the system in the light of values and expected results of the patients. Thanks to its transparency and traceability, we consider that both the assessment and the subsequent follow-up work were facilitated. Thus, the UCEA framework supported a holistic user-centered perspective. The framework may be further developed and tested, but in this study it successfully served as a working tool for assessing ethical consequences of WT as a part of user-centered aspects.

Acknowledgement. We cordially want to thank the participants of the EMPARK (Remote monitoring of Parkinson's disease - Empowerment of patients and improved treatment using ICT-based tools) project, both patients and care professionals, as well as developers, researchers and students working in the project. We also want to thank the funding organization, KK Foundation in Sweden.

References

- 1. Haux, R., Koch, S., Lovell, N., Marschollek, M., Nakashima, N., Wolf, K.-H.: Health-enabling and ambient assistive technologies: past, present, future. Yearb. Med. Inf., 76–91 (2016)
- 2. Demiris, G.: Smart homes and ambient assisted living in an aging society. New opportunities and challenges for biomedical informatics. Methods Inf. Med. 1, 56–57 (2008)
- 3. Koch, S., Marschollek, M., Wolf, K.H., Plischke, M., Haux, R.: On health-enabling and ambient-assistive technologies. What has been achieved and where do we have to go? Methods Inf. Med. **48**, 29–37 (2009)
- Remagnino, P., Foresti, G.L.: Ambient intelligence: a new multidisciplinary paradigm. IEEE Trans. Syst. Man Cybern. Part A Syst. Hum. 35, 1–6 (2005)
- Wan, D., Taveras, L.: The business of pervasive healthcare. In: Bardram, J., Mihailidis, A., Wan, D. (eds.) Pervasive Computing in Healthcare, pp. 275–298. CRC Press, Boca Raton (2007)
- Saranummi, N.: IT applications for pervasive, personal, and personalized health. IEEE Trans. Inf. Technol. Biomed. 12, 1–4 (2008)
- Bardram, J.: Pervasive healthcare as a scientific discipline. Methods Inf. Med. 47, 178–185 (2008)
- 8. Martin, S., Kelly, G., Kernohan, W., McCreight, B., Nugent, C.: Smart home technologies for health and social care support. Cochrane Database Syst. Rev. 4 (2008)
- Haux, R., Hein, A., Kolb, G., Künemund, H., Eichelberg, M., Appell, J.-E., et al.: Information and communication technologies for promoting and sustaining quality of life, health and self-sufficiency in ageing societies - outcomes of the Lower Saxony Research Network Design of Environments for Ageing (GAL). Health Soc. Care 39, 166–187 (2014)
- 10. Zwijsen, S.A., Niemeijer, A.R., Hertogh, C.M.: Ethics of using assistive technology in the care for community-dwelling elderly people: an overview of the literature. Aging Mental Health **15**, 419–427 (2011)
- van Hoof, J., Kort, H.S., Rutten, P.G., Duijnstee, M.S.: Ageing-in-place with the use of ambient intelligence technology: perspectives of older users. Int. J. Med. Informatics 80, 310–331 (2011)
- Scandurra, I., Blusi, M., Dalin, R.: A living lab method for innovations to increase quality of life for elderly - a pilot case. In: Zhou, J., Salvendy, G. (eds.) ITAP 2015. LNCS, vol. 9193, pp. 123–133. Springer, Cham (2015). https://doi.org/10.1007/978-3-319-20892-3_13
- 13. Liu, L., Stroulia, E., Nikolaidis, I., Miguel-Cruz, A., Rincon, A.R.: Smart homes and home health monitoring technologies for older adults: a systematic review. Int. J. Med. Informatics **91**, 44–59 (2016)
- Palm, E., Nordgren, A., Verweij, M., Collste, G.: Ethically sound technology? Guidelines for interactive ethical assessment of personal health monitoring. In: Schmidt, S., Rienhoff, O. (eds.) Interdisciplinary Assessment of Personal Health Monitoring, pp. 105–114. IOS Press, Amsterdam (2013)
- Kolkowska, E., Avatare Nöu, A., Sjölinder, M., Scandurra, I.: To capture the diverse needs of welfare technology stakeholders – evaluation of a value matrix. In: Zhou, J., Salvendy, G. (eds.) ITAP 2017. LNCS, vol. 10298, pp. 404–419. Springer, Cham (2017). https://doi.org/ 10.1007/978-3-319-58536-9_32
- 16. Beauchamp, T.L., Childress, J.F.: Principles of Biomedical Ethics, 6th edn. Oxford University Press, Oxford (2009)

- Whitehouse, D., Duquenoy, P.: Applied ethics and eHealth: principles, identity, and RFID. In: Matyáš, V., Fischer-Hübner, S., Cvrček, D., Švenda, P. (eds.) Privacy and Identity 2008.
 IAICT, vol. 298, pp. 43–55. Springer, Heidelberg (2009). https://doi.org/10.1007/978-3-642-03315-5_3
- 18. Collste, G.: Ethical, Legal, and Social Issues in Medical Informatics. IGI Global, Hershey (2008)
- Sánchez, V.G., Taylor, I., Bing-Jonsson, P.C.: Ethics of smart house welfare technology for older adults: a systematic literature review. Int. J. Technol. Assess. Health Care 33, 691–699 (2017)
- Hofmann, B.: Toward a procedure for integrating moral issues in health technology assessment. Int. J. Technol. Assess. Health Care 21, 312–318 (2005)
- Kolkowska, E.: Privacy principles in design of smart homes systems in elderly care. In: Tryfonas, T., Askoxylakis, I. (eds.) HAS 2015. LNCS, vol. 9190, pp. 526–537. Springer, Cham (2015). https://doi.org/10.1007/978-3-319-20376-8_47
- Kosta, E., Pitkänen, O., Niemelä, M., Kaasinen, E.: Mobile-centric ambient intelligence in Health- and Homecare-anticipating ethical and legal challenge. Sci. Eng. Ethics 16, 303–323 (2010)
- Nordgren, A.: Personal health monitoring: ethical considerations for stakeholders. J. Inf. Commun. Ethics Soc. 11, 156–173 (2013)
- Friedman, B., Kahn, P.H., Borning, A., Huldtgren, A.: Value sensitive design and information systems. In: Doorn, N., Schuurbiers, D., van de Poel, I., Gorman, M.E. (eds.) Early Engagement and New Technologies: Opening Up the Laboratory. PET, vol. 16, pp. 55–95. Springer, Dordrecht (2013). https://doi.org/10.1007/978-94-007-7844-3_4
- 25. Sjölinder, M., Scandurra, I., Avatare Nöu, A., Kolkowska, E.: To meet the needs of aging users and the prerequisites of innovators in the design process. In: Zhou, J., Salvendy, G. (eds.) ITAP 2016. LNCS, vol. 9754, pp. 92–104. Springer, Cham (2016). https://doi.org/10. 1007/978-3-319-39943-0_10
- SOSFS Swedish National Board of Health and Welfare: National Advice on values in elder care (2012)
- 27. Myers, M.D.: Qualitative Research in Business & Management. Sage Publications, London, UK (2009)
- Kulyk, O., Kosara, R., Urquiza, J., Wassink, I.: Human-centered aspects. In: Kerren, A., Ebert, A., Meyer, J. (eds.) Human-Centered Visualization Environments. LNCS, vol. 4417, pp. 13–75. Springer, Heidelberg (2007). https://doi.org/10.1007/978-3-540-71949-6_2
- 29. Barros, A.C., Cevada, J., Bayés, A., Alcaine, S., Mestre, B.: User-centred design of a mobile self-management solution for Parkinson's disease. In: MUM. ACM, 02–05 December 2013 (2013)