

Ethical Challenges by Using Assistive Technologies in Dementia Home Care – Potential of Advance Care Planning

Desafíos éticos del uso de tecnologías asistenciales en el cuidado de la demencia en el hogar - potencial de la planificación anticipada del cuidado

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ABSTRACT: Recently, an increasing number of technologies have been developed to assist in the support of people in need of care. People with dementia (PwD) are also potential users of such systems when used at home. The consequences of the illness for clients and their families and the use of technical systems in the home setting have resulted in specific ethical challenges. A difficulty lies in the clients' expressing their will to use the systems and in the dependency of ethical risks on the actual system and its direct application. Integrating technical scenarios into the discussion about future care within the concept of Advance Care Planning offers a potential to address ethical problems prospectively. Furthermore, it can promote client-centered care of PwD and their families with regard to the use of assistance systems. Questions remain regarding the consequences of non-use of assistance systems and their impact on the home care situation.

KEYWORDS: Dementia, technical assistance systems, ethics, advance care planning

RESUMEN: Recientemente, se ha desarrollado un número cada vez mayor de tecnologías para asistir a las personas que necesitan cuidados. Las personas con demencia (PcD) también son usuarios potenciales de estos sistemas en el hogar. Las consecuencias de la enfermedad para los pacientes y sus familias, así como el uso de dichos sistemas técnicos en el hogar, han dado lugar a desafíos éticos específicos. Una de las dificultades radica en la expresión de la voluntad de los pacientes de utilizar dichos sistemas y de los riesgos éticos de su aplicación directa dentro del sistema actual. La integración de escenarios técnicos sobre el futuro del cuidado dentro del concepto de Planificación Anticipada de la Atención ofrece la posibilidad de abordar los problemas éticos de forma prospectiva. Además, puede promover el cuidado de las PcD centrado en el cliente y sus familias con respecto al uso de los sistemas de asistencia. Persisten no obstante preguntas sobre las consecuencias de la falta de uso de sistemas de asistencia y su consecuente impacto en la situación de los cuidados a domicilio.

PALABRAS CLAVE: Demencia, sistemas de asistencia técnica, ética, planificación anticipada de la atención

1. Introduction

In Germany around 1.7 million people suffer from dementia (German Alzheimer Association, 2018). Dementia belongs to the group of neurodegenerative diseases. The severity of the symptoms and the course of the disease differ according to the type of dementia. The symptoms cover the reduction of cognitive functions in several areas, including memory, speech, executive functions as well as emotional and behavioral symptoms (Robinson; Tang and Taylor, 2015).

The growing prevalence of the disease makes it increasingly difficult to guarantee adequate care for this group of clients. On the one hand the costs of care are rising



(Leicht and König, 2012) and on the other hand there is a lack of expert care support due to the increased workload and insufficient trained staff (Ernst, 2016). The affected people would prefer to live in their own homes for as long as possible (Kutzleben, Schmid, Halek, Holle and Bartholomeyczik, 2012) where they depend on support from their relatives and/or professional caregivers. This has two positive impacts: firstly, family caregiving uses societal resources (informal caregiving potential) and, secondly, the affected persons' wishes are respected (Blinkert, 2007). However, home care is time-consuming (Grau, Berth, Lauterberg, Holle and Gräbel, 2016) and caring for a member of the family can cause stress (Gilhooly et al., 2016), emotional burden (Cheng, 2017; Lee, Bakker, Duivenvoorden and Dröes, 2017) and affect the family relations (Quinn, Clare and Woods 2009; Wadham, Simpson, Rust and Murray, 2016). The progression of the illness exponentiates these problems; the excessive demands on the family members can be seen as the cause for the institutionalization of the client (Toot, Swinson, Devine, Challis and Orrell, 2017). Dementia causes a need on the part of the affected persons and their relatives for support in home care arrangements.

One possibility for providing support for clients and relatives is the use of technical assistance systems in the own home. These can be an added benefit in different ways for those concerned. For instance, there are web-based programs for the psychological education of informal caregivers. By using modern technologies, support for the relatives can be provided which may not otherwise be possible in person due to spatial distance, lack of appropriate transport or other obligations. Such web-based programs can help reduce the relatives' burdens and thus improve the quality of life of the person with dementia (PwD) (Griffiths, Whitney, Kovaleva and Hepburn, 2016; Kales et al., 2018). Even risks that are caused, for instance, by the local disorientation of the PwD can be reduced with the help of modern technology. Global positioning systems (GPS) system can improve the autonomy of the affected person and reduce the uncertainty and fears of the family caregivers (Øderud et al., 2015; Pot, Willemse and Horjus, 2012). Apart from the systems mentioned, there are monitoring systems (Williams, Arthur, Niedens, Moushey and Hutfles, 2013), complex systems from the field of assisting ambient living (Martin et al., 2013) or robotic systems (Liang et al., 2017). Therefore, the potential of technical assistance systems for improving home care arrangements is high.

The rapid increase in the number and types of technical systems for PwD that have been observed during the last few years are, however, associated with several structural limitations. For instance, sufficient consideration is often not given to the clients' needs (Ienca et al., 2017). Contrary to current research developments, technologies must, however, be oriented to the "technically necessary" and not the "technically possible" if needs-based implementation and usage of modern technology is to be guaranteed (Dockweiler and Razum, 2016). The user orientation of technical systems is of great importance, especially against the background of dementia-specific symptoms and disease progression. It is equally important that the clients are not overwhelmed, confused or frightened by the use of technology. In addition, consideration must be given to the fact that due to the loss of their cognitive abilities PwD are restricted in learning new things, which would be required when using a new technology (Nygård and Starkhammar, 2007; Riikonen, Paavilainen and Salo, 2013). In general, the technologies should be usable in cases of motoric and visual impairments and should be adjustable to the clients' symptom changes (Jiancaro, Jaglal and Mihailidis, 2017).

The study design is a further limitation in researching into new technologies for dementia clients. Most of the studies investigate predominantly the feasibility or usability of systems, so that RCTs and studies concerning the effectivity or safety of applications are lacking. In general, the studies are characterized by small sample sizes and limitations in drop-out and statistical significance (Ienca et al., 2017; Palmdorf et al., 2019) and there is also a lack of research into the long-term impact of such technologies (D'Onofrio et al., 2017). Throughout Germany, only the home emergency button is widely used (Wahl, Kricheldorf and Hedtke-Becker, 2018).

The knowledge about technical support options for solving individual problems is limited. Family caregivers feel they are given either poor information or even none at all about the new technologies available in the field of dementia. This can lead to the existing potential for improving the care situation being left unused (Kramer, 2014). Overall, the use and implementation of modern technologies for PwD and their families face various ethical challenges.

2. Ethical challenges in using assistive technologies

Notwithstanding the challenges created by the implementation of existing assistive technologies, various ethical challenges can also result from their use by PwD and their relatives (Stahl and Coeckelbergh, 2016). In turn, these challenges can have an impact on the care situation. Indeed, both groups should be considered as vulnerable because of the disease and the ensuing burdens. The relatives' vulnerability results from the existing burden of handling the clients, coping with everyday life and finding solutions for challenging situations (Schmidhuber and Grässel, 2018).

In the following, ethical questions arising from the use of assistive technologies in care will be clarified by way of two examples: the first is the social-emotional robot PARO and the second is the use of GPS as tracking systems. The therapeutic impact of PARO has been proven in various studies and it has therefore found increasing use in geriatric care facilities (Baisch et al., 2018; Moyle et al., 2017). In addition, PARO has already been tested in home care settings (Buhtz et al., 2018). In the case of GPS there is a high demand and great acceptance in the home care setting (Megges et al., 2018). Altogether, it is necessary for ethical questions in the context of care and support for dementia clients and their relatives to be identified and critically reflected in the further course of the project.

PARO

PARO is the most common therapeutic pet-type robot used in studies with PwD (Yu et al., 2015). It is a social-emotional robotic device with artificial intelligence software. This enables PARO to respond to the user and the environment (Ienca, Jotterand, Vică and Elger, 2016). PARO looks like a baby harp seal and behaves in a similar way (Ienca, Jotterand, Vică and Elger, 2016). The robot is used as a therapeutic intervention to reduce challenging behavior, for example depression or anxiety and for lowering stress (Godwin, 2012; Chang and Sung, 2013). The use of PARO in caring for PwD brings numerous ethical questions with it, which can be sub-divided into various dimensions. Using social-emotional robots can lead potentially to (1) the deception of PwD, (2) a substitute for human attention, (3) data protection

problems, (4) unexplained side-effects, (5) unclear responsibilities and (6) social injustice in the context of uncertain financing.

The *deception of a PwD* when using PARO is part of the therapeutic intervention (Kreis, 2018; Sharkey and Wood, 2014). The robot imitates the behavior of a baby seal. The positive reactions to the robot are based on the transmission of animal characteristics or needs to the robot (e.g. the need for nearness or touching). Creating empathy towards the robot and the resulting relationship are part of the intervention without which PARO would potentially not work (Moyle et al., 2017). By creating a new reality, feelings are developed by the PwD that can neither be fulfilled nor reciprocated and which are associated with the baby seal (Sharkey and Sharkey, 2012). The illusion creates expectations towards communication and relationship building, which the robot can only fulfill within its limited programmed options for action. On the other hand, the behavioral options of a real animal are more diverse and a mistake in relationship building can lead to the animal retreating or reacting defensively. Furthermore, an animal is able to receive and respond to a variety of signals from the interacting person. The robot is also restricted in this respect. Overall, communication is much more fragmented than the user expects due to the deception.

When the symptoms progress, the question arises: To what extent do PwD recognize the robot as such and not as a real baby seal? Identifying PARO as a robot leads to less acceptance (Baisch et al., 2018). The aim of interventions for PwD is to promote a return to reality in order to improve orientation and support everyday activities and habits. This is a contradiction to the creation of a changed reality. PwD have no biographical contact with baby seals and this new stimulus has been designed because the PwD are not afraid of the robot as they might be if it were a dog, for example (Moyle et al., 2017). However, knowing about the biography of the PwD is a central aspect in this connection. Conversely, the effects of the intervention on the orientation of PwD are unclear when related to the newly created reality and form of interaction.

That robots are a *substitute for human attention* is a matter that worries many and receives wide agreement in social discourse (Sharkey and Sharkey, 2012; Schnell and Dunger, 2019). There is the expectation that technical systems do not aim to replace human interaction (Abbott, 2007). It is reported that PARO is only used when a caregiver or therapist is present (Moyle et al., 2017; Baisch et al., 2018). The intention to use PARO for substituting human interaction or not is closely connected to the individual care situation. For example, if PARO is used for distraction because the caregiver is tied up with other tasks, the risk is high; if it is used with a therapist present, then the risk is low. Thus, the estimation depends on the individual situation of the PwD and the purpose of the application, which means that each context in which the robot is used has to be reflected (Wynsberghe, 2016). Can PARO be a substitute for interaction and should the technology provide this?

Apart from the discussion about being a substitute for human attention, *data protection regulations* are also particularly important for the application of PARO. PARO has to gather a lot of very different data in order to be able to react adequately to its users and to recognize them again (Millings and Collins, 2018). From the perspective of informational self-determination, the question of the transparency of information flows and the legitimacy of data collection and processing arises (German Ethics Council, 2017), especially in connection with people who have cognitive restrictions. Due to the progression of the illness, it is not clear to what

extent PwD can understand information (such as data processing and storage) within the frame of the informed consent. It is also uncertain how far the digital competences of PwD allow them to make an informed consent or how their vulnerability influences the decision. If the responsibility for the informed consent is transferred to the caregiver, then the digital competence would again have to be examined and this depends on how the information is prepared. It is also unclear to what extent the consent by the PwD is sufficiently respected. If data collection by PARO is taken into consideration, then not only PwD but also every other user would have to give an informed consent to his/her data being collected and stored. This is required because PARO records all the users' audio data of that are considered as being person-related and there is therefore the danger of loss of control and the fraudulent use of one's own data by third persons (German Ethics Council, 2017). As a result of the ever-increasing access to intimate information through service providers, it is particularly important to protect data collected at home and to strengthen vulnerable groups of people in their digital sovereignty (Weis, Lucks and Grassmuck, 2017).

The *prevention of side-effects* from an intervention is based on the principle "do no harm" which implies the non-application of harmful or futile intervention. With regard to PwD, the reduced possibility of communicating their needs is a problem when estimating possible side-effects (Smith, Grijseels, Ryan and Tobiansky, 2015). Under some circumstances, fear or stress cannot be adequately communicated so that side-effects created by the intervention are not sufficiently recognized by the caregivers (Sachweh, 2019). Understanding the behavior and remarks of PwD depends on the person and situation and can be influenced by external or internal triggers that may be unconnected to the intervention (Kales, Gitlin and Lyketsos, 2015; Sachweh, 2019). This makes it difficult to register side-effects, especially in relation to the long-term impact of the intervention. Up to now there are no studies regarding the long-term impact of PARO on PwD.

The progressive development with robots leads to an expansion of the functions and an increase in the *unclear responsibilities*. These, for example, consist of undesired side-effects and the resulting consequences of the robot transferring data unintentionally (Stahl and Coeckelbergh, 2016). If robots are allowed to transfer the data they have collected autonomously, then the affected people and users will have to give their consent. This means that the robot's functions must always be controlled (Stahl and Coeckelbergh, 2016; Wynsberghe, 2016). The question is: Can this amount of responsibility and technical competence be expected of PwD and their relatives? On the contrary, PwD, their relatives and their professional caregivers should receive schooling about the use, transfer and storage of data before using the robot, for which they should also receive special training. This would mean, of course, that user-oriented education programs are required. The question of responsibility is important not only ethically but also judicially. On the legal side, questions relating to liability when vulnerable groups of people work with autonomously functioning computer systems remain largely open (Kluge and Müller, 2017).

Since the intervention is not yet regularly reimbursed through the health insurance funds, the financing depends on private or institutional reimbursement (Beck et al., 2013), which could be a potential disadvantage in the care of PwD who do not belong to an institution (e.g. use a particular out-patient care service, or are resident in a home for the elderly). At the same time, PwD who have limited financial resources cannot receive nursing and therapeutic

interventions (Burton, 2013) and this contributes to social and health-related inequalities. Concomitantly, access to health services comprising assistive technologies depends on private financial resources. Apart from the question of acceptance and efficacy of the technology, the development of future business and financing models as well as of social-emotional robots is in the focus of social discussion (Burton, 2013).

Global Positioning Systems (GPS)

Besides social-emotional robots, GPS have become an already widespread form of assistive technology in the care of PwD (Megges et al., 2018). GPS can be used to localize disoriented people or for recording activity patterns for estimating the severity of a dementia (Megges et al., 2018). When the system is used in a person-centered way, it could delay moves and provide independence and freedom (Landau and Werner, 2012). Formal risk assessments using the technology ignore ethical issues that occur. This includes aspects similar to PARO such as deception, data protection and additional aspects like enabling freedom versus restraint.

As already mentioned in connection with the social-emotional robot PARO, the use of GPS can lead to deceiving PwD. This may be the case when a GPS is integrated in shoes, jackets or watches of PwD without them knowing or being informed about the system that is collecting data for therapy or care purposes. The assumption behind the deception lies in a possible rejection of GPS by the user with dementia. If the GPS tracker is discovered, it can lead to problems in the relationship between the PwD and the caregiver. At the same time mutual trust and confidence between the clients and their caregivers is extremely important for their wellbeing (Ericsson, Kjellström and Hellström, 2013). Therefore, the tracking technology should not be used without the cooperation and consent of the PwD.

Apart from the question of *deceiving* PwD, using GPS raises a number of data protection problems and aspects (Michael, McNamee and Michael, 2006; Landau and Werner, 2012). Decisive for the data protection discussion about GPS is the design and the provision of different data at different times (Landau and Werner, 2012). For instance, there are systems in which PwD can move within a defined area around their own home without triggering an alarm (Loh, Schietecat, Kwok, Lindeboom and Joore, 2004; Michael, McNamee and Michael, 2006). Other systems set an alarm off as soon as the person leaves the house or the caregiver is informed in real time of the whereabouts or an alarm is triggered according to certain parameters (Landau and Werner, 2012).

The use of tracking technology generates a conflict in a continuum between *freedom and restraint*, which restricts autonomy (Schnell, 2018; Landau and Werner, 2012). The classification within the continuum in practice is complex and is due to the motives for the usage, the handling of the GPS and the consequences of use or non-use (Faucounau et al., 2009). Motives for the usage could comprise strengthening the freedom and social participation of the PwD by allowing him to be localized in the case of disorientation (Landau and Werner, 2012). If the caregiver prioritizes safety and protection and the alarm systems are activated only if the client leaves the house, it could be used as a restraint, because it limits the range of motion.

On the other hand, using the system may reduce other restraints like sedative medications or environmental restraints (e.g. locked doors), so that the GPS would be the 'better' solution (Landau, Auslander, Werner, Shoval and Heinik, 2010). One study reported that only few

caregivers would give more freedom to a dementia client fitted with such a device (Landau, Auslander, Werner, Shoval and Heinik, 2010). So 'doing the right thing' could be used to justify either restricting an individual's movement (increases safety and reduces caregiver stress) or the opposite (allowing freedom in order to enhance quality of life).

These examples show very clearly the various ethical challenges, which are dependent on the respective design of the technology, the specific handling and consequences of its use or non-use. What they all have in common is the decision to use these systems in the household of one particular client. The question then arises: How to handle the process of deciding, taking the cognitive restrictions of PwD and the growing pressure of the relatives into consideration? There are, in addition, issues in the focus of ethical reflection that arise from the individual care situation in the home, in particular obtaining a declaration of will from a PwD with progressing cognitive restrictions.

3. Advance care planning as one part of a solution?

Advance care planning (ACP) includes one or more face-to-face consultations with healthcare professionals. It is an interprofessional process tailored to the client's situation (Schildmann and Krones, 2015). During the consultation, people are supported in an empowerment approach to "identify personal values, reflect on the meanings and consequences of anticipated illness scenarios, define goals and preferences of care for these situations, and issue appropriate documents and legal instruments that will help direct future healthcare decisions" (Jox 2017, 167). In that way, the clients should gain control over their future life.

The difference between the process of general care planning and ACP is that the consequences of ACP will occur in the future, in the case of the individual's loss of decision-making capacity and/or loss of the ability to communicate wishes to others (NHS End of Life Care Programme, 2007). Therefore, ACP is applied in the context of progressive illness and anticipated deterioration (Harrison Denning, Sampson and Vries, 2019). In contrast to advance directives, ACP is an outreach intervention with continuous responsibility for the healthcare professionals (Schmitten and Marckmann, 2015). Additionally, advance directives ignore the complex process of care planning and considerably simplify the decision-making towards creating a perfect document (Bosisio, Jox, Jones and Rubli Truchard, 2018).

In the context of dementia, ACP has proven to be more effective than advance directives alone (Dempsey, 2013; Poppe, Burleigh and Banerjee, 2013). ACP empowers PwD and relatives to exert control over future care by fostering conversation about dementia-specific illness scenarios (Bosisio et al., 2018). This is very important since a lot of PwD feel or fear a loss of control during the progress of their disease. It could improve the clients sense of control and promote solution-based coping strategies (Zwakman et al., 2018). To reach this goal, ACP should include coping strategies to enable PwD, relatives and healthcare professionals to cope better with these situations (Gaster, Larson and Curtis, 2017; Hanson et al., 2017). It underlines the prospective and relational autonomy and may be more appropriate for elderly people with regard to the decision-making style and the needs (Bosisio et al., 2018).

The challenge in using ACP with PwD is often the late diagnosis of dementia. Dementia is frequently age-associated and considered shameful, which leads to a diagnosis in a later stage of dementia when the PwD is already moderately cognitively impaired. It is questionable how well he might be able to articulate his actual will. Therefore, initiating ACP at the right time is critical (Ryan, Amen and McKeown, 2017) and warrants a specific PwD-centered approach. To initiate ACP at the right moment is critical. Furthermore, future technological innovations as well as a change of will are not covered by ACP, since the client could suffer from severe cognitive impairment at a later date.

ACP and technology

The potential of ACP in the use of technical systems is grounded in providing a basis for later decisions for or against the use of a technical system taking into account the will of the PwD. The concept gives the opportunity to assess individual needs and priorities with regard to the use of technology. These needs are based on previous experiences, age, gender, the expected performance and expense as well as social and cultural influences [Technology-Acceptance-Model].

This leads to a high degree of individual needs of the PwDs and their relatives. The PwDs will could only be manifested in the actual contact with the technology and even then they would be difficult to interpret. Otherwise, the presumed will has to be determined and the responsibility for the decision would then lie with the relatives and the caregiver. Furthermore, empirical research shows that surrogate decision-making (e.g. by relatives) based on the presumed will are at a high risk of not reflecting the client's actual will (Kuehlmeyer, Borasio and Jox, 2012; Shalowitz, Garrett-Mayer and Wendler, 2006). The process and outcome of surrogate decision-making might also depend on whether the decision-maker is a relative or a legal guardian (Jox et al., 2012).

The difficulty in surrogate decision-making is the prioritization of safety over the client's autonomy. It is assumed that the client needs supervision and protection. Therefore, technical systems become ethically valid in the opinion of the decision-makers because their motivation is good and even if the PwD should dislike the GPS-tracking, he would forget the presence of the device. Furthermore, family members may not fully trust a client's cognitive ability to decide whether to use a technology like GPS-tracking or not (Stenwall, Sandberg, Jönhagen and Fagerberg, 2007). ACP provides a possibility to assess the PwD's will and strengthen his autonomy. Without consulting them, professional caregivers cannot be certain whether PwDs would define their wellbeing in terms of safety or would prefer making other choices about their lives, which might include taking some risks. Potential users of the technological systems have different interests in its use, e.g. health professionals would like to have better symptom monitoring and the relatives would prefer the promotion of the PwD's safety through monitoring. These interests can be in conflicts with the PwD's values. It could be challenging in ACP to balance the interests and needs of PwD, relatives and health professionals, because these might be conflicting (Harrison Denning et al., 2019).

Possible topics in the implementation of ACP could be the general use of groups of technologies. Additionally, the PwD could determine how his data should be handled. This would implicate questions about who would be allowed to what extent to get data insight. In the case

of using a GPS-tracking system, the PwDs could decide whether they wanted to use a system which sends a signal in case of emergency or a system which sends continuous tracking data about their location. Another possible topic is the handling of the digital legacy in case the PwD is no longer able to manage his personal data. The discussed technologies should not focus solely on the home setting but also anticipate a possible relocation to a nursing home. To date, needs about the later use of technology are not standardly measured and taken into account in the disease's progress. Furthermore, there are no legally binding procedures for the use of technology that take the style of decision-making as well as the PwD's needs into consideration. The inclusion of relatives with regard to the usage of technology is very important, because their needs have an impact in the possible (future) home care setting. Consequently, potential conflict should be addressed at an early stage when the PwD can still be adequately involved. As a result, more realistic future scenarios can be derived and discussed. Furthermore, the fundamental rights of those affected by the technological systems can be compromised. This refers especially to the use of personal data in their own home. The assessment of a PwD's needs and values is a good foundation for deciding for or against the use of certain new systems that were not developed when the ACP was set up. Ethical questions are going to arise with regards to the use of these systems.

4. Conclusion

One of the challenges of using technical support is the fact that PwD have difficulty in expressing their will clearly, especially when the disease is progressing. ACP offers the possibility of prospectively recording the declaration of intent of PwD with regard to the use of technical systems. This could influence the later decision to use the system. When applying the ACP concept, the question arises as to the complex framework in which the concept should be integrated so that the wishes of the PwD are actually taken into account in later decisions and are not overruled by the ideas of the relatives or the caregiver or superimposed against the background of strong pressure to act.

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