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ORIGINAL ARTICLE

Who Cares? Moral Obligations in Formal and Informal Care Provision in the Light of ICT-Based Home Care

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Abstract An aging population is often taken to require a profound reorganization of the prevailing health care system. In particular, a more cost-effective care system is warranted and ICT-based home care is often considered a promising alternative. Modern health care devices admit a transfer of patients with rather complex care needs from institutions to the home care setting. With care recipients set up with health monitoring technologies at home, spouses and children are likely to become involved in the caring process and informal caregivers may have to assist kin-persons with advanced care needs by means of sophisticated technology. This paper investigates some of the ethical implications of a near-future shift from institutional care to technology-assisted home care and the subsequent impact on the care recipient and formal- and informal care providers.

Keywords Care provision · Caring kin-person · Filial responsibility · Formal care · Health monitoring · Informal care · Informal caregivers · Obligation to care · Surveillance

Introduction

Medical technology is increasingly adjusted to self-care [18] and in the near future, a significant part of health- and social care will be administered and distributed by means of sensors, cameras and robots, postponing the need for assisted-living facilities or nursing homes, enabling care provision in the care recipient's home [42]. A rich plethora of health monitoring devices for personal use have been developed in order to reduce individuals' dependence on institutional care and to facilitate medical and social care-provision in the home setting [26]. This is guided

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by the idea that aging populations require radically different and cheaper care systems. Health care planners typically promote home care as a low-cost alternative of comparable standard to institutional care. With an aging population home care is likely to be the trend, "every home becoming a hospital" [2].

A shift from institutionalized care to home care will have a significant impact on care providers and care recipients.[1] Technology assisted home care is typically launched as a form of care that better accommodates care recipients' preferences than the traditional care [2] and that promotes their independence [38]. Most likely, informal care providers i.e. non-professional care agents such as partners and relatives will become more involved in the caring process. Currently, informal care makes up a significant proportion of elderly care [54], dementia care and care of handicapped individuals. In the future, it is likely to include a broader range of care recipients such as post-stroke patients set up with monitoring device in order to recover at home. As of yet however, informal care providers' interests and needs are seldom mentioned in discussions about the future health care. Despite a mutual dependence between formal and informal care, the characteristics of informal care are poorly investigated [13] and the division of tasks and responsibilities is often insufficiently defined.

A transfer of care from specialized institutions into care recipients' homes raises legal, social and ethical issues. This paper attempts to discuss ethical implications of a near-future transfer to home care prompted by emerging health-monitoring technologies. By analyzing ethical implications of emerging technologies at an early stage, benefits and drawbacks can be identified before proliferation. Ways to avoid negative aspects and to promote positive uses of novel technology can also be suggested. Certainly, accurate and meaningful technological forecasts are difficult to make due to the complexity of the technology development process and the many factors influencing how technology is received and used in society [43]. Technologies can be used in unintended ways and influence human action unexpectedly. And, even if the technology is employed in the way the designer intended, it may still meet unforeseen use practices [58]. In this article, long-term predictions of future use and impact of specific technologies will be avoided. Rather, the ambition is to critically discuss a future technology-based home care as envisioned by health care planners in policy documents and health care plans and as marketed by technology developers. If technology would move into the homes of care recipients, who would the stakeholders be? What interests, rights and duties would they have? And, how should those interests, rights and duties be accommodated? With a growing ratio of home care, formal and informal care givers would have to collaborate why their roles and responsibilities should be made clear. Do kin-persons have moral obligations to provide care to relatives? What can health care professionals rightfully expect of them?

Section "Informal Care" analyzes ethical implications of the shift from institutionalized care to home care and the subsequent impact on informal care. Section "Is There a Moral Obligation to Care" investigates whether kin-persons—in

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[1] The technology discussed facilitates home care and can be used both by care recipients themselves (self care) and by formal and informal care providers offering care and assistance to the patient in his or her home. This paper focuses on the informal care providerś situation in light of ICT-based home care.

particular adult children—have a moral obligation to provide informal care. The fourth section concludes.

Informal Care

Informal care has been defined as “care given to dependent persons, such as sick or elderly persons, outside the framework of organized, paid, professional work” [41]. It is primarily provided in the homes of care recipients but may also be conducted by spouses and relatives to care recipients in assisted living facilities and other care institutions. Furthermore, it is said to be offered on a regular basis by people from the care recipient’s immediate environment by family members (family caregiving, caring kin-persons), friends, neighbours and in some cases, individuals without a previous relation to the care recipient (volunteer caregiving). Recipients of informal care are foremost elderly people and many of those supporting a frail elderly partner are frail elderly persons themselves with limited energy and strength to provide care [4, 21].

Currently 25% of European citizens take care of a dependent relative [2]. Care offered by informal care givers ranges from light instrumental support to rather advanced assistance [21]. Instrumental support covers help with day-to-day tasks like paperwork and domestic work such as cooking and cleaning but it also includes psychosocial- and emotional support. Examples of advanced assistance are support to individuals with complex care needs by means of sophisticated health care technology and assistance to persons suffering from dementia who may require continuous attendance [13, 40]. Studies in Finland, France and Sweden indicate that informal caregivers often serve as a link to the formal health care system and coordinate formal services, particularly for the growing number of elderly patients experiencing cognitive decline [13, 21]. A study conducted on the relation between formal and informal care in Finland show how elderly people who enjoy assistance from their children are more likely to receive formal care than those not receiving support from children since children help their elderly parents in applying for formal care. Likewise, a study conducted in France concludes that individuals with care needs living together with a spouse are more likely to receive formal care than those living alone [21]. However, it should be noted that there are great national differences in how home care is organized and carried out within Europe, reflecting country-specific health care programmes. In some countries, informal care makes up a complement to formal care, in other countries it serves as a substitute for formal domestic aid. An international comparison has showed informal care to be a substitute for formal care in Southern Europe, but not in Central European countries [21].[2] That is, a future shift to home care may look very different depending on underlying structures of health care.

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[2] Genet et al. [21] provide an overview of studies conducted on home care in Europe and conclude that the scientific literature available do not cover core aspects of home care. Likewise, informal care is poorly researched.

Home Care

Following demographic prognoses, by 2050 in Europe there will be two persons of traditional working age for every retired person compared to four per retired person today.[3] A decline in birth rates combined with an increase in life expectancy is taken to mean a decline in the ratio remunerated workers to retirees, leaving few individuals to pay for and support a large group of elderly people in need of assistance. Today, one in four of the EU population receives medical long-term treatment. With an ageing population this ratio is estimated to increase to one in two [2]. Population aging is said to be pervasive, enduring[4] and to have a profound impact on health care. Elderly people typically suffer from chronic diseases like diabetes and cardiovascular disorders. A growing number of individuals with advanced age is taken to mean that many will spend a longer period of their lives in poor health[5] suffering from age-related chronic diseases as well as cognitive-, and physical impairments [35]. In consequence, nursing, care and prevention of complications associated with chronic conditions are estimated to increase and a reorganization of the prevailing health care system is warranted to meet an augmenting need for health- and social services [27]. An aging population is taken to imply a radical increase in health care expenditures and to necessitate a change, not only in the health care system, but also in pension systems and other services for elderly people in order to avoid high public-sector spending. A frequently met rhetoric in debates regarding future welfare in general and health care planning in particular is that of the “old age crisis” or “demographic time-bomb”.[6]

Home care is typically considered a cost-effective answer to the demographic development in Europe [2] and several European countries stimulate the development of home care as a response to longevity and a growing care need [2, 21]. If health care recipients can be assured the same standard of care in their homes as in institutions they are taken to prefer home care over institutional care. A frequently expressed ambition is that future health care should combine the comfort of being at home with the security of institutionalized health care (cf. OECD Health Policy [39])[7] and that elderly people should be supported to continue living at home as long as possible [21]. Health care planners and policy makers typically consider Information and Communication Technologies promising means to enable home care and independent living. Online medical consultations and portable care devices are promoted by the European Commission with the aim to achieve widespread deployment of telemedicine services by 2020 (EU e-Health Action Plan, 2004, [2]).[8]

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[3] The Future of Retirement: The New Old Age, HSBC and the Oxford Institute of Ageing, 2007, 2006, 2005, http://www.hsbc.com/1/2/retirement/future-of-retirement.

[4] UN Report World Population Aging 1950–2050 http://www.un.org/esa/population/publications/worldageing19502050/.

[5] EC Demography Report, 2008, World Population Prospects—The Revision 2008, UN, [57] http://www.oecd.org/dataoecd/20/23/2431724.pdf.

[6] http://ftp.jrc.es/EURdoc/eur22352en.pdf.

[7] http://www.oecd.org/document/61/0,3746,en_2649_33929_45501565_1_1_1_1,00.html.

[8] http://www.epha.org/IMG/pdf/e-health_action_plan.pdf.

In web advertisements, technology developers market personalized health-monitoring technologies enabling individuals in need of health and social care to receive support at home and to remain independent [38] or at least minimally dependent on institutionalized care [8].

Importantly, the assumptions made regarding the demographic development and effects of population aging have been questioned [19, 20, 23, 33, 34]. Aging is a complicated interaction of genetics, physiology and behavior and the effects of longevity are equally complex and difficult to predict [1]. Despite the complexity of demographic prognoses, present trends are typically taken to continue and demographic projections are often considered in isolation, neglecting relevant factors. Certainly, health expenditures tend to increase with age and are primarily concentrated to the later years of life. Nevertheless, high living standards and the advancement of medical science are reasons why individuals live longer. Future advancements within medicine may very well improve the health conditions of individuals of advanced age, not only extend the period when elderly people are in need of care resources but gradually postpone their need of qualified medication and support. In consequence, individuals may work and contribute to the economy for a longer period of time. Hence, the pertinent question seems to be whether people will age in good or poor health. In the following, the accuracy of the prognosis will not be further discussed. Rather, the implications of one of remedies suggested—a turn to home care—will be in focus.

Technology-assisted Home Care

Medical and technological developments are said to enable the execution of health care outside hospitals and nursing homes, especially providing treatment to patients with chronic illnesses. And, ICT-based care devices, it is argued, can make health care more flexible, mobile and less dependent on traditional care units and the active involvement of health care professionals. For example, medical treatments that traditionally have been provided in hospitals exclusively can now be offered to care recipients in their homes by means of personalized health monitoring technology [18]. Depending on individual care needs, the type of home service offered will vary and so will the constellation of care providers—formal and/or informal. In the following, three broad categories of care recipients will be discussed and examples of the care services that may be provided in an ICT-based home care system will be given. Many of the technologies discussed are currently at an early stage of implementation. For each of the categories, the potential impact on formal and informal care providers' role will be mentioned. The three categories are; (1) individuals with light care needs (2) individuals with a complex but temporary care needs and (3) individuals with constant and extensive care needs.

Individuals with Light Care Needs (Temporary/constant)

Individuals with light physical- and/or cognitive impairments in need of practical assistance and/or health monitoring may receive ICT-based support and health monitoring at home, ranging from the rudimentary to the sophisticated. Although not fully implemented in home care yet, assistive technologies that can help care recipients with domestic services, facilitate communication as well as serve as alarm functions are under development and tested in living labs. For instance, assistive robots are developed to support care recipients in daily tasks, with heavy lifts, movements and navigation [5, 7]. Easy-to-use interactive communication devices are launched as means to break the social isolation that individuals with reduced mobility often suffer from. Robot "Giraff"—is a mobile interactive communication device, described as "Skype on wheels", helping the user to stay in touch with his or her health care provider as well as social network. When someone is calling or if the user wishes to call, the robot approaches the care recipient rather than the other way around [42]. Different types of memory support and alarm functions have been developed to assist individuals with mild dementia. Low-tech health monitoring devices like smart-pill boxes, distributing the correct does of medicine and reminding the user when it is time to take medicine can help individuals with light dementia to conduct self-medication [42]. By means of different types of monitoring systems, formal care providers can follow up clients' health and activity status continuously at a distance. Wearable sensors offer continuous health status up-dates irrespective of the care recipient's location. For instance, sensors integrated in watches and clothes (cf. [25]) will enable individuals to measure vital signs and keep track of their health status on their own. Access to continuously updated health data enables health-care professionals to offer well-founded diagnoses, identify deviance in health parameters at an early stage, suggest treatments and follow up their patients at a distance [52].[9] Moreover, sensor-based systems and devices admit remote attendance. Integrated in care recipients' living environments, micro-sensors paired with alarm functions can record, store and transfer information about their daily activities to a care unit e.g. when care recipients raise from bed, enter certain rooms, open windows or the refrigerator etc. The system can be programmed to notify home help service providers in case of a certain period of inactivity in order for them to pay the care recipient a visit to make sure that he or she is alright. Likewise night-vision cameras implemented in the bedrooms of recipients of home-help service allow home helpers to conduct virtual check-ups during the night without paying their clients physical visits [42]. Certainly, technologies are developed to provide both instrumental support and continuous health check-ups but all needs cannot be accommodated by novel technologies. Care recipients with cognitive impairments will still be in need of intermittent help with domestic chores such as cleaning, laundry and grocery shopping. However, these technologies can reduce the need for direct physical attendance by formal care providers and yet prolong the time that individuals with limited care needs can live on their own, postponing their need for more elaborate care in e.g. an assisted living environment.

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[9] Furthermore, health-related data can be transferred electronically to informal- as well as to formal care providers. Electronic health up-dates may not only improve the quality of diagnoses and the security of care recipients but also be of great comfort to relatives living at a distance from an elderly person in need of attendance.

Individuals with a Complex but Temporary Care Need

Advancements within laparoscopic surgery combined with developments in distance monitoring have shortened the time that patients must spend in hospital after surgery and hence reduced the number of in-patients significantly [48]. One decade ago, patients were hospitalized for at least one week after invasive surgery of this kind. Today, they may leave hospital shortly after a successful key-hole surgery to receive post-surgery treatment at home. Likewise, robotized rehabilitation programs are offered to help post-stroke patients recovering at home instead of them having to visit rehab-specialists [5, 7]. That is, with the advancement of rehab and monitoring devices, post-stroke patients may, after the acute phase of stroke care, be offered certain treatment in a home setting. In short, novel health care technology allows for individuals with rather advanced care needs to be treated at home. Post-stroke patients may have complex care needs but are not necessarily in need of care for an extended period of time. In this type of care, the patient and the patient's family are essential members of the rehabilitation team together with formal care providers [12]. Importantly though, even if self-medication, self-reporting and rehab in combination with remote health monitoring may reduce care recipients' dependence on formal care providers, their dependence on additional support from informal care providers may increase. Informal care providers may have to engage in care provision in addition to the household tasks that previously was shared with the spouse/partner.

Individuals with Constant and Extensive Care Needs

Individuals suffering from life-limiting illnesses typically have extensive care needs. Novel technologies allow for them to be treated in their homes. Many of the technical devices previously used in acute care have been simplified and can now be used in home care. Likewise, various ICT-based monitoring systems enable distance control of individuals with rather complex care needs. Before individuals in need of assisted ventilation for respiration were treated in hospitals but are now, to a large extent, receiving care in their homes [18]. This patient group requires continuous support by means of high-tech devices [18, 44]. Advanced care technology developed for domestic use may engage informal care providers in more demanding forms of care then earlier. Cohabitants may be required to carry out medical and technical tasks such as operating and maintaining equipment e.g. oxygen-, respirator- and dialysis technology [18]. Technology assisted respiration is a clear example of assistance that previously has been conducted by skilled care professionals [13, 18].

Elderly people, who earlier were cared for in hospitals, nursing homes and assisted living facilities, can now being discharged to home care with rather extensive care needs. Monitoring systems utilizing infrared sensors, webcams and radio frequency identification are used to control individuals suffering from dementia in need of attendance [26]. As in the case above, this category of out-patients may need quite a lot of assistance from their spouses, partners and relatives. In case of elderly people with extensive care needs, the spouses or partners may well be frail elderly people with limited capacity to provide care.

As can be seen from this brief overview of technology-based home care, in some cases ICT-solutions enable home care and in some cases they facilitate already existing home care e.g. as carried out by district nurses. By offering personalized health monitoring, care recipients' need to visit care institutions or be visited by care professionals may be reduced. Most likely though, a growing ratio of elderly people treated in their homes will increase the need for support from families to dependent seniors. This development motivates a focus on the conditions for kin-persons to provide care.[10]

The Conditions for Informal Care Providers

Little research has been conducted on informal care provision in Europe [21]. From the articles and reports available on informal care provision in care recipients' homes however, two main risks related to informal care and informal care givers can be extracted; stress and social isolation. That is, out of the few articles on informal caregiving, a relatively large ratio report high levels of stress among informal caregivers.

A disease and a concomitant need for care can alter the structure of the family fundamentally. Roles may be reversed when children become the care providers for their parents [36] and spouses become "nurses". At times, children and spouses are forced into unwanted roles [45]. They often feel unprepared to perform certain tasks such as providing intimate care [31] and receive little or no preparation for the caregiving role [36]. In particular this is true about spouses and partners. Family caregivers may assist a partner or relative in addition to remunerated work and face difficulties combining care with work and hobbies. Informal caregivers involved in long-term care often give up their hobbies, social activities and vacations. Social isolation in combination with the at times demanding task of providing care to a relative or partner implies a risk for burn-out [2].

Stress has been recognized as one of the leading causes of chronic health conditions [6]. Work-related stress is prevalent among health care providers and often tied to a heavy workload, unclear work assignments as well as to the emotional costs of caring [32]. Informal caregivers are also vulnerable to stress, depression and isolation due to the time- and energy consuming work of providing care to a partner or relative (cf. [28, 49], [9, 50]). Main causes of stress are: caregivers limited freedom of choice with regard to caregiving and the amount and duration of care [6]. As noted above, informal care givers may face many different types of care needs ranging from a limited need for assistance to rather complex and time consuming care needs. Care provision can be physically as well as emotionally

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[10] Importantly, "home care", "formal care" and "informal care" are notions that are used in many different ways without clear demarcation-lines that causes confusion, not the least in relation to responsibility ascriptions. As understood here, "home care" may include but is not equivalent to home help service (HHS). Home Help Service is provided in order to assist individuals in need of support to remain in their own homes and to avoid institutionalized long-term care. Emerging home care includes HHS, medical care and long-term care. Long-term care exceeds medical care and nursing care and includes assistance with long-term disabilities and chronic illness. Here, home care serves as an umbrella term for the many different types of care that are provided in the home care setting by means of ICT-devices. In below, it is primarily family care that will be discussed under informal care.

burdensome. Generally, the more time consuming, the heavier the care task is perceived. For co-habitants, caregiving may be a 24 h 7 days a week assignment. Informal dementia care is typically a long-term commitment with a strong impact on the psychological, physical and social wellbeing of carers. Partners and relatives providing care to individuals suffering from dementia often struggle with social isolation (cf. [9, 50]). Studies have also shown that informal caregivers often experience insecurity and doubt that the care they provide is properly conducted and sufficient [3].

Social isolation and excessive stress are worrisome for several reasons. Such conditions can lead to physical and psychological problems among informal care providers resulting in burn-outs and/or abusive care with harmful consequences such as maltreatment and neglect of the care recipient. The latter is said to be particularly common within informal dementia care. Studies on care professionals' experiences of maltreatment and abusive care among informal caregivers indicate that in cases of abuse, informal carers have not had the chance to freely choose the care giving role, rather they have seen care giving as their duty [3].

Traditionally, informal care providers have not been performing nursing tasks. An increased technologization of home care however implies that care recipients are offered sophisticated technical support at home. It may also imply that informal caregivers and kin-persons assisting individuals with extensive care needs are asked to operate such care technology.

Recent studies indicate that in cases where this type of care has been introduced in patients' homes, cohabitants have not always been asked whether they are willing to contribute assisting their partners or spouses by means of the technological devices, or how they feel about the technology being implemented in their homes [18]. Although it is recognized that those who are to use advanced technological device in home care must get proper training their emotional needs are seldom noticed [18, 48]. Arguably, a responsibility to assist a partner or relative by means of sophisticated technology may add to the often already stressful situation of providing care to individuals with extensive care needs.

One aspect that may be perceived as stressful, both to the informal care provider and the care recipient, is if home-care technology is reliable in the hands of non-experts [48]. Uncertainty whether the technology has been handled properly or not may generate stress. Without proper training, caring kin-persons may use healthcare equipment in ways perhaps difficult for technology developers and formal care providers to apprehend. Diagnostic errors due to incorrectly measured/reported health data should perhaps be calculated with and safety-measures developed. And, the extent to which the technology can be trusted in reading and interpreting signs correctly/sufficiently merits discussion. Moreover, the division of tasks and responsibilities becoming care recipient, care provider (formal/informal), technology developer, system-provider (and others) respectively must be made clear. But most importantly from an ethical perspective, to what extent can informal care providers be expected to provide care to a parent, spouse or cohabitant?

Is There a Moral Obligation to Care?

An increase in ICT-based home care may to a larger extent then previously involve kin-persons in non-remunerated care work—a development that may conflict with a highly individualistic life-style characteristic of the Western societies where the freedom to pursuit personal life goals is imperative. To what extent then, if at all, can adult children, spouses, partners and co-habitants be morally obligated to provide care?

Married persons have promised to stand by each other "until death do them part"—a promise that carries both legal and ethical obligations. They have promised to commit themselves to take care of each other even in the most challenging of situations. Thus, spouses are bound by certain legal rights and obligations, among them a duty to provide each other reasonable maintenance. Those obligations also hold for civic partners but are not applicable to non-married co-habitants. Hence, from a legal perspective, non-married co-habitants cannot be required to provide maintenance or assistance. Unless co-habitants have explicitly promised to stay by each others side, offering help and support when needed, they cannot be ethically obligated to do so. Choosing to live together with someone is not reason enough to motivate an obligation to care. And, even if spouses and civic partners have promised each other, among other things, support, there may still be reason to ask: within what limits? To what extent should one be morally expected to assist a needy spouse, partner or co-habitant? Here it will be suggested that, as with all rights, a person's rights and liberties are always conditioned by the corresponding rights and liberties of other individuals. One person cannot exercise his or her rights in a way that others are prevented from or significantly restrained in utilizing theirs. In the case of care provision to a needy spouse or partner this would mean that a spouse/partner can be expected to provide care only in so far as he or she also can live a sound life, in accordance with her plans and ideals. Most importantly, an individual should not be expected to sacrifice his or her own well-being in order to accommodate the needs of a spouse, partner or co-habitant.

In the case of children who have not chosen the relation to a set of parents, the responsibility to provide care is even less straightforward. Nevertheless, many nations and states, both in the Western and Eastern parts of the world, have rules and statutes that define filial responsibility requiring adult children responsible to financially support their parents in case they cannot provide for themselves [46, 59] although in the West such laws often are controversial and hard to enforce [46]. Under Chinese Marriage Law, adult children's are legally obliged to care for their aged parents: "Children have an obligation to support and to assist their parents….. When children fail in such duty, parents who cannot work or have difficulty with their living have a right to demand alimony from their children" [59]. Filial responsibility laws are based on a moral duty between parents and children. Since parents provide basic necessities for their children, children are said to have a reciprocal moral duty to provide for their parents when they require assistance.

But let us consider the reciprocity argument underlying filial responsibility laws from an ethical perspective. A symmetric responsibility relation is said to hold between parents and children. Since parents have provided for their children while in need of support, children should respond to the needs of their elderly parents in a similar way. Gratitude and respect can serve as keys to understand the idea of reciprocity. Bringing children to the world and raising them entails a lot of effort. Out of gratitude and respect, it may be argued, adult children owe their elderly parents the support that they themselves have enjoyed.

Filial responsibility as based on reciprocity has been rejected by several scholars though (cf. [11, 14]). A common objection is that the relation parent—child is asymmetric and hence, that a filial obligation to care cannot follow. In most cases, parents chose, or can chose to, have children and with this choice, it is argued, comes as certain obligation to meet the needs that children typically have. Children however, have not decided to have parents and hence, some argue, they should not be obliged to take on a responsibility towards their parents. Following Norman Daniels [11], adult children are not morally obliged to support their elderly parents—at least they are not more responsible for the support of their parents than for any other needy person. Neither does the (genetic or social) parent—child relation entail any particular moral obligations, nor does the level of support and sacrifice that parents have made on behalf of their children matter. Whereas parenthood is a self-imposed obligation, children have not asked to be born or to be adopted and hence, there is a "basic asymmetry between parental and the filial obligations" [11]. Likewise, the idea of a "filial debt" has been rejected. Children cannot even be expected to be grateful for support provided by their parents since they have not asked for it (cf. [14]). Yet there may be other reasons for children to assist their parents. They may for instance be motivated to do so out of love for their parents. A care system relying on filial responsibility however, would unjustly restrict some individuals' (adult children) opportunities and circumscribe their freedom to pursuit their personal life-plans [11].

Within Confucian ethics, Daniels' position has provoked several objections [30, 47, 59]. Quingjie Wang opposes the idea that a moral obligation necessarily presupposes a capacity to choose. Children have a duty to care for their parents even if they have not chosen to be a son or daughter [59]. Wang distinguishes between two different types of moral obligations: a contract-based moral obligation and a natural community-based moral duty [59]. A moral responsibility stem from an autonomous moral agent's informed consent. However, a human being is not only an autonomous moral agent but also a social and communal being and as such he or she has duties to care for others and for the environment. An adult child's filial obligation to take care of their aged parents belongs to the category of moral duty, which is existential rather than consensual. The family, which defines the adult children's filial obligation to their aged parents, is a natural community rather than a social contractarian community [59]. And, in contrast to Norman Daniels, Robert E. Goodin [22] argues that adult children have particular moral obligations to their parents over strangers because they are in a unique position to recognize the vulnerability and needs of their parents and to provide the support that they need. Adult children have special responsibilities towards their parents "precisely because their parents are most vulnerable to them; and the most important component of their vulnerability is emotional rather than material" [22]. Children are, it is assumed, better equipped to recognize and accommodate the needs of their parents than of strangers. In a situation where an elderly parent is in need of assistance, parents would be more vulnerable to their children than what they would be to other people. Hence, adult children have a stronger responsibility to care for their parents than for strangers. However, this responsibility is neither exclusive nor absolute.

In order for a "need-based argument" of the type Goodin defends to be more convincing, a clarification of the specific nature of the parent—child relation has been warranted as well as an explanation of "why adult children would have a larger than average responsibility to satisfy needs of their elderly parents" [53]. Rather than saliency, it has been suggested that emotional closeness, a shared history or other ties are what binds the adult child to the elderly parent in a morally relevant way. The relation child–parent is said to be of a special kind, different from friendship and companionship, and intrinsically valuable [53]. And more specifically, it has been described as "concrete, intimate and long-lasting" determining obligations in a way that few other relationships do [51]. Whereas many scholars have assumed that a filial responsibility requires of adult children to care for their elderly parents in the way themselves have been cared for, others understand filial duties as asking adult children to be "grateful, loyal, attentive and deferential to parents (more than to strangers)" [51]. Following Maria Stuifbergen and Johannes van Delden, parents and children have a mutual responsibility to maintain their relationship e.g. by keeping contact. Adult children should try as far as possible to be sensitive about the parents' needs but they have no duty to provide financial support or to take on demanding care tasks. Care provision should not be assigned to adult children but to public services [53].

Similarly, Nel Noddings [37] focuses on the *de facto* relation between informal care providers and care recipients and argues that a history of abuse within the family must be taken into consideration before asking or expecting a person to care for a parent. A child who has been subjected to abuse by a parent should reasonably not be asked to respond lovingly and caringly to the need of a father or mother. That is, when assessing an individual's capacity to care, family bonds should not be decisive. Rather, the crucial point is what the potential care provider and care recipient mean to each other. "If the question of what they mean to each other is answered in terms of fear, anger, resentment, disgust, or contempt, home care should probably be discouraged" [37].

In most cases however, children have been brought up by loving and caring parents, and parents' needs have a certain moral force that motivates adult children to support them [53]. If the parent–child relation is well-working, the child may, as Goodin argues, be ideally suited to recognize the needs of the parents and see how those needs best can be met. But contrary to Goodin's reasoning, here it will not be concluded that children thereby should be responsible for the practical execution of their parents' care. A child may utilize this particular understanding for the parents' needs to arrange care in their interest but should not be expected to *de facto* accommodate identified needs and to undertake extensive care provision. Most importantly, an elderly parents' care needs should not necessarily trump the needs of an adult child. Adult children often have families on their own, hence they are in a situation where they must provide care for their own children. In addition, they may well be required to meet various obligations in worklife and social life.

Thus, the needs of elderly partents must be balanced against the needs of the adult children. Importantly, care provision may have many facets. Children may help their elderly parents significantly by *coordinating* care corresponding to the parents' interests and care needs and by following up the execution of care. When needed, children can act as a link between professional care providers and the care recipient, look after the parents' interests and make claims on behalf of them. Certainly, many children wish to engage in *de facto* care provision but they should not be obligated to do so.

Noddings suggests a distinction between ethical care i.e. an individual moral obligation to care and natural care i.e. an individual's personal motivation to provide care [37]. When structuring a care system, the assumption should be that individuals who have received care are inclined to provide care themselves. The health care system should be organized so as to promote and provide good conditions for individuals to act on this natural inclination and express natural care rather than legally enforce a responsibility to ethical care. Furthermore, individuals' capacities to assist and provide care should be duly recognized. Depending on a variety of factors such as underlying personal relations, health- and economic status, social network etc., individuals are more or less capable of providing care. Following Noddings, informal care providers cannot be obliged to provide care based on family relations. Nevertheless, society should pay attention to and as far as possible, facilitate the conditions for the growing number of informal caregivers [37].

Reasonable Conditions for Informal Care Provision

How Then can Informal Care be Facilitated?

Many studies focus on informal care providers "care burden", less on caregiver stress and ways of alleviating stress and informal caregivers' perceived need of support and respite care have not been sufficiently investigated [15]. Whereas parents typically receive a certain support during the period of child rearing e.g. parental leave and access to kindergarten, few support mechanisms are in place to alleviate adult children caring for their elderly parents. Although support systems like social networks for informal caregivers and respite care have been established, those are seldom framed as rights becoming informal care providers. Considering the risk of health-related problems and burn-outs, measures to alleviate the burden of caregiving for informal caregivers should be undertaken.

Importantly, informal care providers deserve both technical and emotional support. They need training and monitoring—in particular when it comes to the management of novel, sophisticated health-care technology. With monitoring device in the care recipient's home, informal caregivers will participate in the care provision of relatives and spouses and the interdependence between formal and informal care will increase. Informal care providers need the advice, guidance and skills of health care professionals and formal care providers can gain from family caregivers' deeper understanding for the care recipient and may benefit from good communication regarding e.g. distribution of tasks and responsibilities and from knowledge-sharing. "Formal and informal care complement and sometimes even replace each other" [13]. Importantly, the responsibilities and expectations of formal- and informal care providers respectively must be made clear to both parties.

Informal care providers' general life situation must be recognized and their rights and responsibilities merit further articulation. Those responsible for the planning of health care and health care professionals should pay attention to family caregiver's ability to cope and offer sufficient supervision and support e.g. to their physical and psychological health. Formal care providers should also make clear whether an informal caregiver is the only or main source of assistance for a care recipient or part of a larger network, taking turns and sharing. Care givers attitudes toward the particular tasks that must be done should also be discussed. "Sometimes a caregiver can cope with difficult technical tasks but dreads some particular part of the daily routine" [37]. Formal care providers must bear the responsibility to assess informal care providers' capacity and delimit a reasonable workload with respect to the informal care provider's overall situation. Furthermore, informal caregivers have dual roles. They serve as care partners with professional care providers and are also partner/parent/child of the care recipient, representing the care recipient's preferences and mitigating care. Professional care providers must be sensitive to and respect informal caregivers' different roles and capacities.

Today, informal care is an indispensable yet not adequately recognized part of elderly and dementia care. Unfortunately, informal caregiving is typically considered a voluntary activity (cf. [15, 16, 29]) beyond the question of remuneration and support. However, informal care providers' input must not be taken for granted and their active involvement in care provision should not be taken as a tacit consent to provide care over time. Family caregivers often enter this role without a clear understanding of what the caring role requires of them and the ways in which it will change their lives. It can impose difficult personal care tasks and care of long duration without outside help. Care work may grow in intensity over time [55]. Hence, informal care providers should have the possibility to express their opinion about the caring conditions, be able to accept or reject work assignments and have the chance to opt out when unduly burdened. An agreement to provide informal care should be understood as an open-ended contract without specified content or duration and consent should be viewed as an on-going process. And, even if informal carers may wish to put in as much as possible of their time and energy in support of a loved one, the case has been made that certain burdens are beyond the acceptable and that informal carers may "at times deserve to be alleviated of them selves" [56].

Conclusion

Home-based care is not a novel phenomenon. To the contrary, viewed from a historical perspective, health care has often been delivered in the home of the patient. A technologization and specialization of medical science and health care in the nineteenth century centralized care provision to hospitals. Today, an increased technologization of care instigates yet another shift—back to home care. It should be noted however, that even before this shift, a significant part of care has been carried out in the homes of elderly and handicapped patients. Modern health care technologies facilitate the type of care that has been conducted by district nurses and home-helpers as well as by family caregivers. They enable a broader set of care-services to be conducted in the homes of care recipients than what previously have been possible, allowing (1) health care professionals to follow up their patients' health conditions at a distance (2) home care providers to conduct remote attendance (3) care recipients to manage their own health and (4) cohabitants and relatives to give advanced assistance to care recipients in their homes. A novel aspect is that technologies to a larger extent admit patients with rather complex are needs to receive treatment at home. ICT-based health monitoring systems can prolong the time elderly or handicapped persons can remain at home, support them in day-to-day care and allow them to function rather independently. Home care may be beneficial in terms of comfort, flexibility and, to some extent, in terms of independence. Certainly, monitoring technologies can offer recipients the comfort and freedom of living at home, going on with their ordinary lives as far as possible, despite a care need. With assistive technologies implemented in the homes of care recipients, the need for physical visits by health care professionals may be reduced. However, even if the shift of care (more or less advanced) to the domestic realm may reduce the care recipients' dependence on formal care providers, it may increase their dependence on informal care providers.

A shift from institutional care to home care will, to a greater extent, involve kin-persons in the care process. Several studies claim that care provision, informal as well as formal, is perceived as stressful by care providers. At times, informal care providers become patients themselves with psychological or physical health problems. Informal care providers also risk becoming socially isolated while tending kin-persons. Stress, lack of expertise and fatigue are factors that may influence the quality of care negatively. As of yet however, the situation of informal care providers is poorly researched and the relation between formal and informal care providers are seldom clearly explicated. Responsibility and liability issues must be properly adjusted to the shift from institutionalized- to home care and informal care providers' needs must be recognized and accommodated.

Unfortunately, informal caregiving is often considered a freely chosen activity and a personal matter between caregiver and care recipient. However, informal caregivers' input should not necessarily be understood as voluntary and most importantly—not be taken for granted. Adult children have a certain duty to consider the needs of their parents due to the emotional bonds—that for the most—hold between them. Children can be expected to look ensure that their elderly parents receive the care that they need, but not to carry out the care needed. As far as possible, adult children should keep in touch and look after their interests. And although spouses have promised life-long loyalty and support, constant caregiving may drain the informal caregiver of energy, eventually causing burn-out. Both spouses and civil-partners have legal obligations to provide maintenance. Nevertheless, they should not be expected to provide care to a cost so high that they cannot live decent lives themselves. However, adult children, spouses, civil-partners and co-habitants often wish to support a loved person in need of assistance as far as they can. In those cases, the conditions for care giving should be facilitated.

A failure to accommodate the needs of informal care-givers may result in abusive care and a risk of mistreatment of care recipients. By carefully assessing an informal caregiver's capacity, by supervising and coaching on a practical- and emotional level, the situation of care recipient as well as care provider can be improved. Formal care providers should not only communicate care plans with care recipients but with informal caregivers. Comprehensive information, education and training are crucial but access to social networking and relief should also be offered. Furthermore, formal care providers should differentiate and delineate reasonable work assignments acceptable to informal caregivers. Boundaries should be drawn between care professionals and informal carers' responsibilities. And the latter should have a right to place limits on their availability to the care recipient. In so way, stress can be prevented and the health care system can be protected from unnecessary strain [24]. Furthermore, home care is not necessarily the best solution for all persons, types of health problems or stages of a disease. It should be used only after a careful impact assessment, not as default.

Even if the time-bomb scenario would be an accurate prediction, it is not necessarily so that home care is a more cost effective form of care than what the traditional care is—at least not, all relevant aspects considered. Little evidence exist that the shift of care locus—broadly considered—is economically beneficial [44]. Arguably, informal care implies several costs that seldom are considered in health- and social policy discussions. Examples of hidden costs are foregone employment opportunities, unpaid labor and emotional, physical and social well-being costs [10, 17]. If costs beyond the public sector were considered and if informal care givers' needs for alleviation and support, perhaps even financial remuneration, were properly recognized and accommodated, technology-based home care would no longer be considered as a low-cost alternative and promoted as the care of the future. Hereby a careful consideration of the costs—ethical as well as economical—attached to technology-based home care is warranted!

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