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Ethical Design of Intelligent Assistive Technologies for Dementia: A Descriptive Review

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Abstract The use of Intelligent Assistive Technology (IAT) in dementia care opens the prospects of reducing the global burden of dementia and enabling novel opportunities to improve the lives of dementia patients. However, with current adoption rates being reportedly low, the potential of IATs might remain under-expressed as long as the reasons for suboptimal adoption remain unaddressed. Among these, ethical and social considerations are critical. This article reviews the spectrum of IATs for dementia and investigates the prevalence of ethical considerations in the design of current IATs. Our screening shows that a significant portion of current IATs is designed in the absence of explicit ethical considerations. These results suggest that the lack of ethical consideration might be a codeterminant of current structural limitations in the translation of IATs from designing labs to bedside. Based on these data, we call for a coordinated effort to proactively incorporate ethical considerations early in the design and development of new products.

Keywords Assistive technology · Dementia · Ethical design · User-centered · Neurotechnology · Artificial intelligence · Proactive ethics

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Introduction: A Technology Revolution in Dementia Care?

The information technology revolution in healthcare is transforming the delivery, administration and management of healthcare services worldwide. Advances in robotics and medical engineering are rapidly multiplying opportunities for technology-assisted therapy, surgery, and rehabilitation. In parallel, advances in pervasive and ubiquitous computing (PUC) are increasingly embedding computational capabilities (e.g. prompting, sensing and information sharing) into traditional domestic and institutional environments, as well as worn items. These trends are expected to increase patient safety and the pervasiveness of care delivery (Bharucha et al. 2009; Adlam et al. 2004). In parallel, with the digitalization of patient records and the exponential increase in medical data worldwide, predictive analytics and data mining strategies enable the extraction, aggregation and analysis of large volumes of data.

Dementia care is one of the branches of the health care industry that is most likely to benefit from such technological revolution. The reasons are manifold. First, with the high relative costs of formal and informal dementia care (Alzheimer's Association 2016), technological solutions that can delay or obviate the need for long-term care could alleviate the burden on public finances and offer a viable path for the otherwise endangered provision of institutional services among a rapidly expanding elderly population (Pollack 2007). Second, given the erosion of the caregiver-to-patient ratio (Prince 2015), the massive deployment of robotics-assisted care could complement current care provision, reduce the burden on unpaid caregivers and improve the quality of care (Bharucha et al. 2009). Third, with effective therapeutic solutions still not in sight, big data platforms can reveal insights from large amounts of unstructured data and improve prevention, diagnostics, therapy and care management (Moore et al. 2013). Fourth, the incorporation of computing and, in particular, artificial intelligence (AI) into care agents and care environments could favor the delivery of personalized, adaptive and patient-centered care solutions (Mihailidis et al. 2001). This would not only help fulfill the wishes of patients but also empower them and improve their quality of life. Finally, neuromonitoring/neuromodulation technology and brain-computer interfaces (BCIs) are opening new possibilities for the monitoring and purposeful modulation of the patients' brain activity as well as for external device control using both invasive and non-invasive means (Lee et al. 2013; Ferrucci et al. 2016).

A number of Assistive Technologies (ATs) of these diverse types have been developed to date with direct or indirect application in dementia care. AT is the umbrella term used to describe technological devices or systems which allow people with physical or cognitive disabilities to perform tasks "that they would otherwise be unable to do", or to increase "the ease and safety with which a task can be performed" (Tinker et al. 1999). Bharucha et al. (2009) have introduced the notion of Intelligent Assistive Technologies (IATs) to distinguish ATs with own computational capacity from mere mechanic tools (e.g. walking canes). The spectrum of IATs is wide and encompasses a variety of devices and systems including handheld devices (e.g. tablets, PDAs, GPS trackers), mobility aids (e.g. powered wheelchairs and electronic canes), distributed systems (e.g. smart homes,

integrated sensor systems, mobile platforms etc.), wearable devices (e.g. fitness trackers), humanoid robots, brain-computer interfaces (BCIs), and software applications (e.g. mobile or web-based apps). Ienca et al. (2017) have systematically reviewed the entire spectrum of IATs with current or possible application into dementia care and provided the first comprehensive index of IATs for dementia. Their results show that the number of IATs for dementia is exponentially increasing over time, with an average five-year increase of 400%. As for the technological type, the most common IATs in dementia care are distributed systems, especially Ambient Assisted Living technologies (AALs), followed by humanoid robots and handheld devices. Most of these devices have been developed for supporting older adults with dementia during the completion of ADLs; other applications include monitoring, cognitive assistance and physical assistance.

The Ethics of IATs for Dementia: Time for Proactive Approaches

Due to their pervasive and ubiquitous character, IATs do not exclusively affect the clinical dimension of patients but their emotional, psychosocial and relational dimensions as well. IATs such as GPS trackers and videomonitoring technologies can enhance and partly replace the need for continuous human caregiver supervision (Mégret et al. 2010). Personal care robots and Ambient Assisted Living (AAL) technologies can help older adults with dementia achieve greater independence in their home environment and autonomously perform routine activities (Rashidi and Mihailidis 2013). Cognitive assistants and patient-oriented handheld devices can support the cognitive dimension of patients and partly compensate for the cognitive deficits caused by the progression of their disease (Mihailidis et al. 2004). Neurodevices and BCIs can lead to better preventive diagnostics, and favor interaction through the brain-control of external devices (Compano 2009). Finally, companionship robots can assist the emotional dimension of patients, alleviate agitation, loneliness, social isolation and improve their emotional wellbeing (Mordoch et al. 2013). As such, IATs open the prospects of becoming intimately intertwined in the psychosocial dimension of elders with dementia. Actually, the pervasive dissemination of IATs across various domains of life has the potential to enhance not only delivery, but also to affect the psychology, behavior, and social dimension of patients. Concomitantly, due to the technological novelty and complexity of IATs for dementia, the introduction of such systems into standard dementia care raises a number of ethical and legal issues.

For example, Felzmann et al. (2015) argue that the switch from human care to technology-assisted care could have an unintended impact on the subjective experience of older people with dementia (Felzmann et al. 2015). Other common normative ethical evaluations related to the use of IATs in dementia care include the appropriate acquisition of informed consent (Mahoney et al. 2007), the protection of the patients' personal privacy from unconsented surveillance (Sifford and Bharucha 2010), the protection of patients from restraint (Magnusson and Hanson 2003), and

the normative status of “justifiable benevolent deception” when using socially assistive robots (Marzanski 2000).

A recent literature review has comprehensively evaluated the ethics of AAL technologies for people with dementia (Novitzky et al. 2015). This review identified various types of ethically relevant issues which should be systematically addressed as part of the development of new devices. These include user involvement in product development, informed consent, social isolation and data security (Novitzky et al. 2015). In a similar comprehensive fashion, Zwijsen et al. (2011) have reviewed the relevant literature to identify the ethical implications associated with the use of ATs in the care for community-dwelling elderly people, including people with dementia. Their results identified ethically relevant themes including privacy, autonomy, social stigma, affordability and safety.

Ethical concerns of key stakeholders, especially informal caregivers, have also been at focus of investigation. Mulvenna et al. (2017) examined the views of caregivers of people with dementia on the use of camera-based surveillance ATs, with special focus on ethically relevant values such as autonomy, freedom and privacy. Their results indicate a general willingness among caregivers to make use of camera technology, with some significant caveats around the risks of invading the patients’ privacy or reducing their freedom and autonomy (Mulvenna et al. 2017). Such studies of stakeholder perspectives are crucial to overcome barriers and fine-tune new prototypes of IATs to the end-users’ needs in order to guarantee the ethically sustainable introduction of ATs into standard dementia care.

It has been observed, in fact, that the absence or inadequate translation of ethical considerations is a major obstacle towards the successful adoption of assistive technologies (Ienca et al. 2017; Bharucha et al. 2009). Ethical concerns have been observed to be a major predictor of suboptimal user acceptance and were reported as cause of skepticism towards technology among elderly adults with dementia and their caregivers. For example, Boise et al. (2013) investigated the acceptance of in-home and computer monitoring among elderly adults with mild cognitive impairment (MCI). Their results show that a majority of participants (60%) reported ethical concerns related to privacy and security (Boise et al. 2013).

Most ethical literature on IAT deals with the ethical evaluation of existing products with the aim of establishing standards or norms on how to use and apply new IATs in an ethically appropriate manner. Consequently, ethics, in the context of IATs, plays primarily a *reactive* role: it reacts to pre-determined technological products and services by assessing their compatibility with existing ethical values and principles, and eventually making prescriptive judgments about the appropriate implementation of such technologies. For example, Perry et al. (2009) have investigated the impact of current IAT and telecare solutions for people with intellectual disabilities through the lenses of the four principles of biomedical ethics (Perry et al. 2009). The goal of their analysis was to assess whether present products and prototypes align or conflict with those ethical principles.

In the last two decades, a growing number of researchers have called for incorporating ethical considerations early on in the design process through approaches to product design such as user-centered and value-sensitive design (Ienca et al. 2016; Bharucha et al. 2009; Feng 2000; Van den Hoven 2005). For

example, Van den Hoven has called for “a way of doing ethics that aims at making moral values part of technological design, research, and development” (Van den Hoven 2005). Value-sensitive design is “a theoretically grounded approach to the design of technology that accounts for human values in a principled and comprehensive manner throughout the design process” (Friedman et al. 2013). According to this school of thought, ethical values should be proactively incorporated at the level of design through cooperative efforts of engineers and ethicists, instead of being discussed only at the end of the technology development process (i.e. in relation to finished products). For example, Feng has called for “addressing ethical concerns early on in the design of a technology” and “bringing ethics back into design” (Feng 2000).

While value-sensitive approaches are increasingly raising the attention of IAT researchers, little knowledge is available to date regarding the prevalence of ethical values in IATs. In particular, no study to our knowledge has investigated whether and which ethical considerations are being incorporated into the designs of current IATs for dementia.

In this paper, we fill this gap by providing a comprehensive analysis of the spectrum of ethical values and considerations incorporated into the design of current IATs for dementia. This analysis is relevant for a twofold reason. First, it will provide a quantitative description of current trends in value-sensitive design for IATs for dementia, including evidence about the presence and prevalence of ethical values at the level of product design. In addition, this analysis would lay down the foundations of an evidence-based and empirically-informed approach to the ethical co-design of future products. For example, it would help determine what ethical values are currently underestimated, hence must be more carefully considered in the future to reduce the risk of drawbacks such as low social adoption, breaches for insecurity, and unintended ethical and social consequences. With the rapid introduction of intelligent systems into healthcare, working out how to build ethical systems is “one of the thorniest challenges in artificial intelligence” (Deng 2015). Therefore, it is important to investigate whether and how current systems are meeting this challenge, in particular in the context of intelligent systems used in the care of vulnerable populations, such as people with dementia and neurocognitive disabilities (Ienca et al. 2016).

Methodology

Data Search and Extraction

A systematic literature review was performed to retrieve a comprehensive and the up-to-date list of IATs with application to dementia care. Original research articles and application protocols were searched for the period 2000–2016 in the following search engines and bibliographic databases: IEEE, PubMed, Scopus, PsycINFO, and Web of Science. The following query logic was developed, pilot-tested and, whenever necessary, adapted to the language used by each engine or database: (*“assistive technolog*” OR “assistive device” OR “assistive application”*) AND

("intelligent" OR "ICT" OR "adaptive" OR "computer" OR "robotic") AND ("Alzheimer*" OR "dementia" OR "ag*ing" OR "elder*"). Based on the inclusion criteria, IATs included into the analysis met the following requirements: (1) had own computing capability; (2) showed direct applicability to dementia care, and (3) could be used to assist or compensate for the functional impairments associated with dementia. A total of 617 papers were initially identified. Subsequently, three steps of filtering were performed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria (Moher et al. 2009): additional records identification through secondary sources, duplicates removal (both software-assisted and manual), and eligibility assessment. To minimize subjective biases, each stage of review was performed by at least two authors independently from each other.

Data Analysis and Synthesis

An in-depth review of full-text articles included in the synthesis ($n = 571$) was performed. Such a systematic review resulted in the production of the *Dementia Technology Index 2016 (DTI16)*. 539 IATs with direct application to dementia care were identified and included in the DTI16. Subsequently, the DTI16 was analyzed with the purpose of retrieving the full list of ethical considerations addressed in the design, development or assessment of each indexed technology. Our quantitative document analysis consisted of three sequential steps. First, for each IAT, we screened the presence of ethically-relevant considerations. During this phase, ethically relevant keywords and statements were searched in the full texts of all reviewed articles. This process was performed by two authors using both software-guided keyword search (software used: Endonote X7) and unguided full-text review. Second, we clustered all retrieved ethical considerations into main thematic families using thematically oriented content analysis (Vaismoradi et al. 2013). Based on thematic affinity, our analysis identified six main thematic families: (1) Autonomy, (2) Privacy, (3) Beneficence, (4) Non-Maleficence, (5) Interdependence, and (6) Justice.

The language used to describe the six thematic families was partly grounded on the principles of biomedical ethics (Beauchamp and Childress 2001) and adapted to the specific context of assistive technology for dementia. In particular, given the distinctive nature of privacy issues in information technology (Rindfleisch 1997), we classified privacy as an independent category rather than a sub-component of respect for autonomy. This is in accordance with the growing literature on the distinction between privacy and autonomy (Gross 1971; Laurie 2014; Wacks 2015; Marmor 2015) and the oft stated suggestion that the physical and informational privacy of elderly adults with dementia should be seen as a primary consideration especially in relation to surveillance technology for in-home monitoring (Koontz 2013). In addition, ethical considerations related to the caregiver-carereceiver relationship in dementia care were indexed under the category of *interdependence* (Agich 1993).

Each thematic family was further classified into sub-families relative to specific sub-components of the main ethical theme. When the same IAT description

contained more than one ethical consideration, all considerations were allocated to their respective thematic families and subfamilies. Subthemes were partly derived and expanded from the classifications provided by Novitzky et al. (2015) and Zwijsen et al. (2011). Compared to these studies, we chose to separate safety-oriented considerations from the family of justice considerations since safety and risk-reduction represent critical components of the non-maleficence principle in biomedical ethics and have little in common with justice-oriented considerations (Beauchamp and Childress 2001). This categorization also builds upon Friedman et al.'s list of human values (with ethical import) often implicated in system design (Friedman et al. 2013).

Thematic Families and Subfamilies in this Ethical Taxonomy were Categorized in the Following Manner

Autonomy

The principle of autonomy was understood as the capacity of the person to deliberate or act on the basis of one's own desires, that is the ability to act freely in accordance with a self-chosen plan (Varelius 2006). Subcomponents of the autonomy principle in relation to IATs for dementia are: independence, ageing-in-place, and user-centeredness. It is the case that the ability for autonomous action and deliberation entails that the person's activity is not exclusively dependent on contingent limitations or manipulative and distorting external forces. Therefore, independence (e.g. independent living) is an essential component of autonomy. In the context of dementia care, independence is strictly related to the wish of elders to *age-in-place* (Bharucha et al. 2009). The U.S. Centers for Disease Control and Prevention defines *aging in place* as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level" (CDC 2013). In addition, the respect for autonomy entails that the IAT is designed upon and to better meet the user's needs. Personal autonomy is maximized when users are not passive objects of top-down designs but when the IATs are adapted upon their needs. This notion of autonomy entails both a right that should be respected and a capability that should be promoted.

Privacy

The principle of privacy was defined as the ability and the legal right of an individual or group to seclude themselves, or information about themselves. Two subtypes of privacy could be distinguished: physical and informational privacy. Physical privacy pertains to the capacity to demarcate one's personal physical space. This includes ethical considerations related to the invasiveness, intrusiveness and obtrusiveness of IATs into the intimate and private sphere of elders with dementia. Informational privacy pertains to the capacity to seclude sensitive, confidential or private information. This includes ethical considerations on the protection of sensitive information about the users and the risk of disproportionate data collection. As a necessary prerequisite of informational privacy is the security

of information and the protection of private data (e.g. personally identifiable data), these two are also included as a subtheme.

Beneficence

The principle of beneficence postulates the promotion of the benefit and welfare of the person, and is often considered the main end of medicine. While narrow definitions of beneficence have linked this principle exclusively to the end of healing and not to any other form of benefit (Pellegrino and Thomasma 1988), a growing consensus in biomedical ethics considers beneficence holistically, hence encompassing the notions of quality of life (QoL), care (Branch 2015), and enhancement (Savulescu 2007; Persson and Savulescu 2012). QoL is a complex, multidimensional construct defined by the World Health Organization as ‘*individuals’ perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns*’ (Group 1995). Care-related principles such as empathy, dignity and the protection of vulnerability categorized in the beneficence family, together with ethically relevant aspects of a person’s emotional and psychological well-being. Finally, enhancement refers to the augmentation of human physical or cognitive capacities beyond therapy, that is in relation to or pursuit of non-therapeutic aims.

Non-maleficence

The principle of non-maleficence postulates a moral obligation to avoid or, at least, minimize the causing of harm (Beauchamp and Childress 2001). While every intervention—including technology assisted interventions in dementia care—involves some possible degree of harm, even if minimal, the non-maleficence principle maintains that the harm should not be disproportionate to the benefits of the intervention. This category thus includes ethical considerations incorporated into IAT for risk-prevention and risk-minimization—for example, smart smoke and fall detectors. Relatedly, it includes considerations for the improvement of safety, i.e. the protection from or reduced likelihood of danger or injury.

Interdependence

IATs enable elderly adults with dementia to maintain, restore, reacquire, or support social relations and the capacity to interact with the external social, digital and natural environments. This relational dimension, often articulated as a dialectic of human independence and dependence which is described as *interdependence* (Agich 1993), is of particular relevance in the caregiver-care receiver relationship as well as in the relationship between care receivers and their significant others (Meininger 2001). This category encompasses subthemes related to the relational dimension of elders with dementia including the problem of social inclusion, the risk of loneliness and the loss of human contact.

Justice

The principle of justice postulates a fair distribution of benefits, risks and costs of technology. In the context of health technology, justice articulates into three major subfamilies: equality, fair access and openness. Equality considerations are concerned with enabling patients with equal conditions to use a technology equally. Fair access considerations strive to maximize access to technology and consequent adoption for all socioeconomic classes while affordability considerations are concerned with the development of low-cost IATs with the purpose of preventing technological divides that may exacerbate pre-existing socioeconomic divides. Finally, openness issues refer to the availability to anyone and for any purpose of the software's source codes, licenses, or even hardware components.

Results

Results show that the majority of current IATs ($n = 361$; 67%) are developed in absence of any explicit ethical consideration (Fig. 1).

In the remaining portion of the IAT spectrum ($n = 178$, 33%), ethical considerations at the level of design were detected and analyzed. As several IATs presented multiple considerations (i.e. more than one ethical theme), we detected in total 257 ethical considerations, as presented in Fig. 2. Among these, autonomy ($n = 99$; 38.5%) was by far the most frequent family of ethical considerations, followed by non-maleficence ($n = 52$; 20.2%) and beneficence ($n = 50$; 19.4%). In contrast, justice ($n = 24$; 9.3%), interdependence ($n = 19$; 7.4%) and privacy ($n = 13$; 5%) considerations appeared rare.

Results by Subfamily

Autonomy and Independence

Results show that autonomy, broadly conceived, is the primary and most common concern in current IAT designs. While some IATs ($n = 26$) incorporated *cognitivist* conceptions of autonomy as self-determination—i.e. the ability to act in accordance with a self-chosen plan (Varelius 2006), the most common subtheme within this thematic family was independence ($n = 52$) during the completion of daily activities. The prevalence of independence considerations occurs across all technological types of IATs. For example, assistive robots such as PaPeRo (Inoue et al. 2012), smart mobile apps such as Smartbrain (Yamagata et al. 2013) and mobility assistants such as iWalker (Cortés et al. 2008) were all designed with the purpose of supporting *independent living* among persons with dementia. However, independence considerations appeared particularly prominent among distributed systems such as AAL platforms, smart-home prototypes and other advanced integrated systems. For example, the assistive platform iWall (Kyriazakos et al. 2016), the home sensing environment INHOME (Vergados 2010), the smart house Intelligent Sweet Home (Lee et al. 2007) and the ICT infrastructure LAGUNTXO

Fig. 1 Prevalence of ethical considerations (EC) in IATs for dementia

Ethical Design in IATs for Dementia

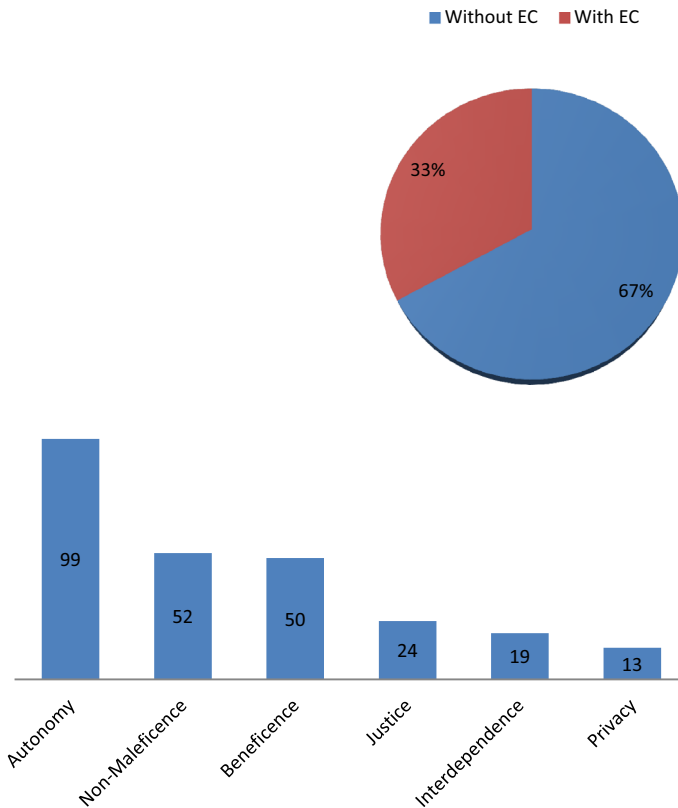


Fig. 2 Distribution of ethical considerations in IATs for dementia by thematic family (n = 257)

(Martinez et al. 2010) had the common objective of promoting or enhancing the degree of independence of older adults with dementia. In contrast, considerations of autonomy as self-determination were more relevant among cognitive assistants such as the information system SJOBOKS (Heijkers et al. 2013).

In addition, issues of user-centeredness and adaptation of IAT to the user needs also covered a significant portion of the technological spectrum (n = 21). These include issues of individualization and personalization of IAT applications according to the users' needs and personal choices, as well as issues of non-patronization. For example, robot SAM's (Smart Autonomous Majordomo) advanced assistive functions were designed to be user-friendly and adaptive to the user's needs (Lebec et al. 2013). Similar considerations were detected also in distributed systems like ISISEMD (Mitseva et al. 2012) and assistive software like DIADEM (Money et al. 2011). Service robot ROBADOM was the only IAT explicitly designed with the concern of not patronizing its users (Wu et al. 2012).

Beneficence

With regard to beneficence-oriented considerations, the major concern in current IAT designs is the promotion of the QoL of elder adults with dementia ($n = 28$). Such QoL-oriented considerations appear frequent across all IAT types. For example, multimedia system ePAD (Tung et al. 2013), AAL system ASTRO-MOBILE (Cavallo et al. 2015), and domestic smart environment RoBOCARE were all designed with the explicit purpose of improving “the quality of life of patients, their relatives, and their caregivers” (Cavallo et al. 2015). QoL considerations appeared particularly focused with the physical wellbeing of elderly adults with dementia. However, a small portion ($n = 5$) focused on the proactive promotion of their emotional wellbeing ($n = 5$). For example, a cloud architecture for family recognition was designed with the purpose of “improving their self-esteem and stimulating the patient with novel technology” (Fardoun et al. 2015). This characteristic was mostly exhibited by assistive systems exhibiting emotional intelligence features.

Care-related considerations also compose an important portion of this thematic family ($n = 20$). These include the promotion of quality of care, the alleviation of caregiving burden, issues of dignity, frailty and vulnerability, or the empowerment of elderly adults with dementia through technology use and the integration of social intelligence features into intelligent systems. For example, the ABLE platform (Giokas et al. 2014) was designed with consideration of the condition of frailty and vulnerability typical of elderly adults with dementia, whereas the design of a robotic home environment addressed the problem of protecting the dignity of users (Güttler et al. 2015). Finally, issues of cognitive and physical enhancement appear relatively rare ($n = 2$).

Non-maleficence, Safety and Risk Reduction

No-harm considerations represent another important portion of ethical considerations incorporated in current IATs and are largely expressed in the form of risk-reduction strategies ($n = 13$) and safety-promoting ($n = 38$) considerations. For example, a number of mobility assistants, such as SmartCane (Au et al. 2008), and ambient assisted living technologies, such as the FOOD Smart Kitchen (Grossi et al. 2014), were designed to reduce domestic risks such as falls and fire. An even greater portion of systems including intelligent powered wheelchairs (Mihailidis et al. 2007; How et al. 2013), robotic walkers (Morris et al. 2003), and assistive robots such as Domeo (Zsiga et al. 2013) were designed to assure the safety of their elderly users.

Interdependence

In spite of the rapid increase in technical opportunities for human-machine interaction in dementia care, ethical considerations associated with the relational dimension of users and the relational capabilities of IATs still represent a small portion of the ethical IAT spectrum. Among them, the problem of social inclusion and the proactive reactivation of the user's relational capacities are a dominant

theme ($n = 13$). For example, a number of IATs including intelligent agent Coaalas (Moreno et al. 2013; Gómez-Sebastià et al. 2016), robot KSERA (Johnson et al. 2014), cognitive prosthetics COGNOW (Meiland et al. 2010), distributed system NOCTURNAL (Martin et al. 2013) and intelligent ebook ALLT (Attarwala et al. 2013) had the shared objective of favoring social inclusion by creating new opportunities for social exchange, supporting social activities and reducing social isolation. In parallel, a smaller number of devices ($n = 5$) including the Monitoring Memory Streams (MMS) iPad application were designed for facilitating interactions between caregivers and people with Alzheimer's disease (AlMazrua et al. 2013). Finally, issues of loneliness and the ethical concern that the expansion of technology assisted care will thereby cause a loss of human contact are considered by a very small portion of intelligent systems ($n = 1$).

Justice

Justice and fairness considerations compose another small portion of ethical considerations in current IATs for dementia. Among these, issues of affordability and cost-control are dominant ($n = 18$). In particular, several IATs are designed with the explicit wish of achieving low-cost products, which could be afforded by a large number of elderly adults with dementia from virtually all socioeconomic classes instead only by the wealthy. These attitudes could be detected among IATs employing low-cost hardware—especially monitoring systems, home automation services and rehabilitation tools. Concomitantly, issues of universal access and fair distribution are considered only in five IATs, with special focus on delivering care in spite of accessibility barriers as in the case of the cloud-based INREDIS service (Murua et al. 2011). Finally, open design (both open-source hardware and software) considerations, where information about the hardware/software is easily discerned to enable other people to reproduce it, were detected in only one occurrence: a freely available dataset of acceleration data coming from a wrist-worn wearable device (Bruno et al. 2014).

Privacy

Privacy considerations encompass the smallest portion of ethical considerations in current IATs. Among these, issues of physical privacy ($n = 7$), especially in the form of non-invasiveness, non-intrusiveness and non-obtrusiveness of IAT into the physical private dimension of elders with dementia, are considered. Issues of informational privacy compose a slightly smaller fraction of ethical coverage ($n = 5$) and are mostly associated with tracking and monitoring technologies. For example, the clinical decision support systems (CDSS) for mobile device incorporated privacy concerns in a context where it interacts with smart homes (Roy et al. 2014), while the user-centered design of an in-home monitoring system (Larizza et al. 2014) addressed the problem of privacy of the information obtained through monitoring. Finally, issues of information security and data protection are proactively considered only in one IAT.

A detailed summary of results by family and subfamily is presented in Table 1.

Table 1 Prevalence and distribution of ethical values in IATs for dementia (themes and subthemes)

Autonomy (n = 99)	Non-maleficence (n = 52)	Beneficence (n = 50)	Justice (n = 24)	Interdependence (n = 19)	Privacy (n = 13)
Independence (n = 52)	Safety (n = 38)	Quality of life (n = 28)	Affordability (n = 18)	Social inclusion (n = 13)	Physical privacy (n = 7)
Autonomy (n = 26)	Risk-reduction (n = 13)	Care (n = 20)	Access (n = 5)	Interaction (n = 5)	Informational privacy (n = 5)
User-centeredness (n = 21)		Enhancement (n = 2)	Openness (n = 1)	Loneliness and loss of human contact (n = 1)	Data protection/information security (n = 1)

Discussion and Recommendations

The finding that the vast majority of IATs for dementia (67%) is designed and developed in the absence of explicit ethical values or considerations indicates that the current prevalence of value-sensitive approaches in IATs for dementia is still low. In addition, since addressing values in design in a principled manner is believed to increase the benefits and reduce the harms of a technology among a stakeholder group (Friedman et al. 2002), it is possible that the low prevalence of ethical values in IAT design might negatively affect the use of IATs by people with dementia.

These results confirm previous research findings showing the persistence in the IAT community of conceptual and practical barriers to the incorporation of ethics into the design phase (Feng 2000; Stilgoe et al. 2013). Closer collaboration among ethicists and engineers might be required to build IATs for dementia that can account for the values of end-users, hence favor effective and responsible clinical use.

The recurrence of issues of *independence* confirms the often stated goal of IAT designers of maximizing the capacity for independent living of older adults with dementia (Bharucha et al. 2009). Independence and independent living are critical factors in IAT research, in particular from the perspective of public health and health economy. Also, technologies that can protract in-home independent living of older adults with dementia will delay or obviate the need for institutionalized care, hence alleviate the financial burden of dementia for health care systems. In addition, the greater independence elders with dementia can maintain at home or in skilled facilities the lower the need for both formal and informal care. This is likely to mitigate the burden on caregivers and may improve the well-being of both care receiver and care providers. However, while independence is crucial, other considerations should be carefully included too.

In particular, the low frequency of justice and access-related considerations highlights a major societal challenge in the future of IATs for dementia. With the

limited number of low-cost and open-source devices and the frequent failure of researchers to address issues of fair and universal access to technology, there is a risk that the adoption of IATs will be limited by socio-economic factors or could even exacerbate existing socio-economic problems. To compensate for this problem, the massive adoption of IATs among the ageing population should be coordinated with health policy plans that minimize the emergence of adverse unintended societal consequences. For example, reimbursement plans and government incentives are crucial strategies to promote fair access to technological innovation and avoid the emergence of a digital divide between elderly adults with dementia who could afford IATs and those who could not. Such a divide could exacerbate existing socio-economic inequalities. In addition, since the prevalence of dementia is not dependent on socioeconomic factors, the benefits of IAT for dementia should not be exclusive for the wealthy but rather shared among all socioeconomic classes. This is particularly relevant from a global health perspective. Since the greatest relative cost increases are occurring in low-income African and in East Asia regions (DESA 2015) it is critical to deploy low-cost IATs that can be afforded by low-income populations in the developing world. While access and affordability are critical predictors of technology adoption, open-source designs should be also pursued. Open design in IAT for dementia would assure that the hardware and software of future IATs is developed in a collaborative manner and can be distributed to anyone without copyright restrictions. This would facilitate the fair distribution of and access to IAT across different world regions and socioeconomic classes and guarantee the *democratization* of such a technological trend.

The dramatically underrepresented frequency of privacy considerations, especially of those related to informational privacy, raises a major ethical concern as it has been repeatedly observed how various types of IATs could be used to access private and sensitive information (George et al. 2011; How et al. 2013; Ienca and Haselager 2016; Al Ameen et al. 2012). Our results show that value-sensitive approaches to accounting for privacy considerations, especially *privacy by design*, are not a priority in current IATs for dementia. We argue that protecting the privacy of older adults with dementia as well as the security of their identifiable information should be a structural requirement of future products. This should be achieved by enhancing the security of future products and integrating tools that can prevent unconsented extraction of private information or filter it out from the information flow processed by the IAT. To achieve this, closer collaboration between IAT designers and information security experts may be required. Ideally, this would result in increased attention to principled approaches to privacy and data protection and in the integration of encryption and jamming technology. However, with security by design being difficult to achieve, measures for securing sensitive (e.g. behavioral, personal or physiological) information should be implemented not only at the level of product development but also of individual use and regulation. With regard to data ownership, older persons with dementia should be legally entitled to claim ownership over the content and the form of their data, either directly, through advanced directives or via a proxy. Since the degree of information security decreases with the amount of awareness of the user, older people with dementia are

in principle ideal targets for cybercrime or unauthorized data extraction. For example, when using a smartphone app for cognitive assistance and training, they might not have enough knowledge or awareness about what information the app is requiring from their device. This could open breaches for insecurity. The problem of privacy and security breaches is exacerbated by the situation that several IATs are not FDA certified—since they are not classified as medical devices, and do not fall under the HIPAA rule (World Health Organization 2010). Consequently, they are not required to hold the same privacy and security standards of medical applications.

The high prevalence of independence, risk-reduction and safety considerations indicates that the priority of IAT designers is to assist elders with dementia during the completion of their ADL. While the successful and autonomous completion of daily tasks is a major leap towards the empowerment of older adults with dementia, designers should look more carefully also at the emotional and cognitive underpinnings of behavior. Although a certain IAT may be extremely successful at enabling users to independently perform task X, yet users might still not perform X because of their state of distress and agitation or due to forgetfulness. Therefore, there is a need for considering more carefully at the design level how IATs can be used to improve the emotional and cognitive dimension of elderly adults. In parallel, strategies should be developed to increase end-users' trust in the system.

Finally, conflicting ethical principles should be balanced in a weighted manner. For example, as observed by Nestorov et al., promoting patient autonomy and reducing caregiver burden through intelligent technology may cause a loss of human contact (Nestorov et al. 2014b). Similarly, minimizing invasiveness and obtrusiveness may result in sub-optimal accuracy of the device in sensing or tracking the user or collecting user data, hence conflict with beneficence-oriented principles of health optimization. Therefore, a weighted balance among conflicting values should be pursued in a case-by-case manner through a cooperative effort involving not only designers and ethicists but also end-users and their caregivers.

Limitations and Future Research

This study presents several limitations. First, it is possible that ethical considerations might be addressed at the level of technology design in an implicit manner, i.e. without being reported in the study protocols or without the use of the explicit terminology. Although the value-sensitive framework prescribes that values in design should be addressed “in a principled and comprehensive manner” (Friedman et al. 2013), unprincipled and implicit considerations might also be relevant in assessing IATs. To minimize this risk, the software-guided keyword search was complemented with a full-text review. This phase of review was performed independently by two researchers. In addition, the lack of ethical considerations at the level of technology design might not necessarily lead to unethical technology. In fact, the absence of ethical values in product design does not necessarily imply poorer ethical outcomes in the application of a certain IAT. A clear distinction between intended ethical values in product design and ethical outcomes is important

to avoid conceptual confusion. Finally, the absence of ethically relevant considerations might not be exclusive to IATs for dementia but common to other trends in medical technology. Some of the findings and implications of this study are likely to apply to IATs designed for different target user populations.

In spite of these limitations, the methodology employed in this study appears as a valuable strategy to investigate the prevalence of value-sensitive approaches in IAT design and test whether and which ethical values are actually incorporated in current products. In addition, research in value-sensitive design has shown that addressing ethical values in a principled manner at the design level can result in increased benefits and reduced harms for technology users (Friedman et al. 2002). Therefore, it is possible that mapping the prevalence of ethical values in IAT design might help develop strategies for the clinically successful and ethical responsible use of IATs among people with dementia.

Further research is required to investigate the ethical values addressed in IATs designed for different target populations such as people suffering from brain and spinal cord injury. In addition, further research is needed to explore the relationship between ethical design and technology acceptance among end-users. One possible strategy is to compare these review results with interview studies or survey involving people living with dementia and their formal and informal caregivers. This triangulation would be particularly relevant in a cross-cultural context, since preliminary findings have revealed that elderly people from different world regions have different degrees of reservations about ethical issues (Nomura et al. 2008).

Conclusion

The technology revolution in dementia care opens the prospects of reducing the global burden of dementia worldwide and enabling novel opportunities to reengineer the lives of elderly people with dementia and maximize their wellbeing. However, with current adoption rates being reportedly low, the potential of IAT in dementia care risks to remain under-expressed or even misused if ethical considerations are not addressed. This article investigated the presence and prevalence of ethical values and considerations in current IATs for dementia. Our screening revealed that the vast majority of IATs are designed in the absence of explicit ethical values and considerations. This raises concerns about the current prevalence of value-sensitive approaches to IAT design, the level of ethical awareness of designers and the ethical sensitivity of current products. As the lack of ethically relevant considerations has often been described as a predictor of sub-optimal user acceptance (Ienca et al. 2017; Nestorov et al. 2014a; Wu et al. 2014), future IATs should incorporate more extensively such considerations in a cooperative and proactive manner. In addition, as issues of justice and equality as well as privacy and information security turn out to be the most ignored, more research is required to make future prototypes affordable and fairly accessible across all socioeconomic classes of users, as well as more secure and protective of users' information, in particular in the context of private and sensitive data. Additionally, in order to match public expectations, technology designs should rely

less on market-driven and inherently paternalistic approaches to product development and integrate factors and values that are considered relevant by end-users. This requires a transition to user-centered approaches to product development and more extensive needs-assessment research among end-users. Given the largely reported failure of top-down approaches to technology design in medical technology, user-centered and value-sensitive approaches should be prioritized.

As ethically designed and successfully implemented IATs open the prospects of improving the lives of people living with dementia, designers and developers have a moral obligation to incorporate ethical evaluations in their products and engage in a proactive debate with ethicists, clinicians, end-users and their caregivers. In this context, participation is critical for responsible development. At the same time, ethicists have a parallel obligation to being proactive instead of merely reactive. Instead of restricting their analysis solely on post-development evaluations of existing products, they should proactively cooperate with designers and developers in the responsible creation of new, ethically sustainable, products.

Compliance with Ethical Standards

Conflicts of interest The authors declare no conflict of interest.

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