
Advanced home care technology: moral questions associated with an ethical ideal

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Advanced home care technology: moral questions associated with an ethical ideal

Health Council of the Netherlands

Centre for Ethics and Health

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Centre for Ethics and Health

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The CEG's annual 'Ethics and Health Monitoring Report' (in Dutch) provides a compilation of these alerts. In June 2004, the second of these monitoring reports was presented to the State Secretary of Health. It contains alerts on seven topics, including the one on Advanced home care technology presented here in translation.

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This report

This report has been drawn up by the Health Council's Standing Committee on Medical Ethics and Health Law (see Appendix 1 for composition). A parallel report was drawn up by the Council for Public Health and Health Care (Council for Public Health 2004).

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Summary

Patients suffering from a range of severe and less severe conditions are increasingly being treated at home using ever more sophisticated medical technology. Some examples of this trend, which is expected to continue, include intravenous treatment of infections, haemodialysis, respiratory support and telemonitoring. The trend has some clear benefits, but also raises ethical questions. This report investigates the main points at issue. The principal topics are the assignment of responsibilities, the quality of care, the possible stress on other members of the household or relatives called on to fulfil the demanding role of carers, and the possibility that the very availability of technology that can be used in a domestic setting will encourage its use even in circumstances where there may be little medical benefit.

Advanced home care technology: moral questions associated with an ethical ideal

1 Introduction

The home care technology programme carried out from 1999 to 2005 by ZonMw, the Netherlands Organisation for Health Research and Development, predicted an increase in almost all forms of home care technology.¹ An important factor in this was that this development would allow more people with a severe medical condition to stay at home. This would in many cases result in an improvement of the level of care and quality of life (Van Kammen 2002). The development of advanced home care technology responds to the wish of very many sick people to remain at home wherever possible. This does not detract from the fact that the increasing use of home care technology also throws up ethical questions (for example, the assignment of responsibilities between healthcare professionals and relatives, the change in 'the home', and access to care). The main impetus behind this report are indications from the field that, despite all the obvious benefits of transferring technological care to a domestic setting, there is a lack of clarity as to who is responsible for ensuring that the technology works properly (for example, when non-professionals [relatives] are asked to perform risky actions such as draining the trachea cannula of a patient receiving artificial ventilation) (Kooijmans 1999). In the case of some forms of sophisticated technology, there is also some concern that the availability of a 'domestic' version may lead to an increasing demand for its use, even when this is not regarded as medically rational.

Providing nursing care at home to a seriously ill patient who is dependent on technology often places great demands on relatives, particularly when this continues for an extended period. A recent Australian review of the effects of caring for technology-dependent children on their families found that insufficient support from professional home carers can lead to delays in discharge from hospital, social isolation of the family, and problems in accessing respite care or short-term admission (Wang 2004).

1 www.zonmw.nl

There are also questions as to the limits of medical options, such as whether or not to continue with a course of treatment that has been introduced, that are transferred from the hospital along with the care to the home setting. These questions touch on the policy of the government, insurance companies and medical professionals to discharge patients from hospital sooner than before and to treat them at home more often than before. They have become pressing as a result of the increase in the number of people who have become dependent on medical technology at home and the increasing degree of intensity and sophistication of the employed technologies. This is the reason for this report and for the parallel report drawn up by the Council for Public Health and Health Care (Council for Public Health 2004).

A constant theme running through this report is the principle that transferring technology from the hospital to the home is (or should be) associated with the transfer or creation of the social network needed to allow the technology (ventilation machine, infusion pump, etc.) to work. This network can itself be dependant on technology (the Internet, phone lines etc.) to operate, but is itself made up of people (relatives, friends, volunteers and healthcare professionals).

The assignment of responsibilities is a crucial feature of networks such as this, and we devote much of this report to this issue. The term 'responsibility' has several meanings, all of which are relevant here. First, there is the responsibility for carrying out specific tasks (task responsibility). Second, often in a more legal sense, there is liability for mistakes in, for example, the use of home care technology. Third, there is the situation where one person is dependent on another (parents are in this way responsible for the welfare and woes of their children).

When considering whether transferring a technology from the hospital to the home setting is desirable and responsible, the issue of transferring and altering the technology's 'habitat' also needs to be considered. Is it possible to transfer the machine and all its peripheral devices to a domestic setting, and what are the consequences for the 'home' when this is done? What requirements does this place on the physical environment and on the willingness of the patient's friends and relatives to take on the associated responsibilities? What new 'collective' (Callon 2002) is created when sophisticated medical technology enters the patient's living quarters?

This report looks at sophisticated, or high-tech, technology. It is difficult to draw an exact demarcation line between high-tech and low-tech technology. Sophisticated technology (as the term is used in this report) should be understood as describing technology that has a complex structure, that places high demands and that has a significant impact on the user's social network, that demands specific skills on the part of its operators and that can, if a mistake is made, have important consequences for the patient's health. This definition covers techniques such as home dialysis, home infusion treatment and telecare, but not clinical thermometers, devices to help people put on support stockings or self-monitoring using a peak flow meter. The definition is not watertight, but meets the objectives of this report, which are to describe the ethical questions and problems associated with home care technology.

The field of high-tech home care technology is extensive and heterogeneous. This report will concentrate on a number of features that are common to all sophisticated medical technologies used in the home and that should provide an impetus to closer ethical investigation.

We need to distinguish between two main forms of home care technology: 1. monitoring techniques (including telecare) and 2. treatment techniques, including support for bodily functions. We will try to set out the current ethical issues surrounding both categories (monitoring and treatment) and to indicate those that may result from possible future developments.

The ethical issues considered in this report relate, among other things, to the requirements that the quality of the technology itself should meet and the requirements with regard to professional support for non-professional carers. Another issue to be discussed is continuing to give the patient the real option to decide to be treated in an institution instead of at home. In some of the forms of domestic technology we will consider, there is a debate as to whether the technology should be made available at all, and on the role that the possibility of transferring it to a domestic setting plays in this context. Increasing availability of home use should have important consequences for this question.

The development we are discussing in this report also gives rise to legal issues, including the assignment of responsibilities. We will only touch in passing on these legal issues, concentrating more on the ethical aspects of the use of sophisticated domestic technology.

A number of examples are presented in the report to serve as illustrations. The selection of examples was based on the following criteria. First, there had to be at least some literature describing the efficacy, feasibility and ethical issues. Second, we had to discuss examples of home care technology used in the case of children, as this can raise particular ethical questions. That is why we look at intravenous antibiotic treatment for children with cystic fibrosis (CF), artificial ventilation for children with spinal muscular atrophy (SMA) and total parenteral nutrition (TPN) for children with severe congenital intestinal abnormalities. Third, we wanted to find examples of monitoring, treatment and support of bodily functions.

2 Overview: sophisticated medical technology at home

The transfer of medical technology from the hospital to the home is not a recent development. One of the first examples of 'home care technology', which can hardly now be regarded as sophisticated, was the use of the clinical thermometer. At the end of the 19th century a fierce debate raged in medical journals as to the use of this device by patients and their families. Some doctors thought that it would be irresponsible to allow patients themselves to undertake such a difficult task as taking a temperature, leaving it to them to decide about whether or not to take further action and call a doctor (Wieringa 2004). But others applauded the development, thinking that the use of the thermometer might reduce the number of unnecessary home visits. The arguments put forward at the end of the nineteenth century regarding what we would regard

as a trivial form of home care technology now also have an important place in the debate on safety, responsibility and competencies.

More sophisticated forms of home care technology also have a longer history. For example, patients with severe COPD have been able to have oxygen administered at home since the 1950s (Petty 1996). Parenteral nutrition and artificial ventilation have been possible in a domestic setting since the late 1960s (Richards 1997).

The development of home care technology has come about for a variety of reasons. First, patients often wish to stay at home for as much and as long as possible even if they are suffering from a severe, or even life-threatening, disease.

Second, there is a political preference, wherever possible, for self-care and non-professional care (Ministry of Health, Welfare and Sport 2001, Thome 2003). Various government statements have stressed that professional care must be restricted to situations where self-care and non-professional care are inadequate ('the primacy of non-professional care'). This means that patients and their informal carers must themselves also be able to use medical technology. See the report by the Council for Public Health and Health Care (Council for Public Health 2004) and its preliminary study (Meulenberg 2004) for more details on the options and limitations associated with non-professional care.

Third, there are indications that sophisticated home care may in some circumstances be better (particularly in terms of quality of life, but sometimes also in terms of life expectancy) than continued intramural care. Finally, we cannot ignore the fact that sophisticated home care technology is a new market for companies operating in the field of medical technology. The extent to which economics are driving this trend remains unclear, but there are clear indications that it is a major factor in the United States, where home care technology is 'big business' (Arras 1994a). There are also instances in the Netherlands of home care technology being advertised directly to patients. For example, Philips advertises its automatic external defibrillator in general terms under the heading 'Saviour in need': 'More than 70% of cases of acute cardiac arrest occur in the home. Fewer than 5% of victims survive. Victims are most likely to survive if they receive an electric shock from a defibrillator within five minutes'.¹ Alongside direct commercial interests, associations representing patients and parents play an important (and in the eyes of doctors sometimes 'pushing') role in the development of home care technology, while in the view of patient associations doctors often have an over-conservative attitude.²

The term 'care as an alternative to hospitalisation' has become an everyday phrase in the Netherlands, and covers part of the topic addressed in this report. It is used to describe forms of care allowing patients who would normally be nursed in hospital to remain at home. This often,

¹ www.philips.nl

² VSCA (Chronic Respiratory Support Cooperation Association). Ethical considerations in conjunction with chronic respiratory support. Ethical pamphlet. www.vcsa.nl

but not always, involves the use of sophisticated technology. The following forms of care as an alternative to hospitalisation were listed in a review (Berendsen 2002):

- early discharge following surgery
- care for stroke patients
- care for patients with chronic obstructive pulmonary disease (COPD) and cystic fibrosis
- monitoring high-risk pregnancies
- treating deep vein thrombosis
- other conditions.

The aim of care as an alternative to hospitalisation is to avoid or minimise admission to hospital. One of the expected consequences of this is a reduction in waiting lists. It should also improve patients' quality of life by preventing hospital-related health problems, but especially by increasing independence and autonomy.

A small number of studies have been conducted into the effect of the various forms and indications of care given at home as an alternative to hospitalisation. Most of these studies show the same outcome: there is no difference in health terms between patients cared for at home and patients cared for at hospital, provided that patients are carefully selected and that the domestic setting allows for intensive nursing (Corrado 2001; Berendsen 2002). The majority of the patients in these studies were more than 65 years old and the most common diagnosis was a cerebrovascular accident. The aforementioned Dutch publication showed that GPs are most interested in care as an alternative to hospitalisation for patients with chronic conditions and for elderly patients (whom they would see as part of their routine work), and that GPs do not necessarily want to take on care for patients discharged early from hospital after an operation. A Cochrane review of eleven randomised studies into home care as an alternative to hospitalisation (independent of indication) found no difference in health, and patients cared for at home were more satisfied than patients receiving the same care at hospital. However, non-professional carers were less satisfied and the financial gain resulting from a shorter stay in hospital was lost as patients needed professional care at home for a longer period (Shepperd 2001).

Descriptions of the options for using home care technology are contained in various documents published by the Foundation for the Future Shape of Technology (STOOM 2000; Van Kammen 2002). The Applied Home Care Renewal Quality Institute (KITZ) has listed the following situations where sophisticated medical technology is used at home in the Netherlands¹:

Monitoring

- self-checks in the context of preventing thrombosis
- pregnant women in high-risk groups taking readings at home
- using telematics to monitor patients with chronic diseases.

1 Source: KITZ 2003 www.kitz.nl

Treatment

- bladder flushing with cytostatics
- sophisticated pain control
- light therapy for patients with skin conditions
- continuous ambulant peritoneal dialysis
- special dressings for patients with epidermolysis bullosa
- catheter-administered and parenteral nutrition.
- blood transfusions at home
- intravenous infusion of drugs, including cytostatics
- drug nebulisation
- automatic external defibrillator for high-risk patients
- home dialysis
- artificial ventilation at home
- treatment at home as an alternative to hospitalisation.

There is little data on the efficacy and suitability for home use of various forms of sophisticated medical technology. The Cochrane library contains systematic reviews of techniques such as artificial ventilation at home (Annane 1999), intravenous administration of antibiotics to children with CF (Marco 2000), administration of oxygen to patients with COPD (Crockett 2004), and home treatment of deep-vein thrombosis (Schraibman 2001). All of these reviews cover a small (ranging from one to five) number of studies.

The first two reviews, dealing with artificial ventilation at home and intravenous administration of antibiotics to children with CF, will be separately discussed below. The results of the other two reviews can be summarised as follows. According to Crockett's review, long-term administration of oxygen to patients with COPD has a clear effect on the survival of individuals with severe hypoxaemia, but this does not apply to individuals with moderate or nocturnal hypoxaemia. Schraibman's review in the Cochrane library looked at three studies to compare home treatment of deep-vein thrombosis using low molecular weight heparins with treatment in hospital. Home treatment was found to be no less safe and effective, and to be preferred by patients. However, the authors of the review do point out that there is, so far, a scarcity of evidence.

The literature reveals considerable differences between individual countries in the use of sophisticated medical technology in a domestic setting. France started administering artificial ventilation at home, including to people suffering from COPD, before other European countries (Chailleux 1996). Another study showed that the long-term administration of oxygen to patients with COPD is (or was) more common in Spain than elsewhere (Conde Clasagasti 1995). US patients with intestinal cancer are more likely to receive parenteral nutrition than European patients with that condition. In Europe, this form of home care technology is reserved almost exclusively for people with an inflammatory intestinal disease, such as Crohn's disease.

However, differences exist not only between countries, but also between doctors, who have differing views as to when it is appropriate to offer home care technology to patients. For example, a number of studies have shown considerable variations between doctors working in the same discipline when it comes to offering domiciliary artificial ventilation for indications such as Duchenne's muscular dystrophy (Gibson 2001), amyotrophic lateral sclerosis (ALS) (Kampelmacher 2004) and spinal muscular dystrophy (SMA) (Hardart 2003). This is worrying, because it can lead to differences in access to sophisticated medical technology.

3 Examples of home care technology

3.1 Monitoring at home

High-risk pregnancy

Home care for pregnant women in high-risk categories is a common form of home care technology. These categories include pregnancies with high blood pressure, diabetes or foetal growth retardation. Women undergoing domestic monitoring wear a portable device that allows midwives to perform cardiotocograms (CTGs) of the baby. Women with diabetes have their blood sugar regularly checked, with CTG checks alongside this. Echograms may also be performed (but at hospital rather than at home).

Two Dutch studies (Iedema-Kuiper 1996; Monincx 2001) showed home care to be safe for women with a high-risk pregnancy (for example, women with hypertension, foetal growth retardation, serotinicinity [excessively long gestation period], diabetes), that it was preferred by the women and that it led to a considerable reduction in the length of time spent in hospital. It made no difference to the health of the mother or child whether care was provided at hospital or at home.

Remote monitoring: telemedicine

Telemedicine was defined in a recent Cochrane review as patient care in which the recipient is in a different location than the healthcare provider, and in which at least two means of communication are used interactively (Currell 2000). Thus, a consultation over the phone does not fall under this definition of telemedicine.

Telemedicine is a form of home care technology that is in its infancy, but for which some have great expectations. The most important benefits of telemedicine lie in the time saved for home care providers, who are in short supply, but also in the possibility of more regular monitoring of a patient who remains at home (for example, in the case of nocturnal home dialysis; see below). Those working on the development of telemedicine also expect patients to greatly appreciate being able to remain at home more often than used to be the case. A Dutch example of telemedicine takes the form of an experiment in which district nurses are in daily contact with elderly patient via a webcam, which is expected to be much more useful than regular telephone contact.

This form of sophisticated home care technology has been, to a limited sense, the subject of evaluation studies. The aforementioned Cochrane review compared the effects of telemedicine on the actions taken by professionals and on the outcome of care with the effects of personal contact. Two of the seven trials focused on telemedicine itself (i.e. remote contact between professionals) and five looked at telemedicine as an instrument of home care and how it could support self-treatment by patients with a chronic condition. The studies revealed no drawbacks for telemedicine, but also did not highlight any clear benefits. The authors concluded that telemedicine is indeed feasible, but offers no major medical benefits. Projects using telemedicine for patients with COPD and other chronic conditions are also taking place in the Netherlands.

A geriatric medicine study published in 2001 showed that telemedicine intervention reduced the number of visits to outpatient departments for fifty patients and was very popular with the patients (Hui 2001).

Moral issues associated with home monitoring

Home monitoring of pregnant women is a good example of domestic technology that seems to raise hardly any ethical questions. This is probably because it is a form of transferred technology in which the social network is made up of professionals. Midwives bear the most important responsibility for the proper use of this form of technology.

The situation is different when it comes to telemedicine. The main ethical questions relating to telemedicine have to do with the quality of communication (from the point of view of the healthcare provider and of the patient) and therefore with the quality of the care that is provided. How far can telemedicine be regarded as an adequate alternative to 'face to face' contact? What benefits of direct personal contact are 'given up' when care is remotely provided? Examples might include the opportunity that a personal discussion offers to raise other subjects, and the total picture that a healthcare provider (GP or district nurse) gains by seeing the patient function in his or her normal surroundings. In addition, patients (many of whom are elderly and live alone) would lose the important social aspect of being visited by a healthcare provider.

Another question is how this form of care fits in with responsibility for treatment and for decisions that are taken on the basis of contact via the Internet. Finally, this development raises questions as to the accessibility of care. Despite campaigns to encourage 'silver surfing', few older Dutch people are familiar with the Internet. However, a small number of studies have shown that elderly people are quite quickly able to grasp this technology (Celler 2003).

3.2 Treatment: parenteral techniques at home

Renal dialysis

Terminal renal failure can be treated in two ways. It is generally accepted that a kidney transplant is the best treatment in terms of life expectancy and quality of life. It also seems to be the most cost-effective treatment. But patients for whom no suitable donor kidney is available have

to undergo renal dialysis for extended periods, sometimes for the whole of their lives. There are two methods for this: via the blood (haemodialysis) and via the peritoneum (continuous ambulant peritoneal dialysis - CAPD).

In haemodialysis, the patient's blood is removed from the body via an arteriovenous shunt, passed through an artificial kidney and then returned to the body after being filtered. CAPD involves surgery to place a catheter in the peritoneal cavity. This catheter is used to insert flushing fluid into the peritoneal cavity. The fluid is replaced several times a day, depending on the patient's renal function. The peritoneum takes over the function of the kidneys in this technique.

A number of requirements must be met for a patient to undergo home dialysis. He or she must be able to operate the dialysis machine and inject himself or herself. He or she must also understand and be familiar with the dialysis process. The stringent requirements imposed on people undergoing home dialysis mean that it is not appropriate for many patients.

A recent British survey was conducted into studies comparing home dialysis with dialysis in a hospital or in a satellite unit. It was based on 27 studies, most of which were, however, of poor to moderate methodological quality (Mowatt 2003). This review found that people undergoing dialysis at home appeared to have a better quality of life, but their partners were less satisfied because they were under greater strain. Despite high start-up costs, all the studies found that home dialysis was cheaper than hospital dialysis. The authors pointed out that these good outcomes might be partly or entirely due to the better state of health of patients undergoing home dialysis. All the studies were conducted on groups of young people with little comorbidity.

Nocturnal haemodialysis is a new development in the field of home dialysis, involving six sessions per week of dialysis carried out for between two and eight hours at night while the patient is asleep. The much longer dialysis sessions that are possible under this method improve quality of life. It is chiefly fatigue, one of the core symptoms of renal failure, that seems to be much less debilitating in this situation (Kooistra 1998). It is true that extra supervision is needed because the patient is sleeping during dialysis. The Dianet foundation, which coordinates most of the home dialysis undertaken in the Netherlands, has opted for remote monitoring in which nocturnal dialysis is monitored on line via an ISDN connection by a team of doctors.

Nocturnal dialysis is only possible for patients who meet a number of criteria: their dialysis regime must be stable and they must not suffer from cardiac dysrhythmia or epilepsy, or need oxygen treatment. They must also have a trained partner living with them, preferably sleeping in the same bedroom, who can respond to an alarm from the dialysis machine if the patient sleeps through it (Kooistra 2003).

Parenteral treatment for children

Patients with cystic fibrosis (CF) regularly contract respiratory tract infections that require intravenous antibiotics, usually for a few weeks. Until a few years ago, patients (mainly children) had to

be admitted to hospital to receive this treatment. Now attempts are being made to give this treatment at home, or to continue it after it has been initiated in hospital. The advantages of home treatment are that it is less disturbing to the routine of patients and their relatives, that it saves on hospital beds, that the patient is less likely to contract hospital infections caused by multiresistant bacteria, that it is cheaper, and that patients and families prefer home treatment.

A Cochrane review carried out in 2000 found seven studies, only one of which met the Cochrane criteria (Marco 2000). This study found that home treatment was just as effective as hospital treatment. Patients treated at home differed from patients treated in hospital in two respects: they underwent less diagnostic examination and their level of activity was greater. There was no difference in complications, such as problems with the infusion, or in the interval between treatment and the next hospital admission. Patients treated at home were indeed more tired, possibly as a result of their greater level of activity. The direct costs of home treatment were lower, but no information is available with regard to indirect costs (such as parents or carers missing work).

A recent Australian review showed that caring for a technology-dependent child at home presented clear benefits to the family (and was wanted by almost all parents). It was, however, also associated with significant drawbacks, such as burnout after a few years of providing care, loss of privacy for the carers, a poorer upbringing environment for the patient and his or her siblings, and social isolation (Wang 2004).

Moral issues associated with parenteral treatment at home

The application of parenteral techniques at home depends on an extensive network of professionals and relatives. The most extreme expression of this is in nocturnal home dialysis. This technique can be performed only if there is a telephone connection to a team of doctors that can respond rapidly to any problems not picked up by the sleeping patient or his or her partner. Another question is how pleasant or desirable it is for the patient to need to have his or her partner present at all times, even though the partner's responsibilities in this case may seem less onerous than where, for example, a patient is receiving artificial ventilation at home (see below).

Ethical questions relating to intravenous antibiotics administered at home relate mainly to the safety of the treatment, the ability to deal with complications at home and the degree of responsibility borne by the child and his or her parents. Home treatment is rarely if ever refused, because this situation concerns children. The question is rather whether the pressure to make use of the opportunities offered by home care technology should not be so great specifically because children are involved.

One form of parenteral home treatment that raises significant moral issues when applied to children is total parenteral nutrition (TPN) for newborn infants with severe intestinal problems. Glover et al raised the question of whether it is sensible to administer this technique to infants (Glover 2001). Having analysed three cases, they came to the following conclusion: it is clearly

acceptable to administer TPN to these children if they need it for a temporary period until their intestines are working again. However, TPN is not acceptable for children suffering from significant comorbidity and who (therefore) have little chance of survival, or for children with severe neurological damage. It goes without saying that the question of the quality of life and death is an important aspect of this.

If TPN would need to continue throughout a child's life (for example, because an intestinal transplant would be difficult or impossible), then the authors take the view that deciding for or against TPN is actually up to the parents. The authors pointed out that deciding on whether it is reasonable to start this treatment may be affected by the fact that it can be given at home: this fact makes TPN more attractive and possibly makes it seem less daunting as well ('if we can do it at home, it can't be that complicated'). This may have the additional effect that the severity of the patient's syndrome is underestimated.

3.3 Long-term artificial ventilation at home

Indications and use

Mechanical ventilation using a hand-operated bellows has been possible since the eighteenth century, and this method is still used today, mainly for victims of drowning. Positive-pressure ventilation, with or without endotracheal intubation or tracheotomy, has been in use since the end of the eighteenth century. The first automatic artificial ventilation device was described by Bowditch in 1880 for use in animal experiments.

The first use of artificial ventilation in the domestic setting took place with the iron lung in the 1960s (Splaingard 1983). Home artificial ventilation (some people prefer the term 'chronic respiratory support') is used mainly with two groups of patients: people who can no longer breathe independently as a consequence of neuromuscular diseases such as amyotrophic lateral sclerosis or Duchenne's disease, and patients with severe thoracic deformities (Goldstein 1998). Other indications for artificial ventilation, such as severe COPD, are much rarer in the Netherlands. There are indications that it is more common for patients with this condition to receive artificial ventilation in France, for instance, than in the Netherlands (Make 1998; Chailleux 1996). The records of the four Dutch centres for home artificial ventilation show that 848 people received chronic artificial ventilation in 2001. More than half of these had a neuromuscular condition and 80% were being treated at home. About two-thirds of patients receiving artificial ventilation required it only at night. Approximately half of all patients (57%) were given non-invasive artificial ventilation (the figure for 1991 was 14%).

Positive-pressure ventilation is by far the most common form of ventilation administered at home. Negative-pressure ventilation, pneumobelts and other similar techniques are much rarer and will not be discussed here. Home ventilation can be invasive (using a tracheostoma), or non-invasive (with a nose tube). A tracheostomy is usually performed if the patient requires 24-hour ventilation or respiratory support for a large part of the day. Patients with neuromuscular

conditions normally become dependent on continuous ventilation at some point in the course of their disease, but patients with scoliosis can often manage with just nocturnal ventilation. These two diagnostic groups differ markedly in their reliance on care and in the requirements imposed on the social network. The difference has as much to do with the condition as with the technology. Patients with neuromuscular conditions are more likely than patients with scoliosis to become completely dependent on relatives, and patients with advanced neuromuscular disease are often entirely dependent on ventilation. An interruption in ventilation (caused, for example, by defective machinery) can very quickly lead to death in the latter group. It is therefore essential for them to always keep a back-up machine at home and that a technician can arrive within a few hours to solve the problem. This is normally guaranteed by the supplier.

A Cochrane review carried out in 1999 concluded that the scientific evidence relating to nocturnal ventilation for these groups of patients is weak, but consistently points to a reduction in the burden of symptoms and an increase in life expectancy. The authors reported that the lack of a randomised study with a larger cohort was keenly felt, as this would allow the establishment of the long-term efficacy and suitability of home ventilation (Annane 1999).

Home ventilation is increasingly being administered to children. A recently published Italian report investigated 15 years of home ventilation in children, where the three most common diagnoses were brain damage, upper respiratory tract obstruction and spinal muscular atrophy (about 25% of each diagnosis) (Appierto 2002). The latter indication has given rise to considerable debate in the past few years. Spinal muscular atrophy (SMA) is a congenital neuromuscular condition with a variable course. The most severe form, type 1 SMA, leads to almost total paralysis of the skeletal muscles, including the respiratory structure, within six months of birth. These children normally die before the age of one unless they receive respiratory support. Until recently, the medical consensus was that these children should not be given artificial ventilation. However, an international debate has started on this point as it has become increasingly possible to ventilate even very young infants at home (partly because of the non-invasive nature of modern forms of artificial ventilation) and in response to pressure from patient/parent organisations (Hardart 2003). Little is known about the effects of administering artificial ventilation to children with type 1 SMA. In the US, Bach's group reported survival lengths of six to eight years, with children undergoing non-invasive artificial ventilation appearing to enjoy a better quality of life than children with a tracheostoma, though the study contained very few details (Bach 2002). Doctors' opinions vary considerably as to whether these children should be offered artificial ventilation.

Moral issues associated with long-term treatment at home

Artificial ventilation at home raises a number of ethical issues. The first of these is whether it is always appropriate to offer artificial ventilation at home to people with neuromuscular conditions, who make up the largest patient group. A Canadian study (Gibson 2001) found that a quarter of doctors did not offer it to all patients with Duchenne's disease, for whom artificial ventilation undoubtedly results in greater life expectancy. The main reason put forward by these

doctors is poor quality of life. These differences are regarded as scandalous by some, now that it has been clear for many years that patients with Duchenne's disease who undergo artificial ventilation at home not only live longer but also have a very acceptable quality of life.

Chronic respiratory support or artificial ventilation can lead to a very particular problem in patients with ALS (Kampelmacher 2004). When combined with parenteral nutrition, patients with ALS who are receiving artificial ventilation can sometimes survive for years until the point when the disease has progressed so far that even the speech and mimic muscles are paralysed and locked-in syndrome results. The patient is then unable to speak, and in extreme cases there is no way of communicating with the patient any longer, and so it is impossible to determine, for example, whether or not the patient wants the treatment to continue. It is therefore vital to discuss these questions with the patient in good time and possibly to have the patient draw up a living will.

A second problem is the choice between endotracheal or nasal ventilation (Invasive versus Non-invasive Positive Pressure Ventilation, IPPV versus NPPV). One important benefit of ventilation via a tracheostoma is that this is less likely to lead to aspiration, a particular problem for patients with swallowing disorders. Drainage is also much easier with a tracheostoma. Against this, we must set the findings of some studies that showed that patients with a stoma are less satisfied with their quality of life than patients undergoing nasal ventilation (Goldstein 1998). The largest British centre operating in this field, King's College, does not normally offer tracheostomy. A number of authors have pointed out in this context how important it is to consult patients and their families at an early stage regarding long-term artificial ventilation options. This must clearly be done before the onset of acute respiratory failure makes a tracheostomy inevitable (Make 1998; Polkey 1999). Some patients initially placed on NPPV will eventually have to be transferred to IPPV when they come to require round-the-clock ventilation. It is important to ensure that starting a patient on NPPV does not automatically mean that he or she will eventually have to undergo IPPV: there must be a way back for patients and their families.

If the patient wants to stop receiving artificial ventilation, there are in principle two options open to him or her: abrupt withdrawal accompanied by adequate treatment of the shortness of breath that will result (anxiolytics and opiates), or gradual reduction in the efficacy of ventilation with which the patient will then slowly sink into a hypercapnic coma (accumulation of carbon dioxide) and will not need medication to combat or prevent the shortness of breath. The latter method may be preferred by healthcare providers and the patient's family, and may fit in better with their ideas of a good death.

The extent of the strain on relatives is an important question when it comes to artificial ventilation at home. This applies not only to the primary carer, usually the patient's partner, who will normally have to devote himself or herself full time to the care of the patient receiving artificial ventilation, but also to any children they may have. Can this care, with all that it requires, fit in to a proper family life (Ambrosino 2002)? Is the constant responsibility, the need to remain alert

for alarm signals from the ventilator, something that family members can be asked to bear? And what about the fear that failing to hear an alarm signal might lead to the patient's death?

In children with type 1 SMA, it is conceivable that the option of administering artificial ventilation at home might influence the decision to start administering ventilation at all. The fact that this procedure can be carried out at home makes it less daunting and almost inevitable. The option of home treatment also exerts a certain pull on the decision to introduce it with adults, if for no other reason than that the alternative is for the patient to be admitted to hospital.

When deciding whether or not to start administering artificial ventilation (at home) to children with type 1 SMA, the point at issue is the quality of life and death of a totally paralysed child. In discussions with parents of children with this condition, they have said that they want their child to have the chance of a good death as well.

One important moral question is whether artificial ventilation at home is an attractive option for all families, and how to deal with families where this is not a good option because they would find it too much of a strain, because their circumstances preclude artificial ventilation at home, or because the individuals concerned are unable (or unwilling) to give up their jobs. The question here is what good reasons are there for refusing home treatment for a family member. It is also important to try to prevent social or financial pressure being brought to bear on an individual to administer artificial ventilation at home to a relative.

Of course, the question of the role of relatives has a legal element: to what extent can risky procedures, such as draining a tracheostomy, be delegated to adults and young relatives? Does it make any difference whether these procedures are restricted procedures as defined by the Individual Health Care Professions Act? Who is legally responsible if anything goes wrong when such procedures are carried out? These questions show that closer legal analysis is needed.

4 The future

The use of home care technology of varying levels of sophistication is expected to increase. There are several reasons for this. First, the ageing population and the associated rise in the number of people with one or more chronic illnesses, and second, the greater ability of medical science to keep seriously ill people alive. The desire of patients and their families to stay at home for as long as possible with chronic conditions will also lead to an increase in the use of sophisticated technology in the home. Another important factor is the advance of technological opportunities and improvements to the underlying infrastructure (specially trained nurses, support from the hospital). The distinction between hospital and home will, in the future, depend less on the type of technology and more on the length of time that it is used. That is, short-term, intensive contact with medical technology will take place at hospital, and long-term contact will take place at home.

As well as an increase in the number of users, there is also likely to be a shift in the forms of home care technology available in the near future. Opportunities for telemedicine in the field of monitoring will increase. It will be possible to measure more bodily functions from the home setting. A recent review referred to the possibility of clothing being developed that could continuously monitor an individual's pulse, body temperature and respiration. In future, patients with chronic conditions, particularly elderly people, may well have a corner of their home set up as a 'care unit' comprising a computer with Internet access connected to the appropriate diagnostic apparatus (such as a lung function measurement device, a glucose meter and a blood pressure meter) (Celler 2003). In most cases, these individuals will have regular contact with a nurse via a webcam. The benefits to the patient's health are hypothetical at the moment, and the social consequences, for example in terms of 'getting out of the house', are as yet unclear. This also applies to the effects on someone's freedom and habits resulting from being under continual visual supervision.

Turning to treatment, we anticipate an increase in home treatment of cancer. This is not only because oral forms of chemotherapy will increasingly be available and parenteral nutrition will become easier to administer, but chiefly because more forms of cancer will become chronic conditions treated by maintenance therapy and occasional treatment of flare-ups. This will probably lead to a rise in intravenous treatment, and appropriate monitoring, at home. New options are also likely to become available for the treatment of children with chronic conditions, and options that are already available will probably be more widely used. The section on artificial ventilation has already addressed this issue.

Are we moving towards a situation where more and more homes will be kitted out with high-tech equipment, and more and more families will (have to) take on the responsibility of caring for their relatives? Where is the largest increase likely to be? A recent publication revealed that around 2,600 patients a year in the Netherlands receive catheter-administered nutrition and estimated that 100 patients receive parenteral nutrition (Van Reeuwijk-Werkhorst 2003). An estimate produced for the ZonMw home care technology programme concluded that between 20,000 and 25,000 people in the Netherlands were using sophisticated medical treatment techniques at home. There will probably be a considerable increase in telemedicine and remote disease management.

This report has pointed to the major differences in levels of home care technology in various European countries. The reasons behind these discrepancies are not entirely clear. Are they due to cultural differences, or the presence of prominent pioneers (as in the artificial ventilation of children with spinal muscular atrophy in the US)? Closer investigation of this issue should be carried out in the European context.

5 Discussion

5.1 'At home' as an ethical ideal

The development of sophisticated medical technology for use in a domestic setting is in accordance with various widely-shared values. The primary one is, of course, the value that our society attaches to autonomy and independence.

The original context within which sophisticated medical technology is used (the hospital) inevitably restricts patients' autonomy. They are bound by the rules and routines of the hospital or outpatient clinic and have little opportunity to live as they would like. The same applies to situations where patients needing sophisticated technology are admitted to a nursing home. Home is the place where many people are able to be most independent and live as normal as possible a life.

Independence seems to be a more difficult ideal to achieve than autonomy, in the sense of freedom of choice, for patients who are chronically dependent on home care technology. Patients who need sophisticated technology for extended periods are, in one sense, a classic example of dependence. They are dependent on the equipment, but also on the help and care of other people (family, friends, professional healthcare providers, suppliers and trouble-shooters).

Another ideal related to autonomy and independence is mobility. People who have to be hooked up to medical machines for extended periods are impaired in their mobility as a result of this, and also, of course, as a consequence of their condition. On the other hand, home care technology can often render them more mobile than if they remained dependent on hospital technology. However, travel can be so problematic that people don't go out even though it might be possible for them to do so. This again is a significant restriction on their environment. Alterations to the design of the technology in question can often improve freedom of movement.

An important normative ideal is that people suffering from a long-term, severe and sometimes life-threatening condition should be able to stay in familiar surroundings as much as possible. Surveys on this topic show that 'being cared for at home' is the preference of most (healthy) Dutch people. We have, however, no clear data on the views of the patients that it involves.

However, it is clear that the issue is not entirely clear-cut. Their own home is not at all an attractive location for long-term care for some people, particularly if such care involves the use of complex technology. This might be the case if, for example, their home is too small or not suited to installing the necessary equipment. It may also be inappropriate for relatives or other members of the household to care for patients where this involves the intensive use of complex technology (for example, if the family situation is riddled with conflict and certainly if the patient was an important player in that conflict). Families under severe strain (for example, where more than

one member is in need of care) would also have difficulty in providing comprehensive care to a sick person dependent on sophisticated technology.

The strain on families depends on a number of factors. First of these is how long care is likely to be required. Predictable short-term care (for example, lasting less than six months) should be manageable for most families. Employees are entitled to care leave for short-term care. This option is essential so that people can provide short-term concentrated care at home for relatives or other members of their household. In view of the increasing use of (short-term) home care technology, further investigation should be carried out to ascertain whether the current provisions are adequate and to see how the regulations work in practice.

The identity of the person receiving care is important when it comes to long-term care. Long-term care for a child by a parent is an extension of the natural relationship of dependence between (young) children and their parents, and is more feasible as two parents can usually share the task. Long-term care for a partner can be a severe strain that often appears impossible after several years (for example, as the carer develops burn-out symptoms or as conflicts increase between the recipient and the provider of care). Most families nowadays are unable to provide long-term care for a parent, certainly if the adult child has his or her own family or a career.

A final important point is whether the recipient of care lives alone and risks becoming isolated if, for example, he or she receives home care in the form of telemonitoring. The patient might benefit in this case from receiving care at a central facility (not necessarily a hospital). All these considerations show that home care technology is not necessarily the only option. Relatives can (depending on their own wishes, capacities and opportunities) take on varying degrees of responsibility for care, but this must never be done simply because no other option for care is available.

It may be that little debate is needed as to whether home care is the ideal solution for children. There seems to be little disagreement as to whether intensive antibiotic treatment at home is preferable to long hospital stays for children with CF. Nonetheless, it is very important to bear in mind that parents may come under intense pressure when home care technology is a feasible option for their child. They may therefore feel morally obliged to take on the care of their technology-reliant child at home. It is important in this context to realise that this pressure is still felt most strongly by women in contemporary society, as it is almost always women who deal with sophisticated home care technology (Arras 1994b).

On the other hand, there is the problem of the pressure exerted by parents on doctors to employ technology that will allow them 'to keep the child with them for as long as possible', even when this has become medically pointless (for example, where their child suffers from type 1 SMA). They have to navigate between Scylla and Charybdis: excessive pressure on parents and excessive pressure by parents.

5.2 Home care technology: new ethical questions

The increased use of sophisticated medical technology in the home is therefore motivated by normative ideals as to what constitutes a good life for someone with a severe (chronic) disease. This does not detract from the fact that transferring sophisticated technologies from healthcare facilities to the home environment can also give rise to new moral problems.

The first question relates to the points made above about how the 'home' is changed by the arrival of sophisticated technology. Home care techniques such as artificial ventilation and renal dialysis profoundly change the home environment, and sometimes require considerable reconstruction work to be carried out. If transferring and translating care technology changes the home into a small-scale hospital, does this not cancel out much of the reason for wanting to transfer the technology into the home? The American psychiatrist Ruddick held that the ideal of home care may be illusory for two reasons. First, because the home is no longer what it was before the introduction of sophisticated technology, and second because the patient is no longer what he or she was before sophisticated life-support technology became necessary. He suggested that there may be things in life that you would rather not do at home, such as undergoing chemotherapy or a blood transfusion (Ruddick 1994). The philosopher Noddings addressed the same issues in aesthetic terms, 'Wherever the patient is located, attention should be given to the aesthetic qualities of the room' (Noddings 1994). She says that introducing sophisticated technology into where people live almost always means turning the living room or bedroom into an ugly place, distorting what had previously been regarded by its residents as pleasant or beautiful.

Responsibility

One of the key elements of any technology is the competence it requires and the responsibilities that devolve on its operators. Or perhaps more accurately, the distribution of responsibilities between people and objects. What can and should children, partners and other informal carers be required to do, and what responsibilities can and should be assigned to the equipment itself? Under what circumstances can informal carers be asked to carry out tasks that would normally be carried out by (or legally restricted to) trained professionals? If one of the characteristics of a good life is that you do what you are competent to do, how far is living with a relative who is dependent on high-tech care a good life for relatively incompetent family members? To take this argument a stage further, how far can non-professional carers be held liable for the consequences of errors in dealing with sophisticated home care technology?

The responsibilities imposed on relatives are the most significant moral problem associated with home care technology. That is exactly why it is important to see responsibility not only as being responsible for a task, or being liable, but also as an answer to the question of who is dependent on whom. Noddings, quoted above, considered that it is important from the perspective of the ethics of care to make it possible for people to care for one another. 'Instead of establishing and trying to enforce rules based on a notion of minimum moral obligation, we ask how we can

encourage the highest possible level of natural caring'. When designing and implementing home care technology, people should not simply be loaded with more and different responsibilities that are imposed on them, but they should rather be put in a position to care for their relatives in the most natural way possible. Consequently, further advances in technology should make a real attempt to take account of the care skills that relatives already have.

But sophisticated home care technology profoundly alters the relationship between family members and other people close to the patient, perhaps just as profoundly as the illness itself. The relationship between the patient and healthcare professionals changes as well, in that relatives often acquire just as much (if not more) expertise in dealing with the technology as the district nurses or GPs who are still the people with the primary responsibility for the patient. Patients and their families become co-practitioners. The moral problem that arises from the redistribution of responsibilities can also be expressed as a possible conflict of roles; does the role of an 'intensive care home nurse' accord with that of a son or daughter? Does this kind of high-technology activity fit in with a good relationship between patient and child, as far as upbringing is concerned (Wang 2004)? Is this a form of good life for children and their parents?

Quality

How should the quality of home care technology be assured? It is important to clarify what requirements can be made in terms of maintenance and support, and that the possibility of problems is kept as small as possible. Equipment suppliers normally organise support, and this gives these suppliers a new role in home care. Equipment suppliers become, as it were, direct players in home care for technology-reliant patients. This creates a closer contact between the industry and the patient than is regarded as desirable in many other areas of healthcare, such as drugs supply. It raises new issues of policy and quality assurance.

This brings us to a second ethical question. To what extent can we accept that the use of technology that is in itself of good quality nonetheless leads to a lower level of quality when used in a domestic setting where the network surrounding the equipment is inadequate (Corrado 2001)?

The legal responsibility for the quality of provided care, and the legal liability for damage caused by mistakes in the operation of equipment, remains unclear. A related issue is whether the responsibility of hospitals under the Healthcare Institutions Quality Act also extends to the quality of care provided at the hospital's initiative as an alternative to hospitalisation.

A separate point of concern is the difference in access to home care technology between those who have the required social and physical environment and those who do not. Much sophisticated technology can only be deployed in homes where comprehensive and competent non-professional care is available. Given the ageing population, this will not always necessarily be the case, and adequate institutional care will therefore always be needed.

In other words, those who want and need intramural care must always be able to access it, while home care technology must be available for those who want it and for whom it is a reasonable option in view of their medical condition. Access to home care technology must not be dependent on the patient's social situation, the preference of their doctor, or other factors.

A way out

Moving on from this, an important issue arises with regard to some forms of sophisticated home care: do patients, or informal carers, have a real option to step back from this route once they have started down it? Informal carers (often women) rarely have the chance to abandon sophisticated home care technology once they have started using it. Perhaps the use of certain forms of sophisticated home care technology should be made dependent on the existence of a real opportunity for both patients and carers to abandon it after having used it for some time.

This option can be threatened in two ways. First, it can be threatened by the progress of the disease, making it physically impossible for patients to express a desire to stop using the technology. Second, it can be threatened by the dual bond between the patient and the relative who is caring for him or her, in that it might be harder to ask a spouse who is acting as a carer for the technology to be withdrawn than it would be to make the same request of a doctor.

On the other hand, sophisticated home care technology (such as artificial ventilation) offers relatives or other members of the household greater opportunities than before to stop the treatment themselves. There is not only the worry about sleeping through an alarm signal, but they can, theoretically, also ignore it (either deliberately or on impulse). There are no indications that this has ever happened, but it is a possibility that demands serious consideration and, perhaps, discussion with those involved.

6 Conclusions and recommendations

The increase in opportunities for people with a severe, life-threatening condition to receive care at home represents a considerable improvement in quality of life for many individuals.

However, as has been made clear in this report, there is still much uncertainty as to the effects of transferring and translating sophisticated technology to the patients' home environment. For most technologies, we still do not know precisely under which conditions and for which patients this approach really results in a better quality of life for people with a severe chronic condition. This requires further investigation.

The government, fund providers and professional groups need, when shaping their policies, to consider what forms of sophisticated home care technology should be encouraged and under what conditions this should be done. Applications of sophisticated home care technology that offer no medical benefit should not be developed. The clearest possible definitions of appropriate and inappropriate use must be devised for all forms of sophisticated home care technology.

Another issue is access to this form of care, which should not, in principle, depend on factors unrelated to the disease (such as affordability, space in the home or the absence of informal carers). However, it will not be possible in practice to exclude these factors from the debate. We still do not know whether the absence of adequate professional home care impedes access.

Where new forms of home care technology are being devised, attention must be paid to the aforementioned normative questions. This is already being done. For instance, forms of technology are being developed that are either suitable for use in existing forms of 'living' or that make new ways of living possible. It may be that some homes, such as housing for the elderly, will have to be constructed in the future in such a way (with a sufficient number of rapid Internet connections, for example) as to accommodate sophisticated care technology, if it is needed.

Sophisticated home care technology is a beneficial development for many patients, particularly those requiring long-term or regular treatment (such as patients with chronic diseases like neuromuscular conditions, COPD and cystic fibrosis). In the case of care at home as an alternative to hospital care following surgery, the benefit to the patient is far outweighed by the social benefit (hospital beds are freed up more quickly, costs are reduced). This type of care should therefore be the exception rather than the rule.

The following points must be taken into consideration if new forms of sophisticated home care technology are to be responsibly introduced. It goes without saying that the safety of the technology must be assured, both in the sense of immediate danger (for example, the risk of explosion when oxygen is administered at home) and in terms of the possibility of human error. The decision to transfer sophisticated technology to the domestic setting must be well-considered, and so the equipment must be protected as far as possible against incorrect use. Furthermore, it is very important that patients and relatives are helped to cope with the technology and with the mental and emotional strain that can be associated with caring for a dependent relative. Sophisticated technology requires a good infrastructure in which problems can be quickly resolved.

Patients and their families must have the option of not making use of sophisticated home care technology, without this detracting from the provided quality of care. This means that real alternatives must continue to be available.

It is very important that guidelines on the use of home care technology be produced. Guidelines should, in some cases, be devoted entirely to home care technology (as in the case of artificial ventilation and peritoneal renal dialysis [CAPD] performed at home), while other guidelines should form a logical part of hospital guidelines, as is currently the case for antibiotic treatment of patients with CF (CBO [Dutch Institute for Healthcare Improvement] consensus 1997).

Many forms of sophisticated home care technology lead to a significant shift in caring activities to the informal care sector. Following on from the ethical issues discussed here, this also raises legal issues. Some consider this to be a legal no man's land, as the activities carried out are

often either classified as restricted to healthcare professionals or, even if they are not so restricted, are regarded as high-risk. In 1999 an advisory committee based in Limburg published advice for GPs recommending that non-professional carers should not be asked to carry out either type of activity (Kooijman 1999). The exceptions to these were administering maintenance doses of insulin and glucagon, administering nutrition by catheter, and administering oxygen. This committee felt that non-restricted high-risk activities such as draining a tracheostoma should not be left to non-professionals, even if they had been well trained. It is doubtful whether these rules can be enforced in the cases of, for example, artificial ventilation or intravenous treatment administered at home.

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Appendix 1

Standing Committee on Medical Ethics and Health Law

(Beraadsgroep Gezondheidsethiek en Gezondheidsrecht)

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